



# Paediatric Integrated Cancer Service

A statewide cancer service for children

## Proposal for a pilot Occupational Therapy Program

### Summary Report

Original report completed May 2010



# Contents

<b>Executive summary</b> .....	<b>3</b>
<b>1.0 Introduction</b> .....	<b>4</b>
<b>2.0 Project purpose</b> .....	<b>4</b>
<b>3.0 Project approach</b> .....	<b>4</b>
3.1 Project scope .....	5
<b>4.0 The service context</b> .....	<b>5</b>
4.1 The patient profile across PICS .....	5
4.2 The service profile .....	6
<b>5.0 Occupational Therapy services for children with cancer</b> .....	<b>8</b>
5.1 The evidence from the literature.....	8
5.2 Evidence of current occupational therapy services in children's cancer.....	11
5.3 Current occupational therapy services at the RCH and MMC Children's Cancer Centres .....	13
5.4 Benchmarking against other services .....	15
5.5 Opportunities .....	16
<b>6. The future occupational therapy service model</b> .....	<b>17</b>
6.1 Vision and guiding principles for Children's Cancer Centre occupational therapy services.....	17
6.2 Occupational Therapy screening, assessment and decision-making tools .....	17
6.3 Occupational therapy interventions .....	23
6.4 Policies and protocols .....	24
6.5 Information resources .....	24
6.6 Strengthening coordination and continuity of care .....	24
6.7 Peter MacCallum Cancer Centre.....	24
6.8 Evaluation of the pilot occupational therapy program .....	25
<b>7 Moving forward – recommendations</b> .....	<b>25</b>
<b>References</b> .....	<b>32</b>
Appendix 1: Occupational Therapy clinical pathway for paediatric oncology across PICS sites	
Appendix 2: Proposed service activity and time allocation by Children's Cancer Centre for 12 month clinical pilot of occupational therapy program	

This document has been produced by PICS to meet specific needs and reflects the state of knowledge and practice as of the date of publication. We ask that no part of this document be used or reproduced in any manner whatsoever without written permission from PICS.

## Executive summary

The Paediatric Integrated Cancer Service (PICS) was established in 2004 as a partnership between the Royal Children's Hospital (RCH), Southern Health (SH – Monash Medical Centre [MMC]) and Peter MacCallum Cancer Centre (Peter Mac). The aim of PICS is to improve the quality of and access to cancer care for children and adolescents with cancer and their families across Victoria.

Children with cancer experience a disruption to their normal childhood occupations. This project has identified that occupational therapy (OT) can play an important role in enabling children with cancer to participate in the everyday childhood occupations of *self-care* (e.g. dressing, grooming, feeding, toileting), *productivity* (e.g. kindergarten/school tasks, routines) and *play/leisure* (e.g. quality of life, social interactions). Currently there is limited OT support available for children with cancer and their families across the Children's Cancer Centres.

Working in collaboration with service providers across the Royal Children's Hospital and Monash Medical Centre Children's Cancer Centres, and building on the current evidence and local expertise, a proposal for a pilot OT program has been developed.

This pilot OT program is guided by the vision of access to high quality OT services, advice and support to enable children with cancer to participate in the everyday childhood occupations of self-care, productivity and leisure across their environments.

There are three key phases of the proposed OT pilot program:

1. Preparation for the OT pilot- 3 months

2. The OT pilot- 12 months

Including:

- The use of an OT Screening tool, by nursing staff, to identify children who would benefit from a referral to OT
- Risk stratification of children identified via screening tool
- Provision of OT intervention within an agreed time-frame

3. Comprehensive evaluation- 3 months

Including:

- Evaluation of the screening tool and risk stratification criteria
- Evaluation of outcomes of OT intervention
- Use of evaluation to inform long term service provision and resource needs
- Development of business cases within the RCH and MMC services to recommend resources required to support the future service.

## 1.0 Introduction

The Paediatric Integrated Cancer Service (PICS) was established in 2004 as a partnership between the Royal Children's Hospital (RCH), Southern Health (SH) and Peter MacCallum Cancer Centre (Peter Mac). The aim of PICS is to improve the quality of and access to cancer care for children and adolescents with cancer and their families across Victoria.

Children with cancer experience a disruption to their normal childhood occupations. Occupational therapy (OT) can play an important role in enabling children with cancer to participate in the everyday childhood occupations of *self-care* (e.g. dressing, grooming, feeding, toileting), *productivity* (e.g. kindergarten/ school tasks, routines) and *play/ leisure* (e.g. quality of life, social interactions).

Working in collaboration with service providers across the RCH and MMC Children's Cancer Centres and building on the current evidence and both local and international expertise, PICS has developed a **proposal for a pilot OT program**.

This report outlines the project purpose and approach and the service context of current PICS services. It provides a brief overview of the evidence supporting the use of OT services for children with cancer, current OT services across the three PICS services, information about international and national models and service developments in this area. This informs the proposal for a pilot OT program.

## 2.0 Project purpose

The initial purpose of this project was to develop a best practice service delivery model to meet OT needs and support the occupational well-being of children and adolescents with cancer across PICS services and associated regional service sites.

The key questions guiding the project were as follows.

- What is the role and benefit of OT for children and adolescents with cancer and their families?
- Which children and adolescents need OT support and how do they currently access this?
- What are the current services and resources?
- What factors are influencing current practice?
- What are the elements of a best practice model?

As these guiding questions were asked and the project commenced, best practice for OT in children's cancer services proved difficult to determine. There was a lack of high level research in the area and limited published guidelines from centres of clinical excellence and OT governing bodies.

These challenges redirected the project purpose to a **proposal for a pilot OT program** for an agreed time period, followed by a comprehensive evaluation of outcomes to inform long term service provision and resource needs.

This revised project purpose provides an opportunity for PICS to make a valuable contribution in the evaluation of the role, benefit and best practice of OT to children with cancer and their families.

## 3.0 Project approach

The Project was undertaken by an occupational therapist working at Monash Medical Centre (MMC), Southern Health. The steering committee for this project consisted of the PICS Program Manager and the OT managers at both the MMC & RCH sites.

This Project has been guided by:

- a service wide perspective of PICS
- consideration of the DHS strategic framework for paediatric health services in Victoria
- a focus on strengthening systems as well as improving access to specialist services
- consideration of workforce issues in particular current and future workforce demands

- a realistic and wise use of resources within the context of the Children’s Cancer Centres.

Background information was gathered through

**Literature review:** This review examined the evidence for the role and benefits of OT for children and adolescents with cancer and their families.

**Internal stakeholder consultation:** This included stakeholder consultations, with occupational therapists, service managers at MMC and RCH sites and other associated service providers including social workers, nurse unit managers and related service managers. Consultation occurred via individual interviews and meetings for key stakeholders.

**Feedback from parents:** this included seeking informal comment from parents attending the CCC.

**Service survey:** a survey was completed at both RCH and MMC sites to identify current services and practices, key service strengths and service challenges.

**Benchmarking and external stakeholder consultation** which included:

- survey (via email) to interstate and international children’s oncology services to identify current service practices.
- consultations (by telephone and email) with OT service providers nationally and internationally to further determine current models and practices.

### 3.1 Project scope

Although the Project was to develop a service model across PICS, the primary focus has been on the two Children’s Cancer Centres.

The majority of children treated at Peter Mac are also linked with RCH or MMC and therefore access OT services at these sites. Children with OT needs who are not linked with RCH or MMC are seen upon referral by Peter Mac OTs.

## 4.0 The service context

As indicated, PICS is a partnership between three major services providing diagnostic, treatment and ongoing services to Victorian children diagnosed with cancer and their families.

### 4.1 The patient profile across PICS

Each year, approximately 170 children in Victoria are newly diagnosed with childhood cancer and are managed by the CCC at RCH and MMC, a small number of whom are from interstate or overseas. The five year survival (and potentially cure) rate across all childhood cancers is estimated to be 70%<sup>1</sup> and increasing.

The following summarises the profile of the children diagnosed in 2005 (see Table 1).

- Just over half (51%) of all new diagnoses are for ‘liquid’ tumours (eg leukaemias)
- 21% of new cases are children with brain tumours
- 27% of new cases are children with ‘solid’ tumours (eg Wilm’s tumour, osteogenic sarcoma)
- 45% of children are aged 5 years and under at time of diagnosis
- 31% are aged 6-12 years
- 24% of children are aged 13 plus at diagnosis.
- 41% of children treated at RCH Children’s Cancer Centre were aged 5 years and younger with just over one quarter being aged over 13 years.
- MMC Children’s Cancer Centre tends to see a younger population with 67% of children being aged 5 years and younger. This may reflect that at that time MMC tended to treat the less complex cancers
- Nearly 40% of children having radiotherapy at Peter Mac were aged 6-12 years, with 30% each being in older or younger age groups.

**Table 1: Profiles of newly diagnosed children by PICS service site, age and disease category in 2005**

Category		Service					
		RCH		MMC		Peter Mac <sup>1</sup>	
		n	%	n	%	n	%
Age	0-5	55	41%	16	67%	21	30%
	6-12	43	32%	6	25%	26	38%
	13 +	37	27%	2	8%	21	31%
	<b>Total</b>	<b>135</b>	<b>100%</b>	<b>24</b>	<b>100%</b>	<b>68</b>	<b>100%</b>
Disease category	Liquid tumours	71	52.5%	11	46%	16	23%
	Brain tumours	29	21.5%	5	21%	28	41%
	Solid tumours	35	26%	8	33%	24	35%
	<b>Total</b>	<b>135</b>	<b>100%</b>	<b>24</b>	<b>100%</b>	<b>68</b>	<b>100%</b>

## 4.2 The service profile

The following summarises the key elements of each service with additional information about OT services being provided in 5.2.

The **RCH Children's Cancer Centre** is the largest paediatric oncology service in Australia treating approximately 70% of Victorian children diagnosed with malignant cancers, across all diagnostic categories, complexity and age groups. It also provides services to children and families from Tasmania, other Australian states and through international referrals.

In addition to managing children with cancer, the RCH Children's Cancer Centre also manages about 40 % of all bone marrow transplants for children in Victoria.

The purpose built RCH Children's Cancer Centre has a 28 bed in-patient facility and co-located day oncology service that treats 15-35 children per day. Children with brain tumours are located on the neurological ward, at least on initial diagnosis. Six outpatient clinics are held weekly with an average of six consultants at each clinic. These are located on the same floor as the in-patient and day oncology services.

Historically there has been no dedicated OT service to the oncology unit apart from the RCH OT department which is funded to attend the monthly Neuro-oncology Long Term Follow Up clinic.

The **Children's Cancer Centre** at Monash Medical Centre is situated within a large tertiary hospital, as part of Monash Children's. The Children's Cancer Centre provides care to approximately 40 of the 170 new cancer patients per annum. Children with acute myeloid leukaemia, needing bone marrow transplant and others needing more complex medical treatment are referred to RCH.

The MMC Children's Cancer Centre is a purpose built ambulatory care facility providing outpatient clinics, day oncology services and general anaesthetic procedure services within the same environment. In-patient care is provided on the two general paediatric wards, depending on the child's age.

<sup>1</sup> Note: Children attending Peter Mac will be predominantly having their primary diagnosis and / or treatment at RCH or MMC and are not a different cohort of children.

The MMC paediatric OT service has no specific funding allocated to oncology and as a result no dedicated service to paediatric oncology. Within their general paediatric role, the occupational therapists provide limited services to oncology children on a needs basis.

**Peter Mac** as a specialist adult cancer service is responsible for providing radiotherapy for children and adolescents. In 2005 just fewer than 70 new patients were referred from RCH or MMC, primarily for curative treatment. Almost all of this treatment is undertaken in the ambulatory setting, with only a small number of children being admitted if they need total body irradiation. A weekly children's outpatient clinic is held.

Given that most children and adolescents will receive between 5-6 weeks of treatment, it is estimated that an average of 5-6 children may be treated per week. However, the numbers of children treated at any one time is very variable.

There is no designated paediatric OT resource for children treated at Peter Mac. The majority of children treated at Peter Mac also have contact with the Children's Cancer Centre at either RCH or MMC, with opportunities for referral to OT. It should be noted that a small number of children or adolescents not linked to the Children's Cancer Centre are treated at Peter Mac (e.g. children from interstate). These children are currently seen by the adult OT service upon referral.

**Regional services:** PICS has established a Regional Outreach and Shared Care Program (ROSCP) with a number of services in regional Victoria.

Occupational therapists across Children's Cancer Centre sites refer to occupational therapists in the child's local community as required with the opportunity to link ROSCP to better service the OT needs of children within their local communities.

## 5.0 Occupational Therapy services for children with cancer

This section summarises the key evidence from the literature about OT services for children and adolescents with cancer and provides discussion of a theoretical model underpinning OT practice. It then reviews evidence of current OT practice in paediatric oncology services nationally and internationally, and within the Children's Cancer Centres.

### 5.1 The evidence from the literature

The literature review explored the following key question:

"What is the role and benefit of OT for children and adolescents with cancer and their families?"

There was limited high level evidence to demonstrate the definitive impact of OT interventions with children and/or adolescents being treated for cancer, with limited research conducted in this area.

However the literature review uncovered many established interventions used by occupational therapists in general paediatrics, adult oncology and adult palliative care. This evidence is presented alongside literature specific to OT for children with cancer with links made to relevant application across these client groups.

The following provides a brief summary of the key evidence.

#### 5.1.1 The role and benefit of occupational therapy

OT enables children to participate fully in the occupations of life. The occupations of children are *self-care* (e.g. dressing, grooming, feeding, toileting), *productivity* (e.g. kindergarten/ school tasks) and *play/ leisure*.<sup>2</sup> Occupational therapists can assess for difficulties in these areas and provide interventions to enable both children's occupational participation and wellbeing.

An important role of occupational therapists working in paediatric oncology is to assist children to be all that they can be<sup>3</sup>. Indeed quality of life is congruent with the philosophical basis and process of OT<sup>4</sup>. Recent statistics point to a continuing increase in survival from childhood cancer; however treatment has been associated with adverse effects for both child and family<sup>5</sup>. As a result, there has been a move toward assessment of quality of life to supplement traditional medical measures<sup>6</sup>. OT advocates for the use of quality of life in practice, research and as an outcome measure, believing engagement in valued occupations allows people to express their identity and gives worth and meaning to people's lives<sup>7</sup>. At its simplest, the key outcome of OT intervention is quality of life<sup>8</sup>.

OT theorizes that a balance of occupation is beneficial to health and well-being, with balance defined in terms of the time spent in self-care, productivity and play/ leisure<sup>9</sup>. Children with cancer often experience an imbalance in occupation during hospitalizations or due to disease treatments with literature identifying the tendency for families of hospitalized children to 'do for' the child<sup>10</sup>. Occupational therapists have a valuable role in maintaining normality for child and family, facilitating routines and structure and continuing to promote age appropriate skill development despite illness and hospitalizations<sup>11</sup>.

Side effects of cancer, its treatment and long periods of hospitalization can result in physical, cognitive or affective changes which in turn can impact on children's occupational wellbeing<sup>12</sup>. Developmental deficits may occur and occupational therapists can pinpoint these and provide rehabilitation to enable smoother re-entry to kindergarten or school<sup>13</sup>. Kindergarten and school aged children need to be able to master a number of tasks to successfully participate in their role as student (e.g. cutting with scissors, engaging with sports, handwriting); occupational therapists can help children having difficulties in skills required for their role as student<sup>14</sup>.

Occupational therapists provide interventions to address physical changes such as fatigue, breathlessness, pain, changes to skin integrity and neurological deficits<sup>15</sup>. Interventions used by occupational therapists found commonly in the literature include facilitation of coping strategies<sup>16</sup>; fatigue management, pacing and energy conservation<sup>17</sup>; support and education for carers<sup>18</sup>; splinting to prevent deformities and

control pain<sup>19</sup>; provision of adaptive equipment (for example wheelchairs, pressure care, bathing aids) and environmental adaptation<sup>20</sup>.

Occupational therapists' training and experience mean they are instrumental in predicting and indicating how the patient is likely to cope on returning home<sup>21</sup>. OT home visits are valued as a means of assessing the patient's environmental risk to facilitate a timely, successful and safe discharge from hospital<sup>22</sup>.

The Victorian Government's Effective Discharge Strategy initiative provided recommendations essential for good transition planning (hospital to community) including the thorough assessment of the patient's home and social circumstances<sup>23</sup>. Assessment of a patient's functioning in their own home environment is a fundamental skill of occupational therapists<sup>24</sup>.

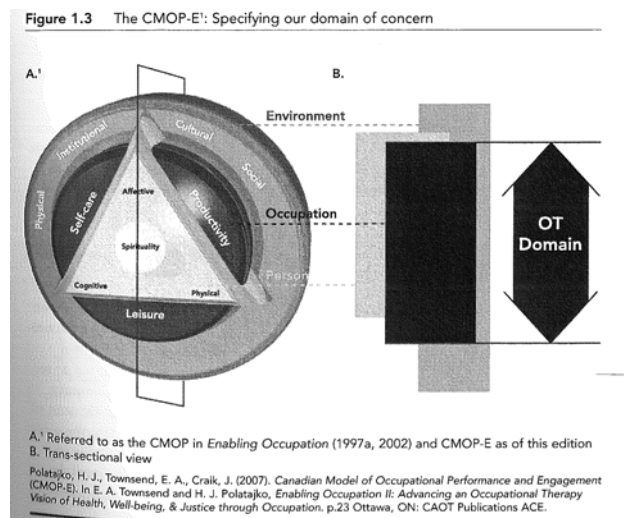
OT home visits for oncology and palliative care patients include interventions to address symptom-related issues, provide education to the patient and carers, prescribe equipment and home modifications, provide psychosocial support and maintain quality of life<sup>25</sup>.

Occupational therapists support the child and family in adapting to the diagnosis and treatment of childhood cancer<sup>26</sup>, provide age appropriate education<sup>27</sup>, opportunities for self-expression<sup>28</sup>, relaxation training and anxiety management<sup>29</sup>, and facilitate psychological adjustment to loss of function<sup>30</sup>. Occupational therapists contribute to retraining of cognitive and perceptual dysfunction where these deficits occur<sup>31</sup>.

### 5.1.2 Theoretical model underpinning Occupational Therapy practice: The Canadian Model of Occupational Performance-Environment (CMOP-E)

The Canadian Model of Occupational Performance- Environment (CMOP-E) is a framework used by occupational therapists to specify OT domains of concern. It conceptualizes occupational performance as the dynamic interaction of the person, their occupation and environment.

The **person** is depicted as a triangle in the centre of the model with three performance components—*cognitive*, *affective* and *physical*—with *spirituality* at the core. **Occupation** is categorized into the purposes of *self-care*, *productivity* and *leisure*. Both the person and their occupation are embedded within their unique **environment**—*cultural*, *institutional*, *physical* and *social*, with **occupation**—categorized into purposes of *self-care*, *productivity* and *leisure* depicted as the bridge between.<sup>32</sup>



**Figure 1: The Canadian Model of Occupational Performance-Environment (CMOP-E)**

### 5.1.3 Application of the CMOP-E to occupational therapy in children's cancer

Occupational Therapists working in children's cancer enable children's participation and performance in the everyday childhood occupations of *self-care*, *productivity* and *leisure*. Refer to Table 2 for examples of activities that fall into these categories.

**Table 2: Occupations of childhood**

<u>Self-Care</u>	<u>Productivity</u>	<u>Play/ Leisure</u>
Occupations for looking after the self	Occupations that make a social contribution	Occupations for enjoyment
<ul style="list-style-type: none"> <li>• Showering/ Bathing</li> <li>• Toileting</li> <li>• Dressing/ Undressing</li> <li>• Grooming</li> <li>• Feeding</li> <li>• Functional Mobility</li> <li>• Transfers</li> <li>• Rest</li> </ul>	<ul style="list-style-type: none"> <li>• Developmental milestones</li> <li>• Kinder/ School tasks</li> <li>• Routines/ Roles</li> <li>• Time Use</li> <li>• Home responsibilities</li> <li>• Vocation</li> </ul>	<ul style="list-style-type: none"> <li>• Quality of life</li> <li>• Play</li> <li>• Leisure</li> <li>• Social interactions</li> </ul>

Children with cancer often experience illness or treatment effects that lead to occupational disruption. In order to enable children's engagement in their occupations, assessment and intervention occurs. The child's performance in *cognitive, affective* and *physical* areas is assessed; as occupation occurs in and is influenced by the child's environment their unique *cultural, institutional, physical and social environment* is also considered.

Assessment and intervention occurs in these areas to enable children to participate more fully in their childhood occupations. Best practice in OT seeks to offer effective, client-centred, occupation-based enablement<sup>33</sup>. Enablement is the core competency of occupational therapists and is beyond the ordinary enablement that occurs in everyday life by parents, friends and others<sup>34</sup>.

At all times, the child's occupational therapist acknowledges spirituality at the core of each client. *Spirituality* underpins the reasons that the child makes decisions and choices; is essential for self worth; is the essence of the unique individual child; and gives consideration to occupations that promote well-being and give meaning to life<sup>35</sup>.

Table 3 identifies the domains of concern for occupational therapists for assessment and intervention.

**Table 3: Domains of concern for occupational therapists:**

<b>PERSON</b>	<b>OCCUPATION</b>	<b>ENVIRONMENT</b>
<b>Performance and Engagement:</b> <ul style="list-style-type: none"> <li>• Cognitive</li> <li>• Affective</li> <li>• Physical</li> </ul> <b>Essence of the person</b> <ul style="list-style-type: none"> <li>• Spirituality</li> </ul>	<b>Areas of Occupation</b> <ul style="list-style-type: none"> <li>• Self-care</li> <li>• Productivity</li> <li>• Leisure</li> </ul>	<b>Environmental Components</b> <ul style="list-style-type: none"> <li>• Cultural</li> <li>• Institutional</li> <li>• Physical</li> <li>• Social</li> </ul>

#### 5.1.4 Client-centred practice

Occupational therapists embrace client-centred practice which is an integral component of the professions philosophy. Therefore:

- a collaborative approach and partnership exists between therapist, patient and family with patients and families actively involved in decision making
- occupational therapists demonstrate respect for clients' experience and knowledge and interventions are relevant to the client's lifestyle
- occupational therapists act as an advocate with, and for, the client
- OT outcomes are judged in relation to the client's goals

- OT is provided in a way that is appropriate to the age and developmental needs of the child / adolescent
- OT focuses on abilities rather than disabilities.

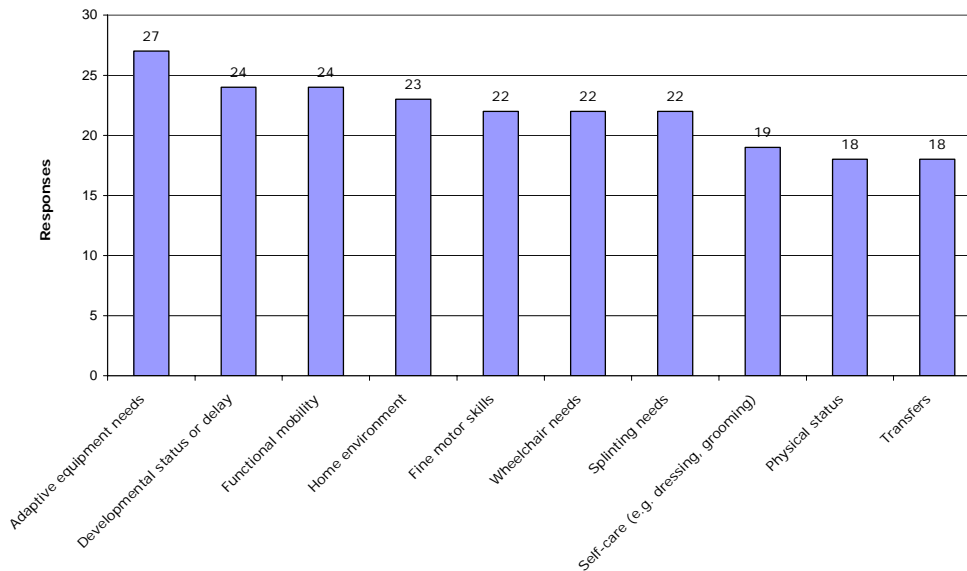
## 5.2 Evidence of current occupational therapy services in children’s cancer

A survey developed for this project was circulated via email to national and international centres treating children with cancer to gather evidence of current service practices. Thirty six health professionals responded (44.4% occupational therapists, 41.7% nurses and 13.9% other health professionals) with 27 complete surveys.

Findings from this survey are outlined below.

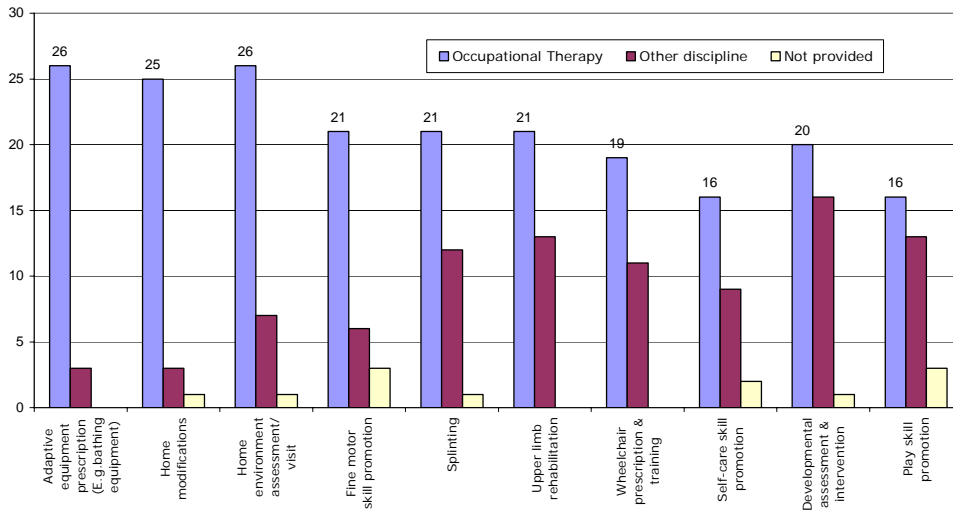
Occupational therapists receive referrals for a range of concerns impacting upon a child’s participation in their self-care, productivity and/or play. The concerns outlined in Graph 1 were identified by respondents as most commonly resulting in a referral to OT for a child attending their service.

**Graph 1: Ten most common concerns resulting in referral to OT for child attending service**



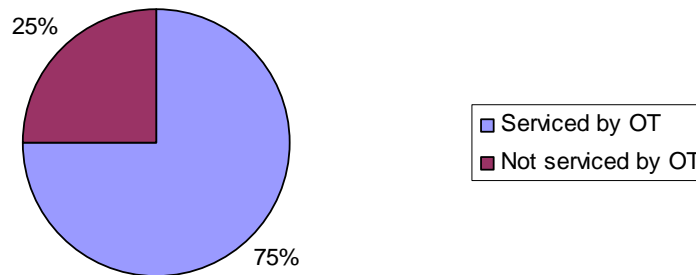
Allied Health professions often overlap in the skills, services and interventions offered to children and families. Some overlap occurs between OT and other disciplines; however Graph 2 clearly identifies interventions that were more commonly provided by OT than any other discipline across services for children with cancer, indicating the importance of including an OT in the multidisciplinary team.

**Graph 2: Ten interventions more commonly provided by OT than any other discipline in the service**



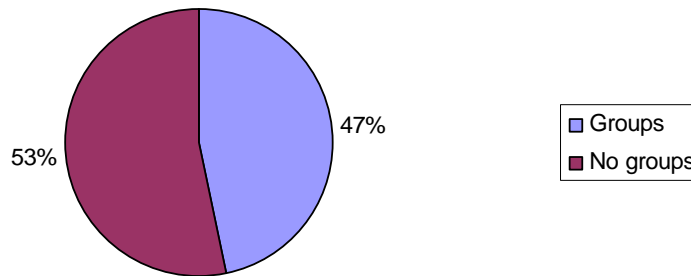
Seventy-five percent of survey respondents report accessing OT services for children requiring admission to the Bone Marrow Transplant Unit. The remaining 25% includes the Bone Marrow Transplant Unit at RCH, which does not currently have access to an OT service.

**Graph 3: Services with Bone Marrow Transplant Units – Access to OT**



Group programs in services treating children with cancer are facilitated by a range of health professionals. Graph 4 demonstrates that OTs have a place for contributing to groups, with nearly half of respondents indicating OTs contribute to or facilitate groups in their service. RCH and MMC do not currently contribute to the existing group programs, however as indicated by this survey could have a role in contributing to groups in the future.

**Graph 4: Occupational therapists contributing to or facilitating groups in service**



### 5.3 Current occupational therapy services at the RCH and MMC Children’s Cancer Centres

Historically there has been no dedicated OT service to the RCH oncology unit. The lack of comprehensive OT service at RCH has been a concern to the OT department which has limited capacity to respond to the needs of children with cancer due to significant resource limitations outlined in this report (Refer to 5.3.2).

RCH OT receives individual referrals for children with the majority of referrals to facilitate a safe discharge from hospital. Some referrals are also received for concerns in the following areas—self-care, developmental status or delay, splinting needs, home environment, fatigue, pressure care and coping at home. RCH OT also provides a service to the monthly Neuro-oncology Long Term Follow Up clinic.

The MMC paediatric OT service has experienced growth over recent years due to increasing acknowledgement of the valuable contribution by occupational therapists, statewide initiatives and targeted philanthropic funding. However, there has been no funding allocated to oncology and as a result no dedicated service to paediatric oncology. Within their general paediatric role, the occupational therapists provide a limited service to oncology children on a needs basis.

MMC OTs attend daily paediatric ward handover meetings where they identify children who may require OT services. In addition, referrals are accepted from medical, nursing and allied health staff. The majority of OT intervention occurs with inpatients for concerns in the following areas— self-care, developmental status or delay, splinting needs, home environment, pressure care, fine motor skills, play skills & behaviours, functional mobility, wheelchair needs, adaptive equipment needs, physical status, upper limb status and transfers.

Box 1 demonstrates the role of the OT working with Tom, a patient treated for leukaemia in the Children’s Cancer Centre.

#### Box 1: Tom’s Story

Tom was a 14 year old with leukaemia. He had many medical complications leading to an ICU admission. On transfer to the ward Tom had pressures sores and contractures. He required assistance for all occupations (self-care, productivity & play/leisure) and became very withdrawn with little motivation to get out of bed.

Tom was asked by his occupational therapist what he most wanted to achieve. His goals were to return home, to use a computer and to be able to stay in touch with friends via SMS.

Tom worked towards his goals during daily intensive OT. Initially reluctant, his enthusiasm for OT increased as he moved closer to achieving his goals. On discharge Tom was independently able to use a computer; send and read SMS messages on his phone; feed himself; dress his upper body; transfer onto a commode and his electric wheelchair from bed; and drive himself in an electric wheelchair.

The OT completed a home visit and ensured all of the required equipment was in place for discharge. Tom was so excited to be able to return home and to continue OT in the community to strive towards achieving new goals.

Box 2 demonstrates the role of the OT working with Molly, a patient treated for a brain tumour in the Children’s Cancer Centre.

#### Box 2: Molly’s Story

Molly was a 2 year old, diagnosed with a brain tumour and referred to OT due to concerns surrounding her development.

The OT completed an assessment to determine Molly’s strengths and difficulties in self-care and play, set goals with her parents and provided OT sessions and a home program to foster her development.

On a three month review, Molly had made significant gains in her play, self-care and development.

#### 5.3.1 Occupational therapy services – patient contacts

##### Analysis of patient contacts

A three month audit of patient contacts was undertaken in the OT departments at RCH and MMC. Given the different information data systems at each service site, it is difficult to assess the range of patient contacts or encounters across the two Children's Cancer Centres in a uniform way. Caution should be used in making comparisons between services.

Findings from the three month audit included the following:

- A minimal OT service is currently provided at both sites. Over the duration of the audit the EFT service was equivalent to 0.12 EFT at RCH and 0.07 EFT at MMC.

### **5.3.2 Occupational therapy service issues across sites**

The following summarises the issues identified by stakeholders across Children's Cancer Centre sites.

#### ***Resources***

- Limited resources limit the capacity to:
  - promote the role of OT for generation of relevant referrals
  - attend the relevant Children's Cancer Centre multidisciplinary meetings
  - see out patients
  - undertake quality improvement activities and research
- In addition, limited EFT at RCH also constrains the ability to:
  - respond to the OT needs of patients and families upon referral
  - provide interventions that are not essential for safe hospital discharge
  - respond to referrals for children transferred from MMC Children's Cancer Centre or other sites

#### ***Referral***

- Inconsistent referral types across Children's Cancer Centre sites with a broader range of concerns resulting in a referral to OT
- Few referrals received for outpatients potentially missing OT intervention in a period when families are not concurrently dealing with the stressors of hospital inpatient admission
- Late referrals received (e.g. patient medically cleared for discharge) may potentially result in delayed discharges and increased length of stay or unmet OT needs
- Difficulty determining timeliness for OT intervention when disease and treatments result in the child fluctuating in occupational performance and participation

#### ***Links to Children's Cancer Centre team***

- OTs do not regularly attend CCC meetings which limits links to CCC team, opportunities for referrals, and up to date knowledge of the child and families medical and psychosocial situation

#### ***Staff Education***

- Other health care providers need increased knowledge about the role and benefit of OT and the referral pathway/ patient priorities
- OT providers may need an increased understanding of disease and treatment factors that may influence the level of OT required

#### ***Continuity of Care***

- There is variable knowledge of when children are transferred between RCH, MMC and/or regional services which constrains appropriate information transfer

#### ***Need for research***

- There is limited high level evidence to guide practice
- The need to develop a stronger evaluative/ research base

## 5.4 Benchmarking against other services

### 5.4.1 Analysis of Benchmarking

It is difficult to make simple comparisons between the OT services across various national and international services. We cannot assume that a service with less OT EFT results in children and their families unable to access interventions provided by occupational therapists.

For example, OTs at some other Australian sites provide procedural preparation and procedural pain intervention. At RCH and MMC, this service is provided by the Comfort First program, a specialist procedural pain intervention program offered to all newly diagnosed children and their families. Comfort First clinicians are employed from a range of backgrounds including OT.

Some interventions provided by occupational therapists overlap with those provided by other disciplines. RCH and MMC Children's Cancer Centres have teams providing emotional and psychological support including mental health clinicians, social workers, play therapists, music therapists, nursing and medical staff: these concerns result in referrals to OT in other services.

The RCH OT department does not contribute to paediatric oncology groups, unlike OTs in some other national and international services. However, both RCH and MMC Children's Cancer Centres regularly run sibling and adolescent groups, facilitated by a range of professionals, currently including an occupational therapist at MMC.

Although some overlap in skills occurs between OT and other professionals, it is important to acknowledge the unique contribution that can be made by occupational therapists to the multidisciplinary team. In a survey developed for this project (see Section 5.2) over 90% of respondents identified that occupational therapists were the discipline to provide adaptive equipment prescription, home environment assessments/visits and home modifications—fundamental skills of occupational therapists. Other interventions identified as more commonly provided by OT than any other discipline in the service included fine motor skill promotion, splinting, upper limb rehabilitation, wheelchair prescription and training, self-care skill promotion, developmental assessment and intervention, play skill promotion, fatigue management, physical rehabilitation, structuring routines and time use and functional mobility assessment/intervention.

In addition, occupational therapists are uniquely positioned in the team to use skilled interventions to enable children to be engaged to their fullest in the meaningful occupations of self-care, productivity and leisure.

### 5.4.2 Comparison with children's cancer services

The following is a summary of data obtained which shows the service profile and OT resources and practices across PICS and other children's cancer services (national and international). This review compared key data for RCH and MMC with four other national children's cancer services. The following observations can be made:

- Four of the centres have a similar number of new patients per annum, however unlike these centres the RCH:
  - does not have an OT as a designated member of the children's cancer centre team
  - does not have a blanket referral system for inpatients
  - see paediatric oncology patients by referral only
  - does not see the majority of paediatric oncology children
  - does not run paediatric oncology groups (groups at RCH Brisbane & PMH)
  - has 0.5EFT compared with 1-2.5EFT at the other Australian hospitals however, the role of the OT differs substantially across sites.
- MMC has similar number of new patients per annum as one other hospital, however unlike this hospital does not have designated OT EFT or an OT designated as part of the team or run paediatric oncology groups.
- The average OT EFT across the 4 national children's cancer services equates to 0.5EFT for 40 new diagnoses per year (number of new diagnoses per annum MMC)

or 1.9EFT for 140 new diagnoses per year (number of new diagnoses per annum RCH).

- Prioritisation for OT services was not consistent across different centres which appeared to be influenced by local resources and practice models. Commonly sited criteria for high priority included discharge planning, children under 2 y.o. and children/ families experiencing trauma and/or anxiety.
- OTs at two hospitals have well established roles in facilitating adjustment to illness, detecting maladjustment to illness, assisting children and families to cope with medical traumatic stress and sibling support. OTs at RCH and MMC do not currently receive referrals for these concerns.
- Two hospital departments OTs provide procedural preparation and procedural pain intervention which are not provided by RCH and MMC OT departments as this service is provided by Comfort First Program.

## 5.5 Opportunities

A number of opportunities have been identified that may support the development of a pilot program for OT services across PICS.

- The development of a screening tool to be used by nursing staff to inform referrals to OT.
- Introduction of Monash Children's at MMC may open up opportunities for paediatric oncology OT services in the future.
- The move to the new RCH site in 2011 will focus resources and staffing on providing improved patient-centred and coordinated multidisciplinary care. This is an ideal opportunity to establish the OT role as a core member of the team, providing a much needed service.
- Limited OT services are currently available for children receiving radiation at Peter Mac. This project provides an opportunity to review the specific OT needs of children receiving radiation therapy.
- Nursing in-services at both sites provide opportunities for OT to educate nursing staff about the potential roles and benefits of OT for children with cancer and their families.
- There is the potential for OT staff to play a more pro-active role in raising children's occupational performance and participation within the multidisciplinary meetings.
- The Victorian Government's Effective Discharge Strategy initiative<sup>36</sup> provided recommendations essential for good transition planning (hospital to community) including the thorough assessment of the patient's home and social circumstances— a fundamental skill of occupational therapists.
- The DHS Strategic framework for paediatric health services in Victoria<sup>37</sup> recommends the proactive identification of vulnerable children where there is developmental or environmental risk in achieving their potential, and of building parents' and families' understanding of the impact of the child's health on siblings, relationships, school and general participation in normal activities— skills of occupational therapists.
- The DHS Strategic framework for paediatric health services in Victoria and PICS are both guided by the principle of quality services provided as close as possible to the child's home. This provides opportunities to CCC OT in consulting with regional OTs to support children in their local areas.
- The annual meeting of Australian and New Zealand Children's Haematology / Oncology Group (ANZCHOG) and the local OT paediatric special interest group provide opportunities for occupational therapists across paediatric oncology services to come together to exchange ideas and experiences and identify opportunities for collaboration in the future.
- The PICS Regional Outreach and Shared Care Program (ROSCP) provides opportunities for Children's Cancer Centre OTs to strengthen links to regional OTs to better service the OT needs of children within their local communities.

## 6. The future occupational therapy service model

### 6.1 Vision and guiding principles for Children's Cancer Centre occupational therapy services

The vision for OT services in Children's Cancer:

*Children and their families will have access to high quality occupational therapy services, advice and support to enable children with cancer to participate in the everyday childhood occupations of self-care, productivity and leisure across their environments.*

The following will inform OT service provision.

#### 6.1.1 DHS Strategic Plan for paediatric health services in Victoria

The DHS Strategic Plan for paediatric health services in Victoria provides service principles for planning and providing paediatric health services. The following principles would guide the future OT service.

1. Service is of high-quality and safe
2. Child and family-centred practice is of key focus
3. Service is built on evidence, research and knowledge
4. Service works in partnerships with families and other service providers to ensure integrated care
5. Children with similar health care needs have equitable access to high quality care
6. Service is community based and provided as close as possible to child's home
7. Service is cost effective and sustainable
8. Skilled, innovative flexible workforce provides service
9. Complex activity is planned to optimize outcomes, maximize efficiencies and ensure sustainable solutions
10. Networking and evaluation frameworks enable change, monitor outcomes and improve services.

#### 6.1.2 Values, Philosophy and Strategic Plans- RCH, Southern Health and PICS

The vision and guiding principles for the Children's Cancer Centre OT service will work alongside the values, philosophy of care, and strategic goals and objectives of Southern Health, the Royal Children's Hospital and PICS.

### 6.2 Occupational Therapy screening, assessment and decision-making tools

This project proposes a pilot OT program for children diagnosed with cancer and their families for an agreed time period, followed by a comprehensive evaluation of outcomes, with the evaluation used to inform long-term service provision and resource needs.

The following process is proposed for **all** children newly diagnosed or with a new recurrence.

An **initial triage** is undertaken by medical or nursing staff to identify children who would benefit from referral to OT. The OT **Screening Tool** aims to assist medical and nursing staff to identify these patients.

**Risk stratification** occurs to identify current concerns and priority of OT need (high, medium and low).

All referred patients will then be **seen by an OT within the agreed time-frame** for their priority level; within 24 hours for those in the high priority group, 48 hours for

those in the medium priority group and within 1 week for those in the low priority group.

**Ongoing monitoring** of the OT needs of children/ adolescents will be reassessed at regular intervals in accordance with established protocols identifying changes in risk categories and resulting intervention levels.

Consistent and high quality systems will be established to support the timely identification and management of children / families who require initial and / or ongoing OT.

These include:

- agreed and consistent criteria and triggers for referral
- clear and consistent documentation of OT support within the patient medical record
- systems to facilitate timely information transfer across Children's Cancer Centre service sites and regional services
- OT interventions in accordance with established protocols across the Children's Cancer Centre and associated service sites
- common tools and processes across the Children's Cancer Centres and associated services
- streamlined processes and systems that will optimise the effective use of limited resources, within and across services

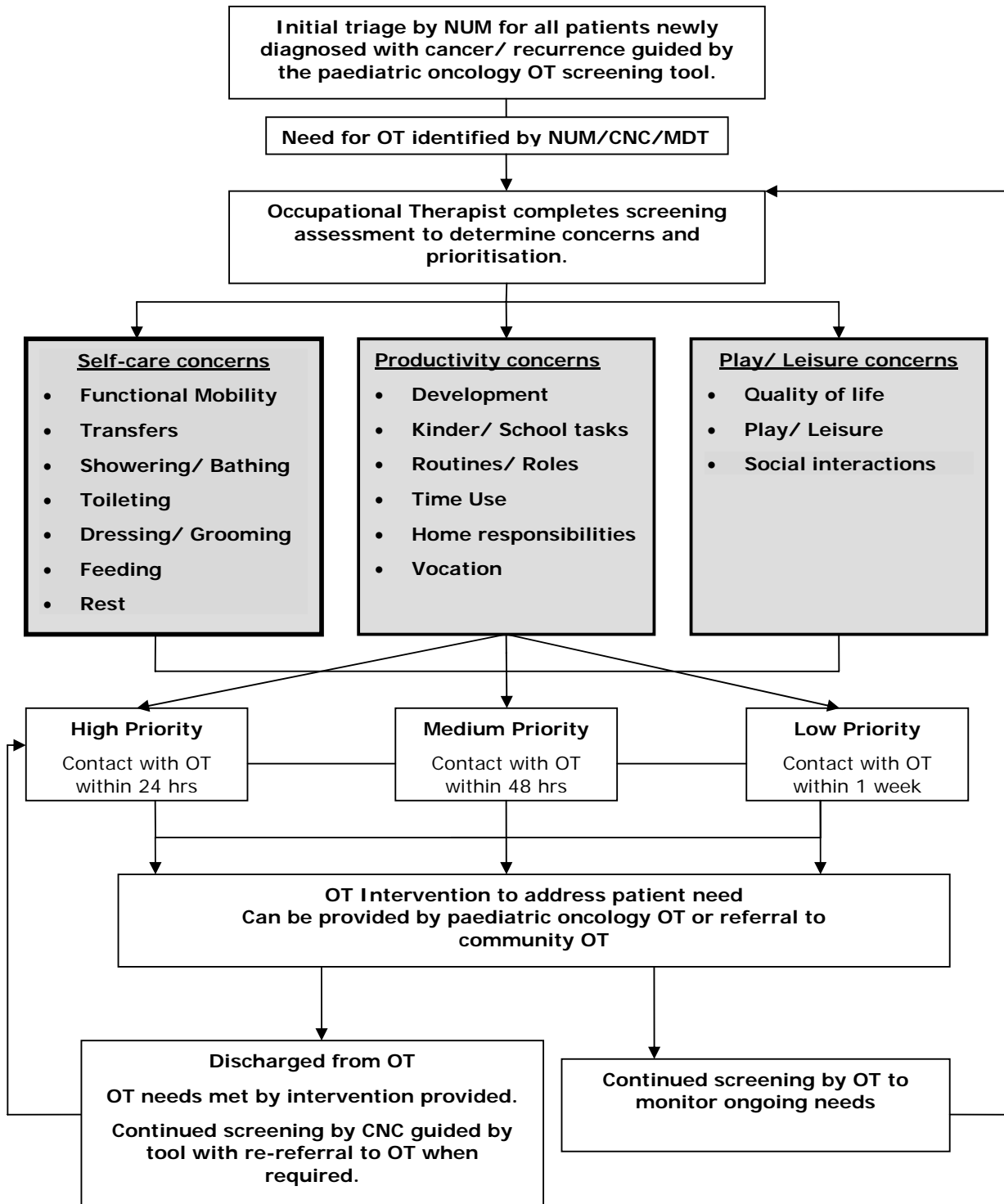
OT staff will:

- be suitably qualified in line with the appropriate grades and competencies required for their roles with specific knowledge and skills in paediatric care
- work with an approach that values and respects the skills of all team members within and across services, sites and regional services
- be committed to evidence based practice, evaluation, continuous quality improvement and research in order to improve future services for children and families
- Actively seek opportunities for collaboration with local, national and international clinical and research colleagues.

Figure 2 provides an overview of the patient pathway for all patients newly diagnosed with cancer or with a disease recurrence.

Appendix 1 outlines the OT clinical pathway for paediatric oncology across PICS sites.

Figure 2: Occupational Therapy pathway and service model



\* Intervention decision-making will be informed by the decision-making algorithm.

**Figure 3: Occupational Therapy Screening Tool**

Occupational Therapists enable children to participate fully in the occupations of life. A child's occupations are

- Self-care (showering/ bathing, toileting, un/dressing, grooming, feeding, functional mobility, transfers, rest)
- Productivity (development, gross/ fine motor skills, kinder/ school tasks, time use, routines/ roles, home responsibilities, vocation)
- Leisure (quality of life, play, recreation, social interactions)

OTs can *assess* for difficulties in these areas and *provide interventions* to enable children's participation.

**Please refer to occupational therapy if a child and/or family experience any of the following:**

*Occupational performance and participation concerns*

- significant levels of assistance required for self-care (e.g. showering, grooming, transfers) not typical of a child their age
- significant difficulties with productivity (e.g. kinder/ school tasks) or play/ leisure not typical of a child their age
- adaptive equipment required for occupations/ discharge (e.g. wheelchairs, shower/ bath aids, pressure care)
- significant decline in functional mobility
- difficulty coping in home environment or would benefit from OT home assessment
- child <2 y.o. spending significant portion of life in hospital
- concern surrounding development, motor skills or skills required for kindergarten/ school tasks
- concern surrounding transitions (e.g. kindergarten→school)
- difficulty structuring routines & managing time use
- lack of participation and engagement in meaningful occupations
- concern surrounding child's quality of life

*Diagnoses, symptoms, treatment stages & treatment received*

- brain tumours or other neurological conditions
- bone tumours or amputations
- complications including hemiplegia, weakness, balance difficulties or other physical impairment
- cognitive changes
- significant levels of fatigue, breathlessness or pain impacting upon occupations
- significant deconditioning (e.g. in bed or ICU > 2 weeks)
- treatments involving neurotoxic agents (such as vinca alkaloids, platinum compounds) which are likely to result in neuropathies
- commencement of palliative care

Table 7 provides some examples of criteria used to determine priority level based on a three tiered model.

Clinical decision making for OT prioritisation includes:

- necessity of OT for safe hospital discharge
- diagnosis, symptoms, treatment phase and treatment received
- performance in self-care, productivity and play/ leisure
- environmental concerns
- patient quality of life
- types of OT interventions required

Further work may need to be undertaken to clarify prioritisation criteria and the types of OT services offered within each level. Policies and protocols also need to be developed to guide practice (see 6.4).

**Table 7: Occupational Therapy Prioritisation**

Level	Prioritisation criteria (examples only)
<p><b>High Priority</b></p> <p>Contact within 24 hours of referral</p>	<p><b>High Priority children/ adolescents should be seen as quickly as possible.</b></p> <p><u>High priority children/ adolescents have issues including:</u></p> <ul style="list-style-type: none"> <li>• OT required for safe discharge</li> <li>• significant levels of assistance required for self-care (e.g. showering, grooming, transfers) not typical of a child their age</li> <li>• significant difficulties with productivity (e.g. kinder/ school tasks) or play/ leisure not typical of a child their age</li> <li>• significant decline in functional mobility</li> <li>• significant deconditioning (e.g. in bed or ICU &gt; 2 weeks)</li> <li>• carer/ family/ child expressing significant difficult coping with child's occupational needs outside of hospital</li> <li>• concern surrounding child's quality of life</li> <li>• brain tumours or other neurological conditions</li> <li>• bone tumours or amputations</li> <li>• treatments involving neurotoxic agents (such as vinca alkaloids, platinum compounds) which are likely to result in neuropathies</li> <li>• complications including hemiplegia, weakness, balance difficulties, vision or other physical impairment</li> <li>• cognitive changes</li> <li>• commencement of palliative care</li> <li>• undergoing radiotherapy</li> </ul> <p><u>High priority children require OT Interventions such as:</u></p> <ul style="list-style-type: none"> <li>• upper limb rehabilitation</li> <li>• transfer training</li> <li>• retraining of cognitive and perceptual dysfunction</li> <li>• adaptive equipment required for occupations (e.g. wheelchairs/seating, shower/bath aids, pressure care)</li> <li>• splinting</li> <li>• coping strategies for symptoms such as fatigue, breathlessness and pain</li> <li>• relaxation training and stress management</li> </ul>

Level	Prioritisation criteria (examples only)
	<ul style="list-style-type: none"> <li>• manual handling intervention for carers</li> <li>• home assessments</li> <li>• intervention to maximize coping with child's occupational needs at home/ outside of hospital</li> </ul>
<p><b>Medium Priority</b></p> <p>Contact within 48 hours of referral</p>	<p><b>Medium priority children/ adolescents require a level of therapeutic OT.</b></p> <p><u>Medium priority children/ adolescents have issues including:</u></p> <ul style="list-style-type: none"> <li>• difficulties with self-care, productivity or leisure/ play</li> <li>• concern surrounding development, motor skills or skills required for kindergarten/ school tasks</li> <li>• children &gt;2 years old who have spent significant portion of their life in hospital</li> <li>• concern surrounding transitions (e.g. kindergarten→school, school →workplace)</li> <li>• significant levels of fatigue, breathlessness or pain impacting upon occupations</li> <li>• significant lifestyle imbalance</li> <li>• difficulty structuring routines &amp; managing time use</li> <li>• lack of participation and engagement in meaningful occupations</li> </ul> <p><u>Medium priority children require OT Interventions such as:</u></p> <ul style="list-style-type: none"> <li>• enablement to participate in self-care, productivity or play/leisure</li> <li>• assessment &amp; promotion of normal development and age appropriate skills</li> <li>• lifestyle management, client goal setting and achievement of lifestyle balance</li> <li>• fatigue management</li> <li>• meaningful activity engagement</li> <li>• client-centred goal setting</li> </ul>
<p><b>Low Priority</b></p> <p>Contact within 1 week of referral</p>	<p><b>Low priority children have minimal deficits in self care, productivity and play.</b></p> <p><u>Low priority children/ adolescents have issues including:</u></p> <ul style="list-style-type: none"> <li>• requiring consultation from OT to maximise skills and participation in self-care, productivity and leisure</li> </ul> <p><u>Low priority children require OT interventions such as:</u></p> <ul style="list-style-type: none"> <li>• advice and education to family</li> <li>• consultation/ onward referral to the child's community or school to enable participation in self care, productivity and/ or play</li> </ul>

### 6.3 Occupational therapy interventions

The Canadian Practice Process Framework (see Figure 3) graphically illustrates the evidence-based, client-centred OT enablement that would be used for patients across all three priority levels.

Figure 9.1 Canadian Practice Process Framework (CPPF)

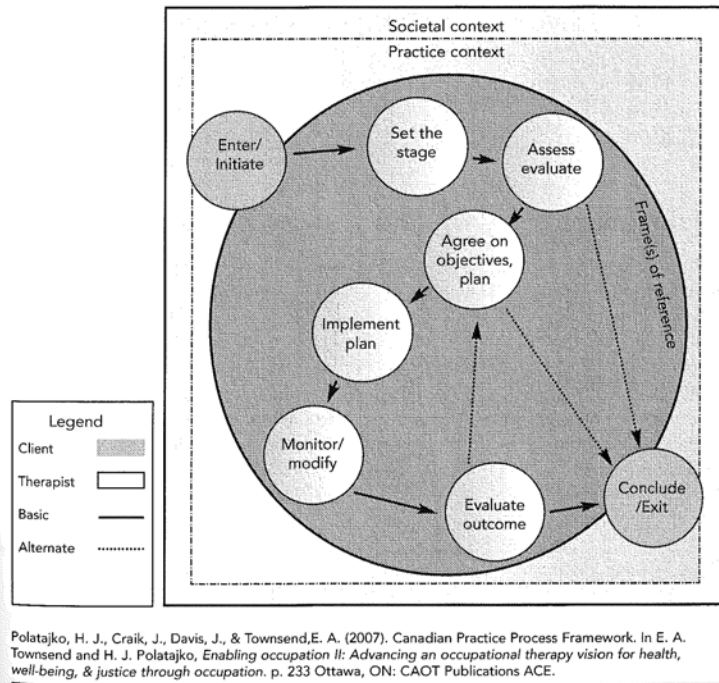


Figure 3: Canadian Practice Process Framework (CPPF)

## **6.4 Policies and protocols**

To support this proposed pilot OT program a range of written policies and protocols that guide OT service provision across all service and service providers need to be developed. Of critical importance is that:

- all service providers (specialist or generalist) adhere to an agreed decision-making algorithm
- treatment protocols and OT practices are reviewed regularly to ensure that children are accessing appropriate levels of support. Changes in treatment protocols may increase or decrease the need for OT interventions.

## **6.5 Information resources**

OTs at both sites report there is a lack of understanding about the role and benefit of OT amongst hospital staff and subsequently children and families. Provision of information to staff, children and families about services offered by OT could be disseminated in a variety of ways:

- OT service brochure available for families and Children's Cancer Centre staff
- Information included in the Children's Cancer Centre Information book
- In-services and training provided to staff in role and benefit of OT
- OT contribution to multidisciplinary meetings in both inpatient and outpatient settings to promote understanding of OT role and build links with teams

## **6.6 Strengthening coordination and continuity of care**

The coordination of care within the Children's Cancer Centres could be maximised by OTs being more available to attend in-patient ward rounds, outpatient clinics, the multidisciplinary team meetings and by having access to the Children's Cancer Centre electronic information.

The proposed pilot OT program also needs to pay attention to enhancing continuity of care across services. Given the increasing two-way transfer of children between the Children's Cancer Centres and shared care with regional centres, a continuing relationship between the OT staff at services needs to be maintained.

The use of common protocols, good information flow and preparation for the child / family for transfer to another service is essential to enhance continuity of care. Access to the Children's Cancer Centre database may also facilitate information flow.

Similarly timely communication, information transfer and providing advice and support to regional centres or to Peter Mac is essential to optimise care for the child and family at these different services.

This communication across Children's Cancer Centres, Peter Mac and regional centres can only be achieved if the OT needs of the child / family are flagged as part of the information required for transfer. Again, the Children's Cancer Centre Haematology Oncology (HO) database may facilitate this.

## **6.7 Peter MacCallum Cancer Centre**

An opportunity of the pilot OT program is to review the OT needs of children receiving radiation therapy at Peter Mac.

Radiation therapy and treatment side-effects have the potential to significantly impact children's participation in their daily occupations—as such this review is a high priority for the pilot OT program.

Peter Mac plans to explore its model of care in providing radiotherapy services to children with cancer, which may also guide how the OT needs of children having radiotherapy should be best met.

Consideration must be given to:

- information transfer from the referring service

- accessible OT services that take into consideration:
  - that families are visiting Peter Mac daily for up to six weeks
  - may have only intermittent visits to the referring Children's Cancer Centre while having radiotherapy
  - may have been referred almost immediately to Peter Mac and have limited contact with staff at the referring Children's Cancer Centre.

## 6.8 Evaluation of the pilot occupational therapy program

Following a 12 month trial of the OT pilot program, a comprehensive evaluation of outcomes is required in order to inform long term service provision and resource needs. Evaluation of the pilot includes the following steps:

### 1. Evaluation of the OT screening tool

Review of adequacy of OT screening tool to identify appropriate referrals to OT

### 2. Evaluation of risk stratification

Review of prioritisation criteria and categories to adequately inform children's OT level of need

### 3. Evaluation of OT services provided

Evaluation of the outcomes of OT intervention provided as part of the pilot

### 4. Consideration of long-term resource needs and future service provision

Use of the evaluation to inform long-term resource needs and future service provision.

## 7 Moving forward – recommendations

Working in collaboration with service providers across the RCH and MMC Children's Cancer Centres and building on the current evidence and both local and international expertise, PICS has developed a **proposal for a pilot OT program**.

It is recognised that this pilot OT program will guide the long-term service needs and resource requirements. The following recommendations are made to progress the achievement of this pilot OT program.

### Recommendations

1. The PICS Program Manager and OT managers at RCH & MMC endorse the pilot OT service proposal actively work for its successful achievement. The report is reviewed and supported by the Allied Health managers of both sites, the PICS CAC and submitted to the PICS GEC.
2. Short-term funding resources are sought to:
  - Pilot the OT service program
  - further develop the Children's Cancer Centre OT screening tool for use by nursing staff
  - trial the screening tool for an agreed time period to stratify OT needs of children coming into the CCC
  - provide OT services to children identified via screening tool
  - evaluate program outcomes
  - inform long-term service needs
  - inform long-term resource requirements.
3. This role should be for an agreed time frame initially with identifiable goals and outcomes. The role should be reviewed upon trial completion and decisions then made about the ongoing role.

4. Following a successful trial, the RCH and MMC Occupational Therapy service managers should develop business cases within their services to achieve the recommended resources required to support the future OT service.
5. RCH and MMC OT services develop handover processes to facilitate smooth transitions for patients requiring OT services across CCC sites.
6. RCH and MMC OT service managers and associated staff explore and develop a common dataset that will enable evaluation of practice across services.
7. RCH and MMC OT departments build partnerships with national and international paediatric cancer services and with local and national research groups to enhance patient outcomes.
8. OT services are supported to build their knowledge and expertise to enable them to develop a leadership role for national OT services for children with cancer and their families.

**APPENDIX 1: Occupational Therapy clinical pathway for paediatric oncology across PICS sites**

Action	Outcome	Further Information/ Exceptions
<p><b>Referral</b> Referral for OT received via</p> <ul style="list-style-type: none"> <li>- NUM/CNC/Nurse/MDT member use of screening tool</li> <li>- identification by ward OT following attendance at MDT/ ward round/ handover meeting</li> <li>- identification by member of MDT</li> <li>- child already known to OT</li> </ul>	<p>Discussion with MDT &amp; ward staff. Screened to determine concerns and priority level. Referral accepted if appropriate. Allocated to occupational therapist.</p>	<p><i>Inappropriate referral</i>- Referral declined and referrer informed.</p>
<p><b>Initiate contact</b> Occupational therapist initiates involvement and informs family of purpose of the assessment, date, time and venue.</p>	<p><i>High Priority</i>- Contact within 24 hrs <i>Medium Priority</i>- Contact within 48 hrs <i>Low Priority</i>- Contact within 1 week Consent for OT gained.</p>	<p><i>Child too ill</i>- Liaison with nursing/ medical team for appropriate timing of involvement <i>Unable to contact family</i>- Send letter to family requesting contact with OT department</p>
<p><b>Assessment</b> OT assessment undertaken. This may occur over a number of sessions.</p>	<p>Standardised and non-standardised assessment, within an agreed OT model and approach. Assessment documented in notes as appropriate. Verbal feedback of assessment provided to family and referrer/ staff as appropriate.</p>	<p>Assessments required vary based on child's individual needs. Assessment times vary in accordance with assessments required. <i>Example OT Assessments:</i></p> <ul style="list-style-type: none"> <li>• Initial interview with parents/ caregivers (1-2 hrs)</li> <li>• Observation of daily routines on ward and with parents (1-2 hrs)</li> <li>• Observations during self-care, productivity and play (1-3 hrs)</li> <li>• Physical assessment of transfers and functional mobility (1-2 hrs)</li> <li>• Upper limb assessment (1-2 hrs)</li> <li>• Bayley Scales of Infant and Toddler Development (2 hrs)</li> <li>• Miller Function &amp; Participation Scales (2hrs)</li> <li>• Bruninks-Oseretsky Test of Motor Proficiency (2hrs)</li> <li>• Peabody Developmental Motor Scales (2 hrs)</li> <li>• Handwriting Speed Test (0.5hrs)</li> <li>• Children's Assessment of Participation and Enjoyment (0.5hrs)</li> <li>• Play and leisure interests assessment (0.5hrs)</li> </ul>

		<ul style="list-style-type: none"> <li>• Home Assessment (2-4 hrs)</li> </ul> Child and family coping in home environment (1 hr) Preschool/ School Visit (2-4 hrs) Other (0.5+ hrs)
<b>Set objectives and plan</b> OT objectives, interventions and plan discussed and agreed with family.	Evidence-based measurable outcomes.  Agreed goals and treatment plan documented.	<i>Family from the country-</i> Onward referrals made to OT services in child's local community as appropriate
<b>Intervention</b> OT intervention plan implemented. Monitor and modify plans as required.	OT intervention plan implemented.	Interventions vary based on child's individual needs. Time required for intervention is dependent on the number, duration and frequency of interventions required.  <i>Example OT Interventions:</i> <ul style="list-style-type: none"> <li>• Enablement to participate in self-care, productivity and play (1+ hrs)</li> <li>• Promotion of normal development &amp; age appropriate skills (1+ hrs)</li> <li>• Upper limb rehabilitation (1+hrs)</li> <li>• Transfer training (1+ hrs)</li> <li>• Adaptive equipment prescription (1+ hrs)</li> <li>• Splinting (2+ hrs)</li> <li>• Manual handling intervention for carers (0.5-2hrs)</li> <li>• Advice and education to family (0.5-2hrs)</li> <li>• Coping strategies for symptoms such as fatigue, breathlessness and pain (1+ hrs)</li> <li>• Retraining of cognitive and perceptual dysfunction (1+hrs)</li> <li>• Relaxation and stress management (1+hrs)</li> <li>• Client-centred goal setting (0.5+ hrs)</li> <li>• Lifestyle balance achievement (0.5+hrs)</li> <li>• Meaningful activity engagement (1+hrs)</li> <li>• Consultation to child's pre-school/ school (0.5-4 hrs)</li> <li>• Home visits and home modifications (2-8 hrs)</li> <li>• Onward referrals to child's community to enable participation self-care, productivity, play (2-4hrs)</li> <li>• Other</li> </ul>
<b>Evaluation and Discharge</b> Conclude treatment. Evaluate	Outcomes evaluated. Therapeutic targets met.	<i>Therapeutic targets not met-</i> Onward referral if indicated (community or another professional)

outcomes. Discharge.	Discharged from OT.	<i>Requires further review</i> - File remains open until OT review completed (e.g. 1 month, 3 month)
----------------------	---------------------	--

**APPENDIX 2: Proposed service activity by Children’s Cancer Centre for 12 month clinical pilot of occupational therapy program**

Activity	Site	Level of activity
<b>Referral, risk stratification, discussion with MDT, allocation to OT</b>	RCH	129 children seen by OT per annum <ul style="list-style-type: none"> <li>• 100% (29 of 29<sup>^</sup>) newly diagnosed with brain tumours (1 hr per referral)</li> <li>• 20% (20 of 100<sup>^</sup>) of newly diagnosed liquid/ solid tumour who require a therapeutic level of OT (1 hr per referral)</li> <li>• 20% (20 of 100<sup>^</sup>) of newly diagnosed liquid/ solid tumour who require consultative OT (0.5 hr per referral)</li> <li>• 25% (10 of 40<sup>^</sup>) children with recurrence per annum (1 hr per referral)</li> <li>• 40 children per annum who need reassessment for other reasons (1 hr per referral)</li> <li>• 10 (33% of 30<sup>^</sup>) children requiring BMT (1 hr per referral)</li> </ul>
	MMC	<b>33 children seen by OT per annum</b> <ul style="list-style-type: none"> <li>• <b>100% (6 of 6<sup>^</sup>) newly diagnosed with brain tumours</b></li> <li>• <b>20% (6 of 29<sup>^</sup>) children newly diagnosed with liquid/ solid tumour requiring therapeutic level of OT</b></li> <li>• <b>20% (6 of 29<sup>^</sup>) children newly diagnosed with liquid/ solid tumour requiring consultative OT</b></li> <li>• <b>25% (5 of 20<sup>^</sup>) children with recurrence per annum</b></li> <li>• <b>10 children per annum who need reassessment for other reasons</b></li> </ul>
<b>Contact with family, family informed of purpose of assessment</b>	RCH	<ul style="list-style-type: none"> <li>• An estimated 129 contacts pa (0.5 hr per contact)</li> </ul>
	MMC	<ul style="list-style-type: none"> <li>• <b>Estimated 33 contacts pa (0.5 hr per contact)</b></li> </ul>
<b>Occupational Therapy Assessment</b>	RCH	<ul style="list-style-type: none"> <li>• 29 newly diagnosed brain tumours (4 hrs Ax per child)</li> <li>• 70% (70 of 100) other referrals requiring therapeutic level of OT (2 hrs Ax per child)</li> <li>• 30% (30 of 100) other referrals requiring consultative level of OT (1 hr Ax per child)</li> </ul>
	MMC	<ul style="list-style-type: none"> <li>• <b>6 newly diagnosed brain tumours (4 hrs Ax per child)</b></li> <li>• <b>70% (19 of 27) other referrals requiring therapeutic level of OT (2 hrs Ax per child)</b></li> <li>• <b>30% (8 of 27) other referrals requiring consultative level of OT (1 hr Ax per child)</b></li> </ul>

<b>Objectives and plan formulated with child and family</b>	RCH	<ul style="list-style-type: none"> <li>Estimated 129 encounters (0.5hr per objectives/plan)</li> </ul>
	MMC	<ul style="list-style-type: none"> <li><b>Estimated 33 encounters (0.5 hr per objectives/plan)</b></li> </ul>
<b>Occupational Therapy intervention</b> <b>Intervention monitored and modified as required</b>	RCH	<ul style="list-style-type: none"> <li>29 newly diagnosed brain tumours (12 hrs 1x per child)</li> <li>70 children requiring therapeutic OT (8hrs 1x per child)</li> <li>30 children requiring consultative OT (2hrs 1x per child)</li> </ul>
	MMC	<ul style="list-style-type: none"> <li><b>6 newly diagnosed brain tumours (12 hrs 1x per child)</b></li> <li><b>19 requiring therapeutic OT (8hrs 1x per child)</b></li> <li><b>8 requiring consultative OT (2hrs 1x per child)</b></li> </ul>
<b>Conclusion of intervention and evaluation of outcomes</b>	RCH	<ul style="list-style-type: none"> <li>29 newly diagnosed brain tumours (1hr per child)</li> <li>70 requiring therapeutic OT (1 hr per child)</li> <li>30 requiring consultative OT (0.5 hr per child)</li> </ul>
	MMC	<ul style="list-style-type: none"> <li><b>6 newly diagnosed brain tumours (1 hr per child)</b></li> <li><b>19 requiring therapeutic OT (1 hr per child)</b></li> <li><b>8 requiring consultative OT (0.5 hr per child)</b></li> </ul>
<b>Attendance at MD and ward meetings</b>	RCH	<ul style="list-style-type: none"> <li>4 hours per month for 12 months</li> </ul>
	MMC	<ul style="list-style-type: none"> <li><b>2 hours per month for 12 months</b></li> </ul>
<b>Regional support for shared care</b>	RCH	<ul style="list-style-type: none"> <li>Average of 2 hour per week</li> </ul>
	MMC	<ul style="list-style-type: none"> <li><b>Average of 20 minutes per week</b></li> </ul>

## References

---

- <sup>1</sup> Wallace W, Blacklay A, Davies H, Hawkins M. Developing strategies for long-term follow up of survivors of childhood cancer. **British Medical Journal**. 2001. 1995. 323:271-274.
- <sup>2</sup> Polatjko HJ, Townsend EA, Craik J. Enabling occupation II: Advancing an occupational therapy vision of health, well-being & justice through occupation. Ottawa: CAOT Publications ACE; 2007.
- <sup>3</sup> Tester C. Occupational therapy in paediatric oncology and palliative care. In: Cooper J, editor. *Occupational Therapy in Oncology and Palliative Care*. 2<sup>nd</sup> ed. West Sussex: Wiley; 2006. p. 107-124.
- <sup>4</sup> Liddle J, McKenna K. Quality of life: an overview of issues for use in occupational therapy outcome measurement. *Aus Occup Ther J*. 2000 47: 77-85.
- <sup>5</sup> Eiser C, Havermans T, Craft A, Kernahan J. Development of a measure to assess the perceived illness experience after treatment for cancer. *Arch Dis Child*. 1995 72: 302-307.
- <sup>6</sup> Eiser C, Havermans T, Craft A, Kernahan J. Development of a measure to assess the perceived illness experience after treatment for cancer. *Arch Dis Child*. 1995 72: 302-307.
- <sup>7</sup> Liddle J, McKenna K. Quality of life: an overview of issues for use in occupational therapy outcome measurement. *Aus Occup Ther J*. 2000 47: 77-85.
- <sup>8</sup> College of Occupational Therapists, HOPE The Specialist Section of Occupational Therapists in HIV/AIDS, Oncology, Palliative Care and Education. *Occupational therapy intervention in cancer. Guidance for professionals, managers and decision-makers*. London. COT. 2004.
- <sup>9</sup> Doble SE, Santha JC. Occupational well-being: Rethinking occupational therapy outcomes. *Can J Occup Ther*. 2008; 75(3):184-190.
- <sup>10</sup> Case-Smith J, Allen AS, Pratt P. *Occupational Therapy for Children*. 3<sup>rd</sup> Edition. St Louis: Mosby; 1996.
- <sup>11</sup> Sidhu R. Tutorial: The role of the oncology OT at Princess Margaret Hospital. Unpublished; 2007.
- <sup>12</sup> Strong J. Occupational therapy and cancer rehabilitation. *Brit J Occup Ther*. 1987; 50(1): 4-6.
- <sup>13</sup> Strong J. Occupational therapy and cancer rehabilitation. *Brit J Occup Ther*. 1987; 50(1): 4-6.
- <sup>14</sup> Nelson A, Allison H. A visiting occupational therapy service to indigenous children in school: results of a pilot project. *Aus J Indig Ed*. 2004 33: 55-60.
- <sup>15</sup> Cooper J, editor. *Occupational Therapy in Oncology and Palliative Care*. 2<sup>nd</sup> Edition. West Sussex: Wiley; 2006.
- <sup>16</sup> Lloyd C, Coggles L. Psychosocial issues for people with cancer and their families. *Can J Occup Ther*. 1990 October; 57 (4): 211- 215.
- <sup>17</sup> College of Occupational Therapists, HOPE The Specialist Section of Occupational Therapists in HIV/AIDS, Oncology, Palliative Care and Education. *Occupational therapy intervention in cancer. Guidance for professionals, managers and decision-makers*. London. COT. 2004.
- <sup>18</sup> Armitage K, Crowther L. The role of the occupational therapist in palliative care. *Europ J Pall Care*. 1999 June (5): 154-157.
- <sup>19</sup> Cooper J, editor. *Occupational Therapy in Oncology and Palliative Care*. 2<sup>nd</sup> Edition. West Sussex: Wiley; 2006.
- <sup>20</sup> Romsaas EP, Rosa SA. Occupational therapy intervention for cancer patients with metastatic disease. *Am J Occup Ther*. 1985 39(2) 79-87
- <sup>21</sup> Welch A, Lowes S. Home assessment visits within the acute setting: a discussion and literature review. *Brit J Occup Ther*. 2005; 68(4): 158-64.
- <sup>22</sup> Atwal A, McIntyre A, Craik C, Hunt J. Occupational therapists' perceptions of pre-discharge home assessments with older adults in acute care. *Brit J Occup Ther*. 2008 71(2):52-58.
- <sup>23</sup> Victorian Government Department of Human Services. *Improving patient transition from hospital to the community: A good practice guide for hospitals* 2003.
- <sup>24</sup> Hoy J, Twigg V, Pearson E. Occupational therapy home assessments: more than just a visit? An audit of occupational therapy practice in oncology and palliative care. *Brit J Occup Ther*. 2008 Feb 71 (2): 59-63.

- 
- <sup>25</sup> Hoy J, Twigg V, Pearson E. Occupational therapy home assessments: more than just a visit? An audit of occupational therapy practice in oncology and palliative care. *Brit J Occup Ther*. 2008 Feb 71 (2): 59-63.
- <sup>26</sup> Sidhu R. Tutorial: The role of the oncology OT at Princess Margaret Hospital. Unpublished; 2007.
- <sup>27</sup> Sidhu R. Tutorial: The role of the oncology OT at Princess Margaret Hospital. Unpublished; 2007.
- <sup>28</sup> Stowell M. Psychosocial role of the occupational therapist with pediatric bone marrow transplant patients. *Occup Ther Ment Health*. 1987.7(2): 39-50.
- <sup>29</sup> Ewer-Smith C, Patterson S. The use of an occupational therapy programme within a palliative care setting. *Europ J Pall Care*. 2002 9 (1):30-33.
- <sup>30</sup> Cooper J, editor. *Occupational Therapy in Oncology and Palliative Care*. 2<sup>nd</sup> Edition. West Sussex: Wiley; 2006.
- <sup>31</sup> Cooper J, editor. *Occupational Therapy in Oncology and Palliative Care*. 2<sup>nd</sup> Edition. West Sussex: Wiley; 2006.
- <sup>32</sup> Strategic framework for paediatric health services in Victoria (2009). Victorian Government Department of Human Services.
- <sup>33</sup> Polatjko, H.J., Townsend, E.A., Craik, J. (2007). Canadian Model of Occupational Performance and Engagement (CMOP-E) in E. A. Townsend and H.J. Polatjko, *Enabling Occupation II: Advancing an Occupational Therapy Vision of Health, Well-being & Justice through Occupation*. p.23 Ottawa, ON:CAOT Publications ACE.
- <sup>34</sup> Polatjko HJ, Townsend EA, Craik J. *Enabling occupation II: Advancing an occupational therapy vision of health, well-being & justice through occupation*. Ottawa: CAOT Publications ACE; 2007.

<sup>36</sup>Victorian Government Department of Human Services. *Improving patient transition from hospital to the community: A good practice guide for hospitals* 2003.