



PAEDIATRICS

A NATIONAL MODEL OF CARE FOR PAEDIATRIC HEALTHCARE SERVICES IN IRELAND

CHAPTER 14: CHILD & ADOLESCENT CANCER SERVICES



Féidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Clinical Strategy and Programmes Division



**ROYAL
COLLEGE OF
PHYSICIANS
OF IRELAND**

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14.0 INTRODUCTION

Children and young adolescents with cancer require treatment from staff with particular skills and expertise. Children and adolescent cancer services are best provided at a specialist children's cancer centre. Diagnosis and initiation of treatment for a child or young adolescent with cancer is generally undertaken in consultation with a registered medical specialist with credentials in paediatric oncology. Best practice is based on the concept of integrated multidisciplinary care. Multidisciplinary teams of specialist paediatric medical, nursing and health and social care professionals provide care and services to meet the clinical, physical, social and psychological needs of children with cancer and their families. This multidisciplinary approach is directed towards maximising quality-of-life outcomes associated with cancer treatments and long-term survival. The clinical service is supported by a range of subspecialty paediatric services.

Services operate a 'shared-care model', with a comprehensive cancer centre providing a specialist referral centre for children and young adolescents with cancer. After initial assessment and treatment, children return home (where possible) and care is provided locally, according to agreed protocols, under the supervision of the local registered medical specialist with credentials in paediatrics, with input from a specialist at the comprehensive children's cancer centre. The intention of the shared-care model is to provide high-quality, safe and effective clinical and supportive care in appropriate environments as close to the child's home as possible.

Children's cancer services involve the close interaction between radiation oncology services and surgical services. Surgical oncology services for children involve the initial biopsy of a tumour, tumour resection and the insertion of venous access devices. Surgical services for children are provided by paediatric surgeons, orthopaedic surgeons, neurosurgeons and other specialist surgeons. The main type of treatment for childhood and young adolescent cancer is systemic chemotherapy; however, other modalities, such as haematopoietic stem cell transplantation, surgery, radiation, biological therapies and immunotherapy, may also be used, either alone or in conjunction with chemotherapy. The management and administration of systemic therapy is complex.

Children's and young adolescents' cancer service activities include:

- Diagnosis and assessment
- Psychosocial evaluation and support
- Management of newly diagnosed or recurrent cancer
- Prescription, preparation and administration of systemic and oral therapy
- Management of side effects of treatment
- Planning and delivery of radiation therapy in conjunction with a radiotherapy service
- Planning of surgical treatments in conjunction with surgical services
- Transfusion of blood and blood products, and apheresis
- Allogeneic and autologous haematopoietic stem-cell transplantation
- Ongoing assessment and follow-up of patients during and after completion of therapy
- Provide nutritional assessment and support through intensive treatment
- Psychological and neuropsychological assessment, formulation and intervention.
- Rehabilitation planning in conjunction with appropriate services
- Provision of palliative care

Chemotherapy should be administered in line with published guidelines and standards on the safe handling and disposal of chemotherapeutic drugs and related waste. The prescribing and dispensing of oral chemotherapy must

be carried out to the same service standards as for parenteral chemotherapy. Chemotherapy may be prescribed only by registered medical practitioners with an understanding of the common and unusual toxicities associated with cytotoxic therapy.

The Haematology/Oncology Department at Our Lady's Children's Hospital Crumlin (Crumlin) has excellent clinical leadership (both medical and nursing), excellent outcomes, and excellent shared care networks, and is a model for other specialities to follow.

14.1 CURRENT SERVICE PROVISION

Crumlin is the centralised tertiary unit providing a national childhood and young adolescent cancer programme for the country. The unit provides a shared care model with 16 other units nationally.

The top six conditions seen are:

1. Central nervous system tumours, including spinal cord tumours (26% of patients diagnosed in 2011)
2. Acute Lymphoblastic Leukaemia (24% of patients diagnosed in 2011)
3. Neuroblastoma (8% of patients diagnosed in 2011)
4. Non-Hodgkin lymphoma (5% of patients diagnosed in 2011)
5. Wilms 'Tumour (4% of patients diagnosed in 2011)
6. Hodgkin's disease (4% of patients diagnosed in 2011)
7. Myeloid Malignancies - AMKL, AML, APL and MDS (4% of patients diagnosed in 2011)

Current Statistics

The following data relates to the Childhood and Adolescent National Cancer service in Our Lady's Children's Hospital, Crumlin:

Number of Paediatric Oncology/Haematology Consultants	Oncology – 3, Haemato-oncology - 2
Number of Paediatric Oncology/Haematology SpRs	Oncology – 1, Haemato-oncology - 1
Number of Paediatric Oncology/Haematology Registrars	Oncology - 1, Haemato-oncology - 1
Number of Paediatric Oncology/Haematology SHOs	Oncology - 2, Haemato-oncology - 1
Nursing – General For all Haematology/Oncology including:	ADON – 1 WTE CNM3 – 1 WTE
- Inpatient ward	Ward
- Haem/Onc Day Unit (HODU)	CNM2 – 1 WTE CNM1 – 3 WTE
- Bone Marrow Transplant Unit (BMT)	Staff Nurses: 34 WTE
	Haem/Onc Day Unit CNM2 – 1 WTE CNM1 – 1 WTE Staff Nurses: 6.5 WTE

Nursing – Haematology/Oncology trained	All Nursing Staff undergo in-house training in oncology/haematology. 2 places are offered to staff nurses to undertake Graduate Diploma in Oncology in UCD on annual basis. Ongoing collaboration and placement with St Jude's in Memphis.
Number of ANP	Oncology - 1, Haemato-oncology - 1
Advanced Nurse Practitioners	First assigned ANPs within children's nursing nationally and at OLCHC Interdisciplinary link between all healthcare professionals Benefits of ANP role within Haem/Onc Reduced waiting times for children receiving chemo Earlier discharge Nurse led clinics
Number of CNS, Haem/Oncology	CNS – 6 WTE CNFs – 2 WTE Aphresis – 1 WTE CNM2 & Staff Nurse 1 WTE BMT Coordinator – CNS 1 WTE, Staff Nurse 1 WTE
Health and social care professionals (Allied Health Professionals)	Dietitian – 2 WTE Physiotherapist – 1.5 WTE Psychologist – 1 WTE Occupational Therapist – 0.5 WTE Speech and Language Therapist – 0.15 WTE Play specialist – 1 WTE Social Worker – 1.5 WTE
Management / administration	Secretarial – 4.5 WTE Data Management – 6 WTE Quality – 1 WTE Shared Care Manager – 1 WTE Receptionist – 1 WTE Ward Clerk – 3.5 WTE
General support staff	Household Staff - 4.5 WTE Healthcare Assistant – 4 WTE
Other patient and client care	Teacher – 1 WTE
Total number of beds	19 inpatient beds (includes 2 funded Bone Marrow Transplant beds) 13 haem/onc day beds

Number of annual referrals, specify number per location	Ballinasloe	2	Limerick	8					
	Cavan	2	Mayo	4					
	Clonmel	2	Mercy	5					
	Cork	8	Mullingar	4					
	Crumlin	18	Portlaoise	2					
	Drogheda	7	Sligo	3					
	Galway	4	Tallaght	6					
	Kerry	2	Temple St	34					
	Kilkenny	2	Waterford	3					
	Letterkenny	7	Wexford	1					
	Primary	10	Cappagh	3					
	Beaumont	26	Unspecified	3					
	St. James's	1	Abroad	1					
	168 (2011)								
Number of children in the service	<p>211 patients on treatment based on</p> <ul style="list-style-type: none"> - 98 on CNS new referral list 2012 (not including maintenance or transplant, off-treatment) - 82 on current ALL Maintenance - 31 on CNS relapsed list 2012 <p>36 patients undergone haematopoietic stem-cell therapy (HSCT) in 2012 to date</p>								
Number of new cases per annum	168 (2011)								
Number of cases where shared care is in place with another hospital	86 (using 2011 newly diagnosed patients as a guide)								
Number admissions for each child	1663 inpatient ward admission episodes in 2011 7807 haem/onc day unit admissions in 2011, includes benign haematology too								
Waiting time for appointments (months)	0-1	1-2	2-3	3-6	6-12	12-24	24-36	36-48	48+
Average length of stay	2.5 – 4.5 inpatient days, occupancy per annum 92%								
Mortality	26 deaths in 2011								

Patient Journey

A patient who presents with symptoms suggestive of childhood or young adolescent cancer should be referred to a Haematologist or Oncologist preferably by telephone, however fax or post is acceptable. Written referrals should be marked as urgent. Patients may be referred via:

- Emergency Department
- Surgical/Medical
- OPD
- General Practitioners
- Paediatricians

Every child and adolescent who develops cancer has their diagnosis established/confirmed, and treatment planned, in Crumlin.

All newly diagnosed children and young adolescents with cancer are assigned a named clinical nurse specialist (CNS). This CNS provides education and support to the families, initiates discharge planning and liaises with the support services in the community, i.e. General Practitioner (GP), Public Health Nurse (PHN), local hospital etc. All patients are given a comprehensive information book, called their “Passport” detailing all aspects of the child’s condition, treatment and supports. Throughout the patient’s journey the CNS provides ongoing support. If a decision is made that cure is no longer possible, the patient is referred for palliative care.

Outside of Dublin

For children living outside of the Dublin catchment area, significant components of their treatment are delivered by their local hospital under the supervision of, and in accordance with the care protocols agreed with Crumlin. These hospitals provide essential supportive care to our shared patients, including management of the side effects of chemotherapy and radiotherapy such as anaemia, thrombocytopenia, febrile neutropenia, severe emesis and nutritional problems in accordance with Crumlin Supportive Care Guidelines. These centres also facilitate Crumlin in the management of scheduled tests and investigations and the administration of non-chemotherapy drugs. Several hospitals administer outpatient based chemotherapy: cytarabine, vincristine/vinblastine/vinorelbine and asparaginase to patients, in accordance with the treatment protocol. In addition to outpatient chemotherapy, The Mercy University Hospital in Cork also administers both inpatient chemotherapy and in certain circumstances facilitates home-delivered chemotherapy.

If children are well enough, their parents organise their transport to their local hospital, or Crumlin, by private vehicle or public transport. If children are in critical condition, they are transported by ambulance. Accommodation services are provided by Home-from-Home and Ronald McDonald House.

In Dublin

For children living within the Dublin catchment area (Co. Dublin, Co. Kildare, Co. Wicklow), Crumlin Haematology & Oncology Department provides all the care for the patient. If children are well enough, their parents organise their transport to Crumlin by private vehicle or public transport. If children are in critical condition, they are transported by ambulance. Phone advice is available to all parents on a 24-hour basis.

There is a dedicated Oncology and Haemato-oncology clinic area with 7 consultation rooms supported by an outpatient nurse and a receptionist.

Weekly Clinics	3 Times/Monthly Clinics	Other
<ul style="list-style-type: none"> Acute Lymphoblastic Leukaemia continuation therapy clinic: Prof. Smith and Dr. O'Marcaigh Haemato-oncology (including post haematopoietic stem-cell transplantation patients) long term follow-up Clinic: Prof. Smith and Dr. O'Marcaigh Oncology active follow-up clinic: Dr. Capra, Dr. Owens and Dr. Pears Radiotherapy clinic with Dr. Caitriona O'Sullivan, Consultant Radiation Oncologist 	<ul style="list-style-type: none"> Oncology long-term follow-up clinic Neuro-oncology clinic with neurosurgery, radiation oncology, neuro-oncology CNS 	<ul style="list-style-type: none"> Monthly joint Endocrine/Oncology long term follow-up clinic Drop in clinic – for any urgent/new outpatient based referred patient not accommodated in routine clinic times.

Crumlin is responsible for providing:

- Support to 16 shared care centres in the management of clinical problems arising from treatment.
- Written communication to the shared care centres for individual patients including a detailed written letter from consultant on diagnosis, discharge summary following every patient admission and timely notification of chemotherapy scheduling.
- A copy of the treatment plan and flow sheet(s) for each patient.
- Supportive Care Guidelines (hardcopy) and access online via Crumlin intranet http://olchcnet.hse.ie/Haematology_Oncology_Shared_Care/
- Regional study days for Shared Care staff.
- On-call consultant haematologist and oncologist available 24/7. The shared care hospital can contact the inpatient ward (24/7) or the patient's named CNS (office hours) for telephone advice as required.
- Shared care is formalised and an extensive number of national guidelines (recently revised) were tabled and will soon be available in 'app' format. Haematologists in Cork and Galway (Drs. Clodagh Ryan and Ruth Gilmore) both have sessional commitments to Crumlin and have contributed to national guidelines - an excellent model for shared care.

The service interacts with a number of other specialties:

Specialist Radiology	Nuclear Medicine (bone scans, MIBG, DMSA) – Crumlin Interventional Radiology – Crumlin PET – Blackrock Clinic DEXA – St. Vincent's University Hospital
Radiology	CT, MRI - Crumlin

Theatre	Haematology & Oncology have a dedicated half day (morning) theatre list (Monday – Friday), with dedicated times for specific procedures including Lumbar Punctures, IT chemo, bone marrow biopsies and other procedures performed by the haematologist / oncologist. For procedures that require a surgeon, a request is made for surgery and patients are put on the elective surgical list.
Specialist Laboratory	<p>Haematology, Microbiology, Biochemistry, Genetics are performed in Crumlin.</p> <p>Microbiology (TB) - Mater Misericordiae and St. James's hospitals</p> <p>Virology Reference Laboratory - NVRL</p> <p>Irish Blood Transfusion Service (IBTS) at St. James's Hospital</p> <p>CSF Cytology (if suspicious for malignant cells) - Beaumont Hospital</p> <p>Urinary catecholamines - Beaumont Hospital</p> <p>BHCG tumour marker – St Vincent's University Hospital</p> <p>Analysis of chimerism post allogeneic transplant - Molecular Genetics Lab, St. James's Hospital</p> <p>Alpha iduronidase and uGAGs – Willink Laboratory, RMCH, Manchester</p> <p>Busulphan Pharmacokinetics – ICH, Great Ormond Street Hospital, London</p>
Paediatric Surgery	On-site paediatric surgery team
Neuro-Oncology Surgery	<p>Crumlin, Temple Street & Beaumont Hospital have developed an interdisciplinary team across the three hospitals to care for children with brain tumours, spinal cord tumours or other neuro-oncological diseases. Care of patients under the age of 16 with suspected or proven brain tumours and/or spinal tumours is co-ordinated by paediatric oncologists in Crumlin. Central nervous system tumours may require surgery ± chemotherapy ± radiotherapy, and sometimes only observation. The primary referral is generally made directly to the paediatric neurosurgeons, who decide on the initial management, including the emergency management, where necessary, of raised intracranial pressure (ICP) and subsequent biopsy +/- excision, in consultation with the paediatric oncologists. Younger patients (usually <5) are admitted to Temple Street while older patients have neurosurgical procedures undertaken in Beaumont Hospital. The neuro-oncology meeting is a multidisciplinary meeting held every 2nd and 4th Monday of the month in Crumlin to review new and/or complex clinical management cases and make recommendations concerning the type of therapy and other services most appropriate for each patient. A weekly round table meeting is held in Crumlin with oncologists, neurosurgeons and neuro-oncology CNS to discuss new referrals, recent surgical interventions and appointments prior to the formal monthly meeting.</p>

Ophthalmic Oncology	Patients with retinoblastoma are surgically managed in Temple Street by Prof. Michael O’Keeffe with Crumlin providing adjuvant chemotherapy if applicable with follow-up continuing in both institutions thereafter.
Orthopaedic Surgery	The majority of bone tumour patients have surgery in Cappagh Hospital, with Mr. Gary O’Toole and Mr. Sean Dudeney being the two orthopaedic oncology consultants managing paediatric patients. Planning of surgery is coordinated with CNS in Cappagh Hospital. This service is currently undergoing refiguration.
Pathology	On-site pathology team with Prof. O’Sullivan and Dr. McDermott
Laboratory Work Undertaken Abroad	Minimal – trial specific generally, although specialist molecular analysis, including minimal residual disease (MRD) detection for acute leukaemia (Southern General Hospital, Glasgow).
Radiotherapy	Radiotherapy is performed at St. Luke’s Hospital, Rathgar. The consultant is responsible for an initial referral letter to the consultant radiation oncologist outlining the treatment required. Radiotherapy planning and treatment is planned in conjunction with Dr. Caitriona O’Sullivan, who attends the weekly Tumour Board Meeting and has a weekly Radiotherapy clinic in Crumlin.
Palliative Care	Patients have access to a palliative care team lead by Dr. Mary Devins, based in Crumlin.

There are also links with other services, including:

Pharmacy

The Pharmacy Department in Crumlin operates Monday to Friday between the core hours of 8:30am to 5pm. Outside these hours, nursing administration have access to the pharmacy and the Aseptic Compounding Unit (ACU) to avail of medications needed for the care of emergency patients. To date no formal out-of-hours on-call is recognised or remunerated by hospital management/HSE, however such a service is provided by a dedicated team of oncology pharmacists.

The ACU is part of the main hospital pharmacy. It is located beside the Oncology and Haematology ward and day unit. ACU is responsible for the preparation of all chemotherapy products for the entire hospital. The unit has two clean rooms, one of which is dedicated to chemotherapy preparation while the other is used for the preparation of non-chemotherapy products. Chemotherapy preparation accounts for the majority of the activity of the unit.

Irish Blood Transfusion Service

Supply blood products, HLA typing, Cord Bank, Unrelated Bone Marrow Registry.

Charities

Barretstown, Irish Cancer Society, Canteen, Irish Hospice Foundation, CMRF (Children’s Medical and Research Foundation), Teenage Cancer Trust.

Transition to Adult Services

Adult transition is fraught with difficulties not least differing age definitions for paediatric admission across the country. The agreed cut-off age is the eve of the 16th birthday (except in special circumstances).

14.2 PROPOSED MODEL OF CARE

The oncology shared care model is an excellent example of a hub and spoke model with common guidelines (folder and web-based) and varying degrees of shared care from full shared care with the Mercy University Hospital in Cork to a minor degree of shared care (blood tests) in some paediatric centres. Outreach education sessions are vital to its success. There is currently very little shared care in Dublin, however there may be potential to expand this.

Future Plans and Vision for Service – Key Recommendations

- Delivery of a central service in the new children's hospital, accommodating all tertiary/quaternary paediatric services.
- Extension of hematopoietic stem cell transplant resources, including dedicated haematopoietic stem cell transplant physician and clinical psychologist.
- Employment of a neuro-oncology physician and a dedicated oncology physician with special interest in adolescent/young adult cancers.
- The employment of a dedicated neuropsychologist.
- Additional psychosocial input is required for children & families, including play therapy
- Promote interdependencies, specifically in the domain of rehabilitation, including the National Rehabilitation Hospital, Central Remedial Clinic, Community Disability Teams, early intervention teams and school aged teams who deliver rehabilitation to these children under the guidance of the tertiary clinical specialist physiotherapist in a shared care model.
- Progress development of a dedicated adolescent/young adult cancer service, in conjunction with the adult medical haematology/oncology service in St. James's Hospital.
- In conjunction with the European Network for Cancer Research In Children and Adolescents, develop an electronic patient passport detailing the cancer diagnosis, treatment and clinical problems of each patient to aid long term follow-up and surveillance of all patients in Europe.
- There is significant potential to work in partnership with Northern Ireland and to accommodate patients requiring specialised quaternary paediatric oncology management, for example, bone marrow transplantation, early clinical phase I or II trials.
- Develop Information Technology (IT) infrastructure – engage with the HSE/NCCP to work towards piloting electronic patient record and electronic medication/ chemotherapy prescribing (MOCIS – Medical Oncology Clinical Information System) in preparation for transition to a paperless new children's hospital.

14.3 REQUIREMENTS FOR SUCCESSFUL IMPLEMENTATION OF MODEL OF CARE

14.3.1 Staffing Requirements

Staff Category	Current (WTE)	Proposed (WTE)
Consultant Paediatrician	5.0	8.0
Specialist Registrar	2	4
Registrar	3-4	3-4
SHO	4	4
Nurse	48.5	60
Advance Nurse Practitioner	2	4
Clinical Nurse Specialist/CNF	10	13
Dietitian	1.6	2
Physiotherapist	1.5	3.5
Pharmacist	2	3
Occupational Therapist	0.5	2
Psychologist	1	3
Neuropsychologist	0	1
Social worker	1.5	3
Speech and Language Therapist	0.15	1

Advanced Nurse Practitioners (ANPs) are critical for the smooth running of the service. The ANP role involves carrying out nurse-led clinics (e.g. the maintenance leukaemia clinic run by Ms. L Storey, long-term follow-up clinic run by Ms. F Clinton). This is a successful model of providing care and could be expanded to other specialities.

There are issues around the stem cell transplantation service. Stem cell transplantation indications are increasing (e.g. sickle cell disease, beta thalassaemia, refractory lupus, Hurlers, Epidermolysis Bullosa, primary immunodeficiencies such as SCID and Wiskott Aldrich) and at present bone marrow transplantation cases are transferred to the United Kingdom, which is costly and inconvenient to patients and their families.

14.3.2 Infrastructure

The provision of adequate theatre sessions is problematic. It is recommended that there would be a separate oncology anaesthetic room (central lines and tissue biopsies). The lack of neurosurgery / neuropathology / orthopaedic oncology / radiation oncology / ophthalmology oncology on site are issues, some of which will be addressed by the development of the new children's hospital.

14.3.3 Information Technology

Website portal development will be very important going into the future with the possibility of tracking long-term follow up of patients. In 2013, there was the introduction of a smart phone 'app' for oncology guidelines.

14.4 PROGRAMME METRICS AND EVALUATION

14.4.1 Quality Programmes

- EU Tissue Directive
- JACIE accreditation for HSCT programme was successful
- Education – Shared Care Education Programme, structured clinical placements for nursing & medical • students, academic links with UCD, TCD and RCSI
- National Standards for Safer Better Healthcare
- Healthcare Acquired Infections (HCAIs); Risk Management Framework; Lab Accreditation; Clinical trials

14.4.2 Audits

- An audit of chemotherapy-induced nausea and vomiting in children (2012)
- Clinical Trial Monitoring & Source Data Verification
- Bronchoscopy & broncho-alveolar lavage in the diagnosis of pulmonary disease/infections in children with haematological malignancies (subsequently published in an international peer-reviewed journal)
- Audit of HSCT documentation for 2009 specific to EU Blood & Tissue Directive and review of HSCT related incidents.
- Hygiene Audits; HCAI audits, KPIs, e.g. MRDS, VRE
- Intravenous Chemotherapy Administration by parents in the home setting (2009)

14.4.3 Supportive Care Guidelines

– Available at

http://olchcnet.hse.ie/Haematology_Oncology_Shared_Care/Supportive_Care_Guidelines/

14.4.4 Shared Care Agreement

– Available at

http://olchcnet.hse.ie/Haematology_Oncology_Shared_Care/Communication_Admin/Shared_Care_Agreements/

14.4.5 Clinical Key Performance Indicators (KPIs)

- HSCT specific performance indicators
- MRD for ALL patients
- HCAI KPIs

14.4.6 Data KPIs

- Clinical Trial Information
- European Bone Marrow Transplant (EBMT) data
- Shared Care Admissions

14.4.7 Management KPIs

- Medication Safety Reporting
- Incident Reporting
- Bed Occupancy
- Admission – Day and Inpatient

14.5 ABBREVIATIONS

ACU	Aseptic Compounding Unit
BMT	Bone Marrow Transplantation
CMRF	Children's Medical and Research Foundation
CNS	Clinical Nurse Specialist
COG	Children's Oncology Group
GP	General Practitioner
HSCT	Haematopoietic Stem-Cell Therapy
HSE	Health Service Executive
ICP	Intracranial Pressure
IT	Information Technology
KPI	Key Performance Indicator
MRD	Minimal Residual Disease
OLCHC	Our Lady's Children's Hospital Crumlin
PHN	Public Health Nurse
SHO	Senior House Officer
SpR	Specialist Registrar
WTE	Whole Time Equivalent

14.6 REFERENCES

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