Provincial Council for Maternal and Child Health

building a brighter future

Complex Care for Kids Ontario Standard:
Medical Care Plan

Version Date: May 9, 2017

Medical Care Plan Standard for Medically Fragile and Technology Dependent Children

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Medical Care Plan Standards: Content Short Form

The following are standard data elements to be included in a medical care plan:

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- ☐ **Caregiver Names and contact**
- ☐ **Legal Guardian and contact**
- ☐ **Advance Directives (indicate documented decisions)**
- ☐ **Diagnosis**
- ☐ **Short Non-medical Description of the child**
- ☐ **Complex Care primary contacts: clinical key worker[2], physician**

- ☐ **ER Management**
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  - ☐ **List of Physicians and Programs Followed at Tertiary Hospital or Community**
  - ☐ **Special Needs Strategy: Coordinated Service Planning Care Coordinator**
  - ☐ **LHIN Care Coordinators**

[2] The key clinical worker is the primary point of contact for the child and family and is a regulated health professional, ideally a Nurse Practitioner.

Medical Care Plan Standards: Process Short Form

The following are process standards for the development, sharing, maintenance, and use of medical care plans:

1	**Child/family enrolled in the complex care program have a medical care plan**
2	**Clinical key worker is responsible for the development and maintenance of the medical care plan in partnership with child/parent/and care team**
3	**Child/parent approves the information included in the medical care plan**
4	**Parents coached and educated in the purpose and use of the medical care plans**
5	**Most up-to-date medical care plan is made available in the child's medical record**
6	**The child/parent receives a copy of the medical care plan and works with the clinical key worker to identify the individuals/teams (hospital and community) required to receive the medical care plan**
7	**Medical care plans shared with identified care team (hospital and community) members and parents**
8	**Medical care plans reviewed and updated, as required, after each regularly scheduled complex care clinic visit, hospital admission, or as urgent changes arise**

Background

A medical care plan is a written document that outlines the major medical issues and care needs for a specific child and is created by the health care provider in collaboration with the family[1]. From the literature, and from speaking with families and health care providers, there is agreement that a medical care plan is a useful tool and improves quality of care. Currently each CCKO region has its' own variation and use of the medical care plan. It is important to recognize the amount of time and resources that it takes to create a medical care plan in collaboration with multiple providers and families. Therefore it is important to ensure that the medical care plans are optimized to ensure that important content is included in the medical care plan and that the medical care plan are used effectively.

By standardizing the medical care plan content and process we aim to provide a consistent support to the child and family's enrolled in complex care clinics within the Provincial Council for Maternal and Child Health's 'Complex Care for Kids Ontario (CCKO) Strategy'.

These standards were developed through the CCKO team at PCMCH working with the members of the Medical Care Plan Standards Work Group (see Appendix A)

Information was gathered through various sources, including a survey of medical care plans currently used in each CCKO region, other types of medical care plans, literature, and previous work done by PCMCH (see Appendix B – Definitions and Desired Characteristics. This information was used to guide the medical care plan content and process discussions.

Standard updates and revisions schedule: 12 months, or when new evidence is presented.

[1] Adams et al.: Exploring the usefulness of comprehensive care plans for children with medical complexity (CMC): a qualitative study. BMC Pediatrics 2013 13:10.

Content Standard: Long Form

Standard Content

The following are the minimum data elements and processes to be included in a medical care plan. Regions may choose to add additional content and processes.

Data Element	Comments
Child Identification	Includes child's full name, DOB, health care number, MRN (specify the organization), phone number, home address
Allergies/Reaction/Alerts	Include NPO
Caregiver Names and contact	Include name, number (specify home or cell), parent/caregiver relationship to child
Legal Guardian and contact	This may be a different individual than the caregiver
Advance Directives	Indicates advanced directives Include care directives last updated -where to access the care directive document and team associated with this conversation
Diagnosis	List most important first
Short Non-medical Description of the child	Information about the child's likes and dislikes, ask the parents about what they would like people to know about their child
Complex Care Primary contacts	Include email and phone number for Clinical key worker and Physician at Tertiary Centre
ER Management	Include if there is something special that needs to be done in case of presentation to ER, unique management needs For example, atypical seizure management, unusual medication, unique bloodwork
Medication List • Scheduled and PRN Medication • Parenteral and/or G-tube feeds	Include information re: dose (mg), route, frequency, comments. List prescribed medication first and 'as needed' medication at the end. Comment section should include specific information or comments regarding the medication.

Data Element	Comments
	Include parenteral or G tube feedings. Indicate ml/day, kcal/kg and g/kg protein
Growth parameters & unusual 'normals' in vital signs or physique	Include height, weight, head circumference (<2 years old), date of when measurements were taken Percentile should be calculated according to WHO guidelines Indicate any unique physical findings, for example a lower than standard oxygen saturation parameter, heart murmur, enlarged liver
Communication	Describe how the child communicates, such as crying or other verbal cues Other augmentative communication devices May also be included in *Current Issues or Technology*
Technology/Technology Support	Specify type, make, size, date routine care (eg. suction q4 if applicable) Can include for example, G-Tubes, trach, oxygen, suction catheter, wheelchair, etc.
Current Issues (system based)	Contain relevant (system based) information such as: - Genetic/Metabolic - Neurologic - Ophthalmologic - HEENT - Respiratory - Cardiac - GI/Nutrition - GU/Renal - Musculoskeletal - Dermatologic - Development - Social-school - Relevant family information It is recommended to add a key intervention/action plan such as referral to medical specialist, therapist (OT, PT, SLP etcetera), advocating for services at school meeting. One place to include actions might be in this section, linked to the system issue.

Data Element	Comments
Adaptive seating **Mobility aids**	Can be included in *Current Issues or Technology*
What I want for my child *Commonly referred to as' Patient care goals'*	This will describe the goals of care, generally and specifically how they will allow the child to participate in daily life and reach their potential (family, friends, school) For example, seizures controlled so that the child can attend school safely
Immunizations	Indicate if required childhood immunizations up to date. Indicate addition immunizations related to child's vulnerability i.e. RSV, influenza, etc.
Signature	Name of person updating content and date of update (electronic trail sufficient)
Last updated	Date (electronic trail sufficient if present)
Contact List	**Include name, phone, email, fax**
Family Physician/Paediatrician	
List of Physicians and Programs Followed at Tertiary Hospital or Community	Include name and specialty
SNS Coordinated Service Planning Care Coordinator	Identify that a plan exists and document the name and contact info of the coordinator
LHIN Care Coordinators	This information can be helpful for clinicians to advocate for services

Recommended Content

Recommendation #1: The Items are listed according to the recommended **order of appearance** in a medical care plan.

Recommendation #2: The following are additional recommended **data elements** to be included in a medical care plan:

Data Elements	Comments
Photo of child	Photo should be good quality as the medical care plan may be photocopied

Language Spoken	
Action Items	Include action items that are underway such as referral to other providers. This allows providers to be informed of the referrals and to follow-up on status

Recommendation #3: Recommended additional **contact information** organization/people to include in a medical care plan are:

Contact List	Include name, phone, email, fax
Community pharmacy	
Children's Treatment Centre	
Allied Health	
Respite	
Children's Aid	
Information Support network (family and friends)	
Home care respirator company	
Nursing agency case manager	

Process Standard: Long Form

The following are process standards for the development, sharing, maintenance, and use of medical care plans by complex care programs within the CCKO initiative.

Process indicators that are not provincial metrics, may be useful for quality improvement work within complex care programs.

1	**Child/family enrolled in the complex care program have a medical care plan**

Children enrolled in the complex care programs will have an individualized medical care plan that outlines the major medical issues and care needs for that specific child. Medical care plans will be developed according to the Medical Care Plan Content Standards.

Recommendation: Child/parent have a medical care plan created and finalized within a maximum of 6 weeks from initial complex care visit

Process Indicator: Percentage of children enrolled in the complex care program who have a medical care plan

2	**Clinical key worker is responsible for the development and maintenance of the medical care plan in partnership with child/parent/and care team**

Ensure that families are engaged as partners in this shared care planning process, and as such are encouraged to contribute input to all goals, strategies and plans. The Clinical Key Worker and the Child/Parent are listened to and treated with respect.

3	**Child/parent approves the information included in the medical care plan**

All information included in the medical care plan is approved by the child/family. Child/family feels comfortable with the information that is being shared with medical care plan users. The medical care plan is written in familiar and comfortable language.

4	**Parents coached and educated in the purpose and use of the medical care plans**

Process Indicator: number of parents coached and educated in the purpose and use of the medical care plans.

5	**Most up to date medical care plan is made available in the child's medical record**

Medical care plans stored in the child's medical record

Process Indicator: Percentage of medical care plans uploaded to child's medical record.

6	**The child/parent receives a copy of the medical care plan and works with the clinical key worker to identify the individuals/teams (hospital and community) required to receive the medical care plan**

Child/family receives a copy of the medical care plan. The Clinical Key Worker and the Child/Family identifies together the additional people that should receive a copy of the medical care plan.

Recommendation: Medical care plan shared with families within two weeks of initial medical care plan ready for distribution.

Process Indicator: Percentage of child/family who receive a copy of the medical care plan within two weeks of initial medical care plan ready for distribution

7	**Medical care plans shared with identified care team (hospital and community) members and parents**

8	**Medical care plans reviewed and updated, as required, after each regularly scheduled complex care clinic visit, hospitalization or as urgent changes arise**

The medical care plans remain fluid and is actively used; it can be updated by the Clinical Key Worker as per family and health care providers, which keep it current and establishes it as a continuous feedback and communication tool. Updating the medical care plan is a standard part of each complex care clinic visit, when a hospital admission has been required or urgent clinical issues arise, and the medical care plan is modified in response to child/parents' changing needs.

Processes to maintain the currency of the medical care plan are encouraged within *quality improvement* work at the organizational level.

Important areas to be addressed

While out of scope for this work, the Medical Care Plan Standards Work Group recommends that opportunities to address the following be considered in order to keep the medical care plan a living document:

1. **Centralized access** to the medical care plan by the parents and circle of care
- Automatic alerts when the document has been altered
- Process development to ensure safety, accuracy and agreement

Appendix A - Work Group Members and Change Log

Work Group Membership List

Team Membership List		
Name	Position	Organization
Sherri Adams	Nurse Practitioner	Hospital for Sick Children
Erin Brandon	Nurse Practitioner	Holland Bloorview Kids Rehabilitation
Jason Buera	Patient Information Coordinator	Hospital for Sick Children
Karen Morris	Nurse Practitioner	Children's Hospital of Eastern Ontario
Ashley Inman	Nurse Practitioner	McMaster Children's Hospital
Ryan Smith	Paediatrician	Orillia Solder's Memorial Hospital
Danielle Heibein	Nurse Practitioner	Children's Hospital - LHSC
Rahul Ohja	Paediatrician/Physician	Children's Hospital - LHSC
Kim McCleod	Parent Representative	

- All members should have used care plan

Change Log

Change Log						
#	Description of change	Requestor	Date requested	Date approved	Status	Comments
	Click here to enter text.	Click here to enter text.	Click here to enter a date.	Click here to enter a date.	Choose an item.	Click here to enter text.
	Click here to enter text.	Click here to enter text.	Click here to enter a date.	Click here to enter a date.	Choose an item.	Click here to enter text.
	Click here to enter text.	Click here to enter text.	Click here to enter a date.	Click here to enter a date.	Choose an item.	Click here to enter text.

	Click here to enter text.	Click here to enter text.	Click here to enter a date.	Click here to enter a date.	Choose an item.	Click here to enter text.
	Click here to enter text.	Click here to enter text.	Click here to enter a date.	Click here to enter a date.	Choose an item.	Click here to enter text.

Appendix B – Definitions and Desired Characteristics

The following definitions/assumptions about what a care plan is and what the key characteristics of a shared care planning tool should be were established to ground and guide the PCMCH work related to coordinated care planning. These definitions were endorsed by the participants of the PCMCH Expert Panel.

What is a Care Plan?

A care plan is:

- A goals-based, child & family focused, point of care service plan crafted by an inter-professional team that includes action plans for achieving goals
- A documented, up-to-date, summary of info pertinent to the holistic care of a client
- An outline of major health issues and care needs to assist with care coordination
- An efficient and accurate tool that brings all members of the integrated care team1* up to speed and facilitates dialogue between team members

A care plan is not:

- A comprehensive electronic medical record
- A static document
- Two way communication – in other words, it is not the primary source of communication between integrated care team members*

Important characteristics for a shared care planning tool

PCMCH used the Strategic Framework for the Advancement of Province-wide Integrated Care and Service Coordination for Children with Medical Complexity (See Appendix 1) and a report on leading practices in medical care coordination from Health Quality Ontario (HQO) to develop the following characteristics of an effective plan of care. These characteristics were endorsed by the PCMCH Expert Panel in November 2014:

A shared care planning tool should:

- Be designed for the benefit of the child/youth/family - reflecting their stated goals, needs and preferences
- Address the medical, psychosocial and coordination needs of the child and their family
- Identify all of the integrated care team members and their individual contributions and accountabilities towards the child's care plan goals

- Have an inter-professional focus and be accessible across the continuum of care (i.e., community care, primary care, acute care, rehabilitation, community and social supports and education) and to any person identified as important by the family as important to the child's health and care
- Be anticipatory & reflect that the integrated care team members have thought ahead to consider likely outcomes and alternatives when health status improves or declines
- Include proactive measures to address future health problems and care/life transitions before they occur, including transitions to adulthood/adult services
- Act as a single source of information for the care team
- Include a one to two page summary of critical information about the child and family and their care plan
- Provide flexibility to expand sections of the tool based on the child's care needs (e.g. option to expand medications section to accommodate the number of medications many CMC are taking)
- Remain fluid and is actively used; it can be altered by the family and providers, which keep it current and establishes it as a continuous feedback and communication tool
- Include an action plan and actionable items for future care.*
- Be supported by technology-enabled and in-person communication

Adapted from the following sources: PCMCH Strategic Framework, HQO literature review, ICCM-IECP Phase 1 Overview

**Inserted April 2017*