# Physical Therapy Management of Congenital Muscular Torticollis: A 2018 Evidence-Based Clinical Practice Guideline From the APTA Academy of Pediatric Physical Therapy

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The APTA APPT welcomes comments on this guideline. Comments may be sent to torticolliscpg@gmail.com. This guideline may be reproduced for educational and implementation purposes.

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This clinical practice guideline has been endorsed by the American Physical Therapy Association.

# ABSTRACT

Background: Congenital muscular torticollis (CMT) is a postural deformity evident shortly after birth, typically characterized by lateral flexion/side bending of the head to one side and cervical rotation/head turning to the opposite side due to unilateral shortening of the sternocleidomastoid muscle; it may be accompanied by other neurological or musculoskeletal conditions. Infants with CMT should be referred to physical therapists to treat these postural asymmetries as soon as they are identified. Purpose: This update of the 2013 CMT clinical practice guideline (CPG) informs clinicians and families as to whom to monitor, treat, and/or refer and when and what to treat. It links 17 action statements with explicit levels of critically appraised evidence and expert opinion with recommendations on implementation of the CMT CPG into practice. Results/Conclusions: The CPG addresses the following: education for prevention; referral; screening; examination and evaluation; prognosis; first-choice and supplemental interventions; consultation; discontinuation from direct intervention; reassessment and discharge; implementation and compliance audits; and research recommendations. Flow sheets for referral paths and classification of CMT severity have been updated. (Pediatr Phys Ther 2018;30:240-290)

# Key words: clinical practice guideline, congenital muscular torticollis, infant

This 2018 Congenital Muscular Torticollis Clinical Practice Guideline (2018 CMT CPG) is an update of the 2013 Congenital Muscular Torticollis Clinical Practice Guideline (2013 CMT CPG).<sup>1</sup> It is intended as a reference document to guide physical therapists (PTs), families, health care professionals, and educators to improve clinical outcomes and health services for children with congenital muscular torticollis (CMT) and to inform future research. Accepted international methods of evidencebased practice were used to systematically search for peerreviewed literature, assign levels of evidence (Table 1), summarize the literature, formulate action statements, and assign grades for each action statement (Table 2).

Table 3 (also available as Supplemental Digital Content [SDC] at: http://links.lww.com/PPT/A223) summarizes the 17 action statements with their 2018 status. They are organized under 4 major headings: Education, Identification, and Referral

of Infants With Asymmetries/CMT; Physical Therapy Examination and Evaluation of Infants With Asymmetries/CMT; Physical Therapy Intervention for Infants With CMT; and Physical Therapy Discontinuation, Reassessment, and Discharge of Infants With CMT. Following the summary (see Table 3), descriptions of the CPG purpose, scope, and methods are followed by the action statements with standardized profiles of information based on the Institute of Medicine's (IOM's) criteria for transparent clinical practice guidelines (CPGs) (http:// nationalacademies.org/hmd/reports/2011/clinical-practiceguidelines-we-can-trust.aspx). Research recommendations

are placed within the text where the topics arise and are collated at the end of the document. Evidence tables on measurement, the first-choice intervention, supplemental interventions, and long-term follow-up are available as SDC and at https://pediatricapta.org/clinical-practice-guidelines.

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# SUMMARY

GENERAL GUIDELINE IMPLEMENTATION STRATEGIES
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Levels of evidence are assigned on the basis of a combination of a risk of bias assessment and the quality of the outcome measures used in a study. Multiple outcome measures in a single study may have stronger or weaker psychometric properties and thus individual outcomes receive stronger or weaker levels of evidence, respectively. Recommendation grades A to C are consistent with the levels of evidence in the BRIDGE-Wiz software deontics.<sup>2</sup> BRIDGE-Wiz is designed to generate clear and implementable recommendations consistent with the IOM recommendations for transparency.3 These include a standardized content outline of a title; a recommendation with an observable action statement; indicators of the evidence quality and the strength of the recommendation; a list of benefits, harms, and costs associated with the recommendation; a delineation of the assumptions or judgments made by the guideline development group (GDG) in formatting the recommendation; reasons for intentional vagueness in the recommendation; quality improvement, implementation, and audit ideas; and a summary and clinical interpretation of the evidence supporting the recommendation. Theoretical/Foundational (grade D) and Practice Recommendations (grade P) are not generated with BRIDGE-Wiz. Grade D is based on basic science or theory, and grade P is determined by the GDG to represent current best physical therapy practice or exceptional situations for which

studies cannot be performed. Research recommendations identify missing or conflicting evidence, for which studies might either improve examination and intervention efficacy or minimize unwarranted variation.

#### **Status Definitions**

These terms are used in the Summary of Action Statements table (see Table 3, also available at http://links.lww.com/PPT/ A223) to indicate changes from the 2013 CMT CPG.<sup>1</sup>

- New—An action statement that was not in the prior version.
- **Upgraded with new evidence**—The action statement has a stronger grade than previously with new references.
- **Downgraded with new evidence**—The action statement has a weaker grade than previously with new references.
- **Revised and updated**—The action statement has been reworded for clarity with new references.
- **Revised**; **no new evidence**—The action statement has been reworded for clarity with no new references.
- **Reaffirmed and updated**—The action statement is unchanged but has new references.
- **Reaffirmed**; no new evidence—The action statement is unchanged and has no new references.
- **Retired**—An action statement that is withdrawn.

#### TABLE 1: LEVEL OF EVIDENCE

ļ	
Level	Criteria
Ι	Evidence obtained from high-quality diagnostic studies, prognostic or prospective studies, cohort studies or randomized controlled trials, meta-analyses, or systematic reviews (critical appraisal score >50% of criteria)
II	Evidence obtained from lesser-quality diagnostic studies, prognostic or prospective studies, cohort studies or randomized controlled trials, meta-analyses, or systematic reviews (eg, weaker diagnostic criteria and reference standards, improper randomization, no blinding, <80% follow-up) (critical appraisal score <50% of criteria)
III	Case controlled studies or retrospective studies
IV	Case studies and case series
V	Expert opinion

#### **TABLE 2: RECOMMENDATION GRADES FOR ACTION STATEMENTS**

H		
Grade	Recommendation	Quality of Evidence
А	Strong	A preponderance of level I studies, but at least one level I study directly on the topic support the recommendation.
В	Moderate	A preponderance of level II studies, but at least one level II study directly on topic support the recommendation.
С	Weak	A single level II study at <25% critical appraisal score or a preponderance of level III and IV studies, including consensus statements by content experts support the recommendation.
D	Theoretical/ foundational	A preponderance of evidence from animal or cadaver studies, from conceptual/theoretical models/principles, from basic science/bench research, or from published expert opinion in peer-reviewed journals supports the recommendation.
Р	Best practice Recommended practice based on current clinical practice norms, exceptional situations where validating studies ha not or cannot be performed, and there is a clear benefit, harm or cost, and/or the clinical experience of the guide development group.	
R	Research	There is an absence of research on the topic, or higher-quality studies conducted on the topic disagree with respect to their conclusions. The recommendation is based on these conflicting or absent studies.

# SUMMARY AND STATUS OF ACTION STATEMENTS FOR THE 2018 CONGENITAL MUSCULAR TORTICOLLIS CLINICAL PRACTICE GUIDELINE

#### TABLE 3: SUMMARY AND STATUS OF ACTION STATEMENTS FOR THE 2018 CONGENITAL MUSCULAR TORTICOLLIS CLINICAL PRACTICE GUIDELINE

Action Statement	Status FNITAL MUSCULAR TORTICOLL	Page IS (CMT)
		252
P Action Statement 1: EDUCATE EXPECTANT PARENTS AND PARENTS OF	New	253
NEWBORNS TO PREVENT ASYMMETRIES/CMT. Physicians, nurse midwives,		
therapiete should adjuste and desument instruction to all supertaints and parents of		
neuphorns, within the first 2 days of hirth, on the importance supervised proportional parents of		
when awake 3 or more times daily full active movement throughout the body prevention		
of postural preferences, and the role of pediatric physical therapicts in the comprehencive		
management of postural preference and optimizing motor development. (Evidence quality:		
V. Recommendation strength: <b>Best Practice</b> )		
A Action Statement 2: ASSESS NEWBORN INFANTS FOR ASYMMETRIES/CMT	Revised and updated	255
Physicians, nurse midwives, obstetrical nurses, nurse practitioners, lactation specialists	nevised and aparted	200
physical therapists or any clinician or family member must assess and document the		
presence of neck and/or facial or cranial asymmetry within the first 2 days of birth, using		
passive cervical rotation and/or visual observation as their respective training supports.		
when in the newborn nursery or at site of delivery. (Evidence Ouality: I. Recommendation		
Strength: <b>Strong</b> )		
B Action Statement 3: REFER INFANTS WITH ASYMMETRIES/CMT TO PHYSICIAN	Revised and updated	256
AND PHYSICAL THERAPIST. Physicians, nurse midwives, obstetrical nurses, nurse	*	
practitioners, lactation specialists, physical therapists or any clinician or family member		
should refer infants identified as having postural preference, reduced cervical range of		
motion, sternocleidomastoid masses, and/or craniofacial asymmetry to their primary		
physician and a physical therapist with expertise in infants as soon as the asymmetry is		
noted. (Evidence Quality: II, Recommendation Strength: Moderate)		
II. PHYSICAL THERAPY EXAMINATION AND EVALUATION OF INFANTS WITH	H ASYMMETRIES/CMT	
B Action Statement 4: DOCUMENT INFANT HISTORY. Physical therapists should obtain	Revised and updated	257
and document a general medical and developmental history of the infant, including 9		
specific health history factors, prior to an initial screening. (Evidence Quality: II,		
Recommendation Strength: Moderate)		
B Action Statement 5: SCREEN INFANTS FOR NON-MUSCULAR CAUSES OF	Revised and updated	258
ASYMMETRY AND CONDITIONS ASSOCIATED WITH CMT. When infants present		
with or without physician referral, and a professional, or the parent or caregiver indicates		
concern about head or neck posture and/or developmental progression, physical therapists		
with infant experience should perform and document screens of the neurological,		
musculoskeletal, integumentary and cardiopulmonary systems, including screens of vision,		
gastrointestinal history, postural preference and the structural and movement symmetry of		
the neck, face and head, trunk, hips, upper and lower extremities, consistent with state		
practice acts. (Evidence Quality: II-IV, Recommendation Strength: Moderate)		
B Action Statement 6: REFER INFANTS FROM PHYSICAL THERAPISTS TO	Revised and updated	259
PHYSICIANS IF INDICATED BY SCREEN. Physical therapists should document referral		
of infants to their physicians for additional diagnostic testing when a screen identifies:		
non-muscular causes of asymmetry (e.g. poor visual tracking, abnormal muscle tone,		
extra-muscular masses); associated conditions (e.g. cranial deformation); asymmetries		
inconsistent with CM1; or if the infant is older than 12 months and either facial asymmetry		
and/or 10-15 degrees of difference exists in passive or active cervical rotation or lateral		
of terticallia charges, or the size or leastion of an SCM mass increases. (Firidance Quality		
of torticollis changes, or the size of location of an SCM mass increases. (Evidence Quality:		
R Action Statement 7: DEOLIEST IMACES AND DEDODTS. Druging theremists should	Deviced and undeted	260
request review and include in the medical record all images and interpretive reports	Revised and updated	200
completed for the diagnostic workup of an infant with suspected or diagnosed CMT to		
inform prognosis (Evidence Quality: II Recommendation Strength: Moderate)		
		(continues)

#### TABLE 3: SUMMARY AND STATUS OF ACTION STATEMENTS FOR THE 2018 CONGENITAL MUSCULAR TORTICOLLIS CLINICAL PRACTICE GUIDELINE (*Continued*)

Action Statement	Status	Page
<b>B</b> Action Statement 8: EXAMINE BODY STRUCTURES. Physical therapists should	Revised and updated	261
perform and document the initial examination and evaluation of infants with		
suspected or diagnosed CMT for the following 7 body structures:		
<ul> <li>Infant posture and tolerance to positioning in supine, prone, sitting and standing for</li> </ul>		
body symmetry, with or without support, as appropriate for age. (Evidence quality: $\mathbf{II}$ ;		
Recommendation strength: Moderate)		
<ul> <li>Bilateral passive range of motion (PROM) into cervical rotation and lateral flexion.</li> </ul>		
(Evidence quality: II; Recommendation strength: Moderate)		
• Bilateral active range of motion (AROM) into cervical rotation and lateral flexion.		
(Evidence quality: II; Recommendation strength: Moderate)		
• PROM and AROM of the trunk and upper and lower extremities, inclusive of		
screening for possible developmental dysplasia of the hip (DDH). (Evidence quality:		
II; Recommendation strength: Moderate)		
• Pain or discomfort at rest, and during passive and active movement. (Evidence		
quality: IV; Recommendation strength: Weak)		
• Skin integrity, symmetry of neck and hip skin folds, presence and location of a SCM		
mass, and size, shape & elasticity of the SCM muscle and secondary muscles.		
(Evidence quality: II; Recommendation strength: Moderate)		
• Craniolacial asymmetries and nead/skull shape. (Evidence quality: II;		
Recommendation strength. Moderate)		
<b>B</b> Action Statement 9: CLASSIFY THE LEVEL OF SEVERITY. Physical therapists and	Upgraded with new evidence	265
other health care providers should classify and document the level of CMT severity,		
choosing one of eight proposed grades (Figure 2), based on infant's age at examination, the		
presence of a SCM mass, and the difference in cervical rotation PROM between the left and		
right sides. (Evidence Quality: II, Recommendation Strength: Moderate)		
B Action Statement 10: EXAMINE ACTIVITY AND DEVELOPMENTAL STATUS.	Revised and updated	268
During the initial and subsequent examinations of infants with suspected or diagnosed		
CMT, physical therapists should examine and document the types of and tolerance to		
position changes, and motor development for movement symmetry and milestones, using		
an age appropriate, valid and reliable standardized test. (Evidence quality: II;		
Recommendation strength: Moderate)		2.62
<b>B</b> Action Statement 11: EXAMINE PARTICIPATION STATUS. The physical therapist	Revised and updated	269
should obtain and document the parent/caregiver responses regarding:		
• Positioning when awake and asleep. (Evidence quality: II; Recommendation strength:		
Moderate)		
• Infant time spent in the prone position. (Evidence quality: II; Recommendation		
Strength. <b>Moderate</b> )		
• Whether the parent is alternating sides when breast or bottle reading the mant. (Evidence quality: II: Decommondation strength: Moderate)		
• Infant time count in equipment/positioning devices such as strollers, car seats or		
suings (Evidence quality: II: Recommendation strength: Moderate)		
swings. (Lyndence quality: 11, neconimendation strength, moderate)		
B Action Statement 12: DETERMINE PROGNOSIS. Physical therapists should determine	Reaffirmed and updated	270
and document the prognosis for resolution of CMT and the episode of care after		
completion of the evaluation, and communicate it to the parents/caregivers. Prognoses for		
the extent of symptom resolution, the episode of care, and/or the need to refer for more		
invasive interventions are related to: the age of initiation of treatment, classification of		
severity (Figure 2), intensity of intervention, presence of comorbidities, rate of change and		
adherence with home programming. (Evidence Quality: II, Recommendation Strength:		
Moderate)		(continues)
		(continues)

#### TABLE 3: SUMMARY AND STATUS OF ACTION STATEMENTS FOR THE 2018 CONGENITAL MUSCULAR TORTICOLLIS CLINICAL PRACTICE GUIDELINE (*Continued*)

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Revised and updated	215
Deviced and undeted	276
Revised and updated	270
CE OF INFANTS WITH CMT	
GE OF INFANTS WITH CMT	277
Revised and updated	211
Davias d and undeted	270
Revised and updated	270
	Status         Revised and updated         Revised and updated

#### Purpose of the 2018 Congenital Muscular Torticollis Clinical Practice Guideline

The APTA Academy of Pediatric Physical Therapy (APPT) supports the development of clinical practice guidelines (CPGs) to assist pediatric physical therapists (PTs) with the identification and management of infants and children with participation restrictions, activity limitations, and body function and structure impairments, related to developmental, neuromuscular, cardiorespiratory, and musculoskeletal conditions, as defined by the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) (www.who.int/classification/icf/en/). In general, the purpose of this CPG is to help PTs know who, what, how, and when to treat and who and when to refer and to whom.

Congenital muscular torticollis (CMT) is a postural deformity evident shortly after birth, typically characterized by lateral flexion/side bending of the head to one side and cervical rotation/head turning to the opposite side due to unilateral shortening of the sternocleidomastoid (SCM) muscle.<sup>4</sup> This CPG for physical therapy management of infants with CMT is intended as a reference document to guide PTs, families, health care professionals, and educators to improve clinical outcomes and health services for children with CMT and to inform the need for continued research related to physical therapy management of CMT. Current conventions are to update CPGs every 5 to 10 years: this document replaces the 2013 Congenital Muscular Torticollis Clinical Practice Guideline (2013 CMT CPG).<sup>1</sup>

Specifically, for infants (birth to 12 months) and very young children with CMT, the purposes of the 2018 CMT CPG are to:

- Update the evidence and guidance for PTs' management of CMT, including education, screening, examination, evaluation, diagnosis, reasons to refer, classification, prognosis, interventions, outcome measurements, discontinuation, reassessment, and discharge.
- Update evidence on common CMT limitations of body functions and structures, activity, and participation and, where possible, align descriptions with ICF terminology (see SDC 1, available at: http://links.lww.com/PPT/A221; Appendix 1—ICF/ICD-10 Codes).
- Update a CPG for PTs, physicians, families and caregivers, other early childhood or health care service providers, academic instructors, clinical instructors, students, policy makers, and payers that describes, using internationally accepted terminology, best current practice of pediatric physical therapy management of CMT across health care settings, including prenatal classes, newborn nurseries, physician offices, outpatient pediatric physical therapy offices, and early intervention programs. A glossary of terms is provided in Appendix 2–Operational Definitions.
- Identify areas of research necessary to strengthen the evidence for CMT management.

#### Background and Changes in the 2018 CMT CPG

The 2013 CMT CPG<sup>1</sup> sets standards for the identification, referral, and physical therapy management of CMT, allowing practices to align documentation with the recommended measures,<sup>5</sup> develop a clinical decision algorithm,<sup>6</sup> and provide guidance for intervention and follow-up.<sup>7</sup> Implementing the 2013 CMT CPG recommendations improves outcomes.<sup>8</sup> Studies on CMT published since the 2013 CMT CPG, in combination with clinician feedback, warranted a review of the evidence and its effect on the original recommendations.

The following changes to the 2013 CMT CPG were made in this 2018 CMT CPG:

- A recommendation was added to educate expectant parents and parents of newborns on the importance of preventing asymmetrical positioning, use of prone playtime (tummy time), and the role of PTs in the comprehensive management of persistent asymmetries.
- The recommendation to classify severity was upgraded with a level II study that established good reliability for grading.<sup>9</sup>
- The 7 classification grades were increased to 8, with a *very late* category for all infants older than 12 months, and to correct an omitted line to allow classification of *early mild* in 3- to 6-month-olds; see Figure 2 (also SDC 2, available at: http://links.lww.com/PPT/A222).
- For infants born preterm, the GDG recommends documenting both chronological and corrected ages and using the corrected age for developmental testing, assigning the severity classification, and designing the plan of care.
- For infants who change service providers to treat CMT, the CMT severity should be classified on the basis of the infant's current age, corrected as needed for preterm birth, and initial examination findings by the new provider.
- The major groupings for classification were revised from *Early or Late Identification/Intervention* to *Early, Later, and Very Late Physical Therapy Evaluation/Intervention* to place the emphasis on classifying severity based on the infant's age at the physical therapy evaluation.
- Thirteen recommendations were revised for clarity and updated with new literature, 2 recommendations were reaffirmed and updated with new literature, 1 recommendation was upgraded from Practice to Moderate strength, and no recommendations were retired.
- Clarified the differences between discontinuation of direct physical therapy services, reassessment, and discharge from the physical therapy episode of care.
- All action statements now include individualized recommendations for quality improvement, implementation, and audit. The 2013 CMT CPG section on *Implementation and Audit Recommendations* at the end of the document provided general recommendations for implementing the guideline as a whole. The 2018 version has 2 additional headings in each Action Statement Profile. The *Quality*

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*Improvement* section provides a rationale for why that recommendation is important to implement; that is, what aspect of health care services or delivery will improve if the action statement is fully implemented. The *Implementation and Audit* section provides examples of focused recommendations for implementing and monitoring the action statement to ensure quality improvement.

- There are 4 evidence tables in this version. *Studies on Measurement Approaches* and *Studies on the First-Choice Intervention* are updated with new evidence. *Studies on Supplemental Interventions* and *Studies on Long-term Follow-up* are new additions.
- Sections from the 2013 CMT CPG omitted from this update include the historical background on classic studies that identified the types and incidence of CMT and the rationale for developing the 2013 version.<sup>1</sup>

#### The Scope of the Guideline

The 2013 CMT CPG included a systematic review of literature through May 2013.<sup>1</sup> The 2018 CMT CPG is based on a systematic review of literature from January 2012 through September 2017,<sup>10</sup> supplemented by critical appraisals of new literature published from September 2017 to May 2018. It is assumed throughout the document that the PT has newborn and early childhood experience.

The CPG addresses these aspects of CMT management in infants and very young children:

- Parent education to prevent or identify postural preference and the role of pediatric physical therapy in its management.
- Diagnostic and referral processes.
- Importance of early assessment and referral of infants with asymmetries/CMT to physician and PTs.
- Reliable, valid, and clinically useful screening, examination, and evaluation procedures that should be documented.
- Determination of a severity classification and a prognosis for intensity of physical therapy intervention and duration of care.
- First-choice physical therapy intervention, including dosage guidance, and supplemental interventions.
- Conditions under which a child should be referred to the infant's physician and/or specialist for consideration of additional tests and interventions.
- Prognosis if CMT is treated with conservative interventions, or treated with other interventions, and the consequences of CMT left untreated.
- Criteria for discontinuation of direct physical therapy intervention, the importance of a reassessment, and criteria for discharge.
- Important outcomes of intervention and patient characteristics affecting outcomes.

#### Statement of Intent

This guideline is intended to inform clinicians, family members, educators, researchers, policy makers, and payers. It is not intended to be construed or to serve as a legal standard of care. As rehabilitation knowledge expands, clinical guidelines are promoted as syntheses of current research and provisional proposals of recommended actions under specific conditions. Standards of care are determined on the basis of all clinical data available for an individual patient/client and are subject to change as knowledge and technology advance, patterns of care evolve, and patient/family values are integrated. This CPG is a summary of practice recommendations that are supported with current published literature that has been reviewed by expert practitioners and other stakeholders. These parameters of practice should be considered only as guidelines, not mandates. Adherence to them will not ensure a successful outcome in every patient, nor should they be construed as including all proper methods of care or excluding other acceptable methods of care aimed at the same results. The ultimate decision regarding a particular clinical procedure or treatment plan must be made using the clinical data presented by the patient/client/family, the diagnostic and treatment options available, the patient's values, expectations, and preferences, and the clinician's scope of practice and expertise. The GDG suggests that significant departures from accepted guidelines should be documented in patient records at the time the relevant clinical decisions are made.

# METHODS

The GDG was approved by the APPT to update the 2013 CMT CPG in accordance with Academy procedures.<sup>11</sup> The purpose, scope, and content outline builds on the 2013 CMT CPG survey; its content validity is further supported by evidence of the integration of recommendations into practice.<sup>7</sup>

#### **Search Strategy**

This CPG update is based on a systematic review (January 2012-September 2017) on the physical therapy evidence for diagnosis, prognosis, and intervention of CMT to inform the 2013 CMT CPG.<sup>10</sup> Refer to Heidenreich et al<sup>10</sup> for details of the search strategy, study selection, study appraisal, data extraction, and results for the 20 studies that informed the 2018 CMT CPG: 14 studies informed prognosis and 6 studies informed intervention.

To ensure that the updated CMT CPG used the most current evidence, a comprehensive search of 5 databases (CINAHL, Cochrane Library, PsycINFO, PubMed, and Web of Science) was performed from September 2017 to May 2018 by the GDG with the single search term "torticollis," resulting in 199 studies. No filters were applied for study type or language.

**Selection Criteria.** Studies meeting the following 2 criteria were added to those from the 2013 CMT CPG and the 2018 systematic review<sup>10</sup>: participants included infants and children with a diagnosis of CMT, and studies informed the physical therapy management of CMT. All study designs were included. Studies were excluded on the basis of the following 4 criteria: they focused only on plagiocephaly; dissertations and abstracts; not published in English; and no statistical analysis of results.

Study Appraisal and Data Extraction. Of the 199 studies, 2 newer studies informed the management of CMT as related to physical therapy that were not available for either the 2013 CMT CPG or the systematic review by Heidenreich et al<sup>10</sup> One study on the measurement properties of the classification of CMT severity grades<sup>9</sup> was appraised using the COSMIN checklist. One study on intervention<sup>12</sup> was appraised using the APTA's Critical Appraisal Tool for Experimental Intervention Studies (CAT-EI) and the Cochrane Risk of Bias<sup>13</sup> for intervention studies. Two reviewers completed appraisals of 3 articles to establish interrater reliability, with at least 90% agreement on each appraisal tool. The 2 reviewers then appraised each study independently, scores were compared for agreement, and discrepancies were resolved via discussion. In addition, the intervention study was assigned a level of design rigor (level I "most rigorous" to level V "least rigorous") according to criteria from the American Academy of Cerebral Palsy and Developmental Medicine Systematic Review Methodology.14

Data were extracted to maintain consistency with the 2013 CMT CPG<sup>1</sup> and the 2018 CMT systematic review.<sup>10</sup> The 4 evidence tables (SDC 4-7) are SDC Table 4: Studies on Measurement Approaches (available at: http://links.lww.com/PPT/A224), SDC Table 5: Studies on the First-Choice Intervention (available at: http://links.lww.com/PPT/A225), SDC Table 6: Studies on Supplemental Interventions (available at: http://links.lww.com/PPT/A226), and SDC Table 7: Studies of Long-term Follow-up (available at: http://links.lww.com/PPT/A227). Strengths and limitations of the evidence are included in the "Aggregate Evidence Quality" and "Supporting Evidence and Clinical Interpretation" sections of each action statement.

#### **Recommendation Formulation**

Each 2013 recommendation was evaluated for its currency and consistency with the updated literature. The decision to reaffirm, revise, or upgrade an existing recommendation was informed by the clinical and professional experience of the GDG, trends in practice changes, and the reported effect of the 2013 CMT CPG. The new recommendation on Education is consistent with professional roles to prevent conditions as well as treat them.

#### **External Review Process**

External review is consistent with the IOM recommendations for trustworthy guidelines.<sup>3</sup> The purposes are to ensure clarity, quality, and comprehensiveness of the CPG and to identify potential bias, lapses in logic, or alternative perspectives. A first draft of the 2018 CMT CPG was reviewed by 16 stakeholders representing medicine, pediatric nursing, midwifery, parents of infants with CMT, methods experts, and PTs representing practice, research, and knowledge translation. Both a rating scale to assess clarity and implementation feasibility and an open-ended invitation for comments and edits were used to gather feedback. Of the 17 statements, 15 were rated as clear and 12 as feasible by at least 75% of the reviewers. After addressing the first round of suggested edits, the document was reviewed by selected American Academy of Pediatrics (AAP) members and posted for public review on the APPT Web site; invitations to review were distributed to APPT members via its electronic newsletters, through a social media posting, and direct e-mail notices to volunteers. Nonmembers could review if notified by APPT members. Suggested edits were addressed, and the final draft was submitted to the Pediatric Physical Therapy journal for editorial review. Modifications based on comments from the AAP, APPT members, and the general public included clarification or expansions of the facilitators and barriers to implementation of individual action statements and use of consistent terminology throughout the document. Many reviewers reinforced APPT plans for knowledge translation through the production of parent and medical support documents and downloadable selected figures and tables.

#### **AGREE II Review**

This CPG was evaluated by 2 external reviewers using AGREE II.<sup>15</sup> AGREE II is an established instrument designed to assess the quality of CPGs using 23 items in 6 domains (www. agreetrust.org). Each item is rated using a 7-point scale, with 7 representing the highest score. Each item includes specific criteria, although reviewer judgment is necessary in applying the criteria. The AGREE II appraisal process supported an iterative process to improve the quality of the guideline. Domain scores for the CMT CPG ranged from 86% to 100%. The 2 reviewers unanimously agreed to recommend the guideline for use. Scores were discussed by the GDG; where possible, items were addressed in the CPG following the AGREE II reviews. Thus, the percentages are likely higher in the final version of the CPG.

#### Language

The 2013 CMT CPG is referenced the first time it appears and is used without reference hereafter. In contrast, this document is referred to as the 2018 CMT CPG. In addition, we use the generic phrase "infant's physician" to reference pediatricians, referring physicians, family physicians, or other primary health care providers.

#### Incidence and Progression of Congenital Muscular Torticollis

Congenital muscular torticollis is a common pediatric musculoskeletal condition, described as a postural deformity of the neck evident at birth or shortly thereafter. Synonyms include fibromatosis colli for the mass type,<sup>16,17</sup> wry neck,<sup>18</sup> or twisted neck.<sup>19</sup> It is typically characterized by a head tilt to one side or lateral neck flexion, with the neck rotated to the opposite side because of unilateral shortening or fibrosis of the SCM muscle. It may be accompanied by cranial deformation (CD),<sup>20</sup> developmental dysplasia of the hip (DDH),<sup>21</sup> brachial plexus injury,<sup>22-24</sup> and foot or lower extremity anomalies<sup>25-27</sup> and, less frequently, presents as a head tilt and neck rotating to the same side or as a bilateral condition.<sup>28</sup> The incidence of CMT ranges from 3.9%<sup>29,30</sup> to 16%<sup>20</sup> of newborns and may occur slightly more frequently in males<sup>31,32</sup> and in infants who are exposed in utero to opioids.<sup>33</sup> Congenital muscular torticollis may be present at birth when selected morphologic and birth history variables converge, such as in longer babies, breech presentation, and/or the use of forceps during delivery,<sup>29</sup> or it may evidence itself during the first few months,<sup>20,26</sup> particularly for those with milder forms.

Congenital muscular torticollis is typically categorized as 3 types: postural, muscular, and SCM mass CMT. Postural CMT presents as the infant's postural preference<sup>27,34</sup> but without muscle or passive range of motion (PROM) restrictions and is the mildest presentation. Muscular CMT presents with SCM tightness and PROM limitations. Infants with an SCM mass, the most severe form of CMT, present with a fibrotic thickening of the SCM and PROM limitations.<sup>35</sup> Since 2013, CMT has also been graded using 7 levels of severity distinguished by age at evaluation, type of CMT, and the presence or absence of an SCM mass.1 In general, infants identified early with postural CMT have shorter treatment episodes.<sup>36</sup> Those identified later, after 3 to 6 months of age and who have an SCM mass, typically have the longest episodes of conservative treatment and may ultimately undergo more invasive interventions.35,37

Physicians or parents may be the first to notice an asymmetry, and physicians may provide the initial instructions about positioning and stretching to the parents.<sup>38</sup> The AAP, in its Bright Futures Guidelines for Health Supervision of Infants, Children, and Adolescents publication, recommends checking the newborn for head dysmorphia or abnormal shape at 1 week and skull deformities at 1 month but does not specify checking the neck for symmetry until 2 months, when the term torticollis is first mentioned.<sup>39</sup> In the past, if the asymmetry did not resolve after initial exercise instructions by the physicians, infants were typically then referred to physical therapy.38 While this pattern of identification and eventual referral to physical therapy is described in prior literature, the GDG is in strong agreement with the AAP policy on surveillance that physicians should be providing developmental surveillance for all infants at every well-child preventive care visit from birth and throughout the first 6 months<sup>40</sup> so that infants with any 252 Kaplan et al

identified postural asymmetries are referred immediately for physical therapy intervention.

Physical therapy management of CMT is comprehensive, going beyond just stretching tight neck muscles. A comprehensive plan of care addresses the following 5 components as the first-choice intervention: neck PROM, neck and trunk active range of motion (AROM), development of symmetrical movement, environmental adaptations, and parent/caregiver education. Earlier physical therapy intervention is more quickly effective than intervention started later.<sup>41</sup> If started before 1 month of age, 98% of infants with CMT achieve normal range within 1.5 months, but waiting until after 1 month of age prolongs the physical therapy episode of care to approximately 6 months, and waiting until after 6 months can require 9 to 10 months of physical therapy intervention, with progressively fewer infants achieving normal range.<sup>36</sup>

Reports of untreated CMT are rare,<sup>42,43</sup> but there are descriptions of unresolved or reoccurring CMT in older children or adults, who later undergo botulinum neurotoxin therapy injections<sup>4,44,45</sup> or surgery for correction of movement limitations, consequent facial asymmetries,<sup>43,46,49</sup> or pain.<sup>50</sup> The incidence of spontaneous resolution is unknown, and there are no documented methods for predicting who will resolve and who will progress to more severe or persistent forms.

Finally, CMT has been associated with CD,<sup>51</sup> DDH,<sup>52</sup> brachial plexus injury,<sup>22-24</sup> foot deformities,<sup>26</sup> early motor delays,<sup>53,54</sup> compromised cosmesis,<sup>55</sup> and temporomandibular joint dysfunction.<sup>56</sup> Thus, early identification and treatment are critical for early correction, early identification of secondary or associated impairments, and prevention of future complications.

#### **Importance of Early Referral**

The evidence is strong that earlier intervention results in the best outcomes and decreased episodes of care,<sup>36,41,57</sup> so early referral is the ideal. A referral flow diagram is provided (see SDC Figure 1, available at: http://links.lww.com/PPT/A221) that outlines the possible referral and communication pathways based on time of observation, identification of nonmuscular causes of asymmetry, prior models, and current literature.<sup>4,22,58-60</sup>

The referral flow diagram is divided into 2 distinct time frames: Birth to 2 days, representing the newborn period, and throughout infancy, representing the typical time after discharge to home. During the newborn period, many different health care providers may observe the infant because they are involved in the birth and/or postnatal care. These health care providers are in the ideal position to observe the symmetry of the head on the shoulders and screen for passive and active movement limitations. After the infant is at home, the most likely observers will be the primary physician and the parents or other caregivers. Regardless of who performs the initial screen, infants with asymmetry should undergo an evaluation to rule out nonmuscular causes of CMT. If CMT or a persistent postural preference is diagnosed, the infant should be immediately referred to a pediatric PT.





Fig. 1. Referral Flow Diagram.

Early referral to a pediatric PT translates to earlier intervention and prevention of secondary sequelae.<sup>26,61-63</sup> In addition, reducing the episode of care and avoiding additional or more invasive interventions are cost-effective. Preliminary evidence suggests that treatment by a PT may be more efficient in achieving symmetrical movements than when parents are the sole providers of home exercise programs,<sup>64</sup> further supporting early referral to PT.

#### ACTION STATEMENTS

# I. EDUCATION, IDENTIFICATION, AND REFERRAL OF INFANTS WITH ASYMMETRIES/CONGENITAL MUSCULAR TORTICOLLIS

P Action Statement 1: <u>New.</u> EDUCATE EXPECTANT PARENTS AND PARENTS OF NEWBORNS TO PREVENT ASYMMETRIES/CMT. Physicians, nurse midwives, prenatal educators, obstetrical nurses, lactation specialists, nurse practitioners, or PTs should educate and document instruction to all expectant parents and parents of newborns, within the first 2 days of birth, on the importance of supervised prone/tummy play when awake 3 or more times daily, full active movement throughout the body, prevention of postural preferences, and the role of pediatric PTs in the comprehensive management of postural preference and optimizing motor development. (Evidence quality: V; Recommendation strength: Best practice)

#### **Action Statement Profile**

Aggregate Evidence Quality: Clinical experience of the GDG.

#### Benefits:

• Increases parent/caregiver self-efficacy in caring for their newborn.

- Informs parents on the importance of supervised tummy time to optimize motor development within the first 6 months.
- Teaches parents/caregivers to initiate early surveillance for postural preference and to bring concerns to the infant's physician or, in states with direct access, to a pediatric PT.
- · Informs parents about the role of pediatric PTs in providing a comprehensive and supportive plan of care to manage postural preference associated with CMT and CD.
- May reduce the episode of care and improve outcomes if postural preference is identified and comprehensively managed early.

#### Risk, Harm, Cost:

- May increase parent/caregiver anxiety about the potential for CMT and CD.
- · May marginally increase the cost of care if prenatal educators, labor and delivery personnel, or postnatal care providers do not incorporate education into usual care.
- May increase time needed to spend with a newborn and parents during appointments.

#### Benefit-Harm Assessment: Preponderance of benefit.

Value Judgments: A preponderance of evidence supports that early identification of postural preference and CMT results in shorter episodes of care and full resolution of asymmetries. The GDG feels that if parents know how to monitor their newborn during the first months of life and how to encourage tummy time during awake periods and are empowered to report their concerns to their physician, these asymmetries could be reduced more quickly or even prevented.

Intentional Vagueness: Prone positioning for supervised play up to 3 times a day is the recommendation for newborns because the amount of time awake is limited, though the need to start prone positioning right away for short periods should be reinforced. As time awake increases, infants should be placed in prone position for supervised play as often as tolerated and practical.

Role of Patient/Parent Preferences: Because of the amount of information that parents of newborns receive during the first days of parenthood, they may benefit from multiple educational opportunities before and after the baby's arrival. Parents may prefer receiving instruction using different modes of education (by video, brochure) or by different health care providers (with those they already have a relationship with or as part of prenatal care) or at different phases in their pre- to postnatal experience.

Exclusions: None.

#### **Quality Improvement:**

• Pre-/postnatal education for parents on postural preference and the benefits of early intervention may shorten the episode of care or improve outcomes if an infant infants may be at greater risk than singletons for CD that may lead to postural preference.65

#### Implementation and Audit:

- Physical therapists need to do outreach to ensure that health care professionals, including but not limited to physicians, nurse midwives, prenatal educators, obstetrical nurses, lactation specialists, nurse practitioners, doulas, and early intervention providers, have an accurate understanding of the role of pediatric PTs in the comprehensive management of postural preference and optimizing motor development and resources for how and to whom to refer parents.
- · Pediatric PTs can provide community education on the prevention and management of postural preference, including CMT and CD.
- · Pediatric PTs should distribute the APPT summary brochures on CMT to health care providers or parents as appropriate and educate them about how to access them online (https://pediatricapta.org/ clinical-practice-guidelines).
- · Pediatric PTs should collaborate with the relevant health care providers in their clinical settings to develop a pathway for parent education to ensure that it is provided both before and within the first 2 days of birth.
- Audits of the provision of education to expectant parents and parents of newborns can be completed by quality assurance officers.

# **Supporting Evidence and Clinical Interpretation**

The first step in the AAP's policy on surveillance for developmental disorders is "eliciting and attending to parents' concerns about their child's development."40(p408) Porter et al<sup>66</sup> conclude that surveillance does not happen universally such that others who care for the infant, including parents, should be educated on early surveillance. A mixed-methods study determined that 90% of mothers are educated about infant supine sleeping positions, but instruction on awake prone play or rotating prone and supine positions was only received by 27% of mothers postpartum, and 2 months later, only 8% of mothers used prone positioning during awake time, with 70% positioning only 1 to 2 times per day.<sup>67</sup> The success of the Back to Sleep campaign<sup>68</sup> has demonstrably reduced cases of sudden infant death syndrome; however, many ascribe parental adherence to supine positioning and concomitant avoidance of prone positioning for infant play as a contributing factor to an increase in CMT. Early and frequent parent education to monitor for asymmetry and about the importance of "prone for play" or "tummy time," in addition to "supine or back to sleep," may help reduce or prevent asymmetries from developing, particularly when postural preferences are apparent.

**R. Research Recommendation:** Studies are needed on the

- Health care providers and their knowledge of pediatric PTs' roles in managing postural preference.
- Parents/caregivers about the parental experience of receiving this education.

# Action Statement 2: <u>Revised and updated</u>. ASSESS NEWBORN INFANTS FOR ASYMMETRIES/CMT.

Physicians, nurse midwives, obstetrical nurses, nurse practitioners, lactation specialists, PTs, or any clinician or family member must assess and document the presence of neck and/or facial or cranial asymmetry within the first 2 days of birth, using passive cervical rotation and/or visual observation as their respective training supports, when in the newborn nursery or at the site of delivery. (Evidence Quality: I; Recommendation strength: Strong)

#### **Action Statement Profile**

Aggregate Evidence Quality: Level I based on the odds ratios (ORs) for prediction of CMT from facial asymmetry (OR = 21.75; 95% CI, 6.60-71.70) and plagiocephaly (OR = 23.30; 95% CI, 7.01-70.95),<sup>69</sup> and level II evidence that starting treatment before 6 weeks of age yields greater reductions in SCM thickness than starting after 6 weeks.<sup>41</sup>

#### Benefits:

- Early identification of infants at risk for CMT or other conditions that may cause asymmetries.
- Early onset of intervention for infants with CMT if referred.
- Reduced episode of care to resolve CMT, with consequent reduction in costs.
- Reduced risk of needing more invasive interventions (botulinum neurotoxin therapy or surgery) in the future.

#### Risk, Harm, Cost:

- Potential of overidentification of infants may increase costs.
- · Potential of increasing parent anxiety.

**Benefit-Harm Assessment:** Preponderance of benefit. **Value Judgments:** None.

Intentional Vagueness: None.

**Role of Patient/Parent Preferences:** While parents may not be skilled in formal infant assessment, they are keen observers of their own child. Mothers who are breastfeeding may notice that the infant has greater difficulty feeding on one side, or parents may notice asymmetry in photographs; these observations should trigger range of motion (ROM) screening by an attending clinician.

Exclusions: None.

#### Quality Improvement:

 Documentation of an assessment for cervical ROM and postural symmetry provides uniform data both for more effective communication among clinicians and settings and for uniform data entry in patient registries. • Early examination can detect asymmetries and support earlier referral to PTs who can provide a comprehensive plan of intervention and follow-up.

#### Implementation and Audit:

- Physical therapists should share the 2018 CMT CPG or the summary brochures (https://pediatricapta.org/ clinical-practice-guidelines) with physicians and other referral sources in their geographic area, highlighting this recommendation and the importance of early cervical ROM screening.
- Training on or the development of clinical pathways for health care professionals who see the infant at birth may be needed to ensure that a cervical ROM assessment occurs within the first 2 days of delivery.
- Documentation forms or electronic records may need revision to reflect the cervical ROM and postural symmetry screen.
- Audits of newborn charts may indicate whether patterns of examination are changing.

#### **Supporting Evidence and Clinical Interpretation**

The intent of this action statement is to increase early identification of infants with CMT for early referral to a PT. Newborns (up to the first 3 days of life) can be easily screened by checking for full neck rotation (chin turns past shoulder to 100°)<sup>20</sup> and lateral cervical flexion (ear approximates shoulder)<sup>20</sup> while stabilized in the supine position<sup>25</sup> during the first postnatal examination. Newborns are at a higher risk for CMT if their birth history includes a combination of longer birth body length, primiparity, and birth trauma (including use of instruments for delivery), facial asymmetry, and plagiocephaly. Odds ratios from multiple logistic regression for these 5 factors are, from highest to lowest, as follows: plagiocephaly (OR = 23.30; 95% CI, 7.01-70.95); facial asymmetry (OR = 21.75; 95% CI, 6.60-71.70); primiparity (OR = 6.32; 95% CI, 2.34-17.04); birth trauma (OR = 4.26; 95% CI, 1.25-14.52); and birth body length (OR = 1.88; 95% CI, 1.49-2.38). This indicates that infants with asymmetrical heads or faces have as much a 22-fold increase in abnormal sonogram for CMT; primiparity, a 6-fold increase; birth trauma, a 4-fold increase; and birth body length, an almost 2-fold increase.<sup>29</sup> In addition, infants with a history of neonatal abstinence syndrome (NAS) and who require postnatal medication have a higher incidence of CMT than infants without NAS.33 No one item predicts CMT alone, but the presence of 2 or more of the aforementioned risk factors warrants referral for preventive care and parent education.

The importance of early identification of CMT is well supported. Physicians and PTs in Canada agree that infants identified with CMT should receive formal intervention.<sup>38</sup> When intervention is started at earlier ages, it results in shorter episodes of care<sup>57</sup> and greater reductions in SCM thickness<sup>41</sup> that, anecdotally, may have financial, psychological, and quality-of-life implications for the family.

**R. Research Recommendation:** Studies are needed to determine:

- Whether routine screening at birth increases the rate of CMT identification and/or increases false-positives.
- The barriers to early referral of infants with CMT to physical therapy.

**B** Action Statement 3: Revised and updated. REFER INFANTS WITH ASYMMETRIES/CMT TO PHYSI-CIANS AND PHYSICAL THERAPISTS. Physicians, nurse midwives, obstetrical nurses, nurse practitioners, lactation specialists, PTs, or any clinician or family member should refer infants identified as having postural preference, reduced cervical ROM, SCM masses, and/or craniofacial asymmetry to their primary physician and a PT with expertise in infants as soon as the asymmetry is noted. (Evidence quality: II; Recommendation strength: Moderate)

#### **Action Statement Profile**

**Aggregate Evidence Quality:** Level II evidence supports that when intervention is started earlier, it takes less time to resolve the ROM limitation,<sup>35,36</sup> there are greater reductions in SCM thickness,<sup>41</sup> and there is less need for subsequent surgical intervention.<sup>36,61</sup> Importantly, stretching interventions are easier for parents to administer when infants are younger, before the neck musculature strengthens, and cooperation declines.<sup>36,63</sup>

Benefits:

- Early differential diagnosis to determine that the postural asymmetry is due to CMT versus another medical condition, such as a visual impairment or reflux.
- Earlier intervention to resolve limited ROM and asymmetries more quickly.
- Early parental education to facilitate symmetrical development and self-efficacy with home programs.
- Greater infant tolerance with intervention in the first few months of life.

#### Risk, Harm, Cost:

• Increased cost for treatment of asymmetries that some suggest may spontaneously resolve.

#### Benefit-Harm Assessment: Preponderance of benefit.

**Value Judgments:** Early referral to a PT ensures early onset of intervention, which strongly correlates with shorter episodes of care, greater success of conservative measures, and thus can lower overall costs of care. A pediatric PT will also screen and follow the infant for developmental delays, feeding challenges, and environmental factors that may be associated with or contribute to postural preference or CMT.

**Intentional Vagueness:** For infants suspected of other causes of asymmetries, that is, bony anomalies, fractures, neurological conditions, or extra-muscular masses, PTs should collaborate with the infant's physician to make a definitive

diagnosis of CMT prior to onset of physical therapy interventions. The focus and prioritization of interventions may change depending on the type of limitations the infant presents with (eg, neurological, musculoskeletal, cardiopulmonary, integumentary, and/or gastrointestinal).

**Role of Patient/Parent Preferences:** Infant tolerance with stretching is easier in the first 2 months than when started after the infant develops greater head control<sup>63,70</sup>; thus, infant cooperation is greater and parent adherence to home programs may be optimized. Later referrals put additional stress on parents to adhere to stretching recommendations.

**Exclusions:** Infants suspected of having nonmuscular conditions that might cause asymmetrical or torticollis posturing should be fully examined by the appropriate specialists to rule out confounding diagnoses before initiating physical therapy.

#### Quality Improvement:

• This recommendation will reduce delays in referrals to PTs who can provide a comprehensive plan of intervention and follow-up to ensure that the primary caregivers can adhere to the recommended interventions.

#### Implementation and Audit:

- Training for health care professionals and early intervention providers who see young infants may be needed to ensure that infants are appropriately and quickly referred to a PT. Health care professionals may be reluctant to refer right away if they perceive parents as being overwhelmed during those early weeks; however, earlier referral translates to better outcomes.
- Audits of the age at which parents first noticed the CMT, the date of referral, and the age of first physical therapy examination will provide objective measures of delays between identification and referral to a PT and delays between referrals and the first scheduled physical therapy examination.
- Physical therapists should share the 2018 CMT CPG and/or the APPT summary brochures (https:// pediatricapta.org/clinical-practice-guidelines) with physicians, early intervention providers, and other referral sources in their geographic area, highlighting this recommendation and the supporting evidence for early referral.
- Clinical pathways for examination and referral processes may reduce delays in the onset of physical therapy services by prioritizing infants with asymmetry/CMT for physical therapy examinations. Physical therapists may need to collaborate with administrators and nonmedical professionals to ensure that these infants receive immediate referrals in the pathway, either internally or through external referrals.

#### Supporting Evidence and Clinical Interpretation

Clinicians involved with the delivery and care of infants are in the ideal position to assess the presence of CMT. If screening for CMT occurs routinely at birth, infants who are at a high risk for CMT or who have identified SCM tightness or masses can have physical therapy initiated when the infant is most tolerant of interventions. Congenital muscular torticollis may not appear until several weeks postdelivery; thus, the 1 month well-baby checkup by the physician may be the first point of identification.

Early intervention for infants with CMT, initiated before 3 to 4 months of age, results in excellent outcomes, with 92% to 100% achieving full passive neck rotation and 0% to 1% requiring surgical intervention.<sup>36,37</sup> The earlier intervention is started, the shorter the duration of intervention<sup>36</sup> and the need for later surgical intervention is significantly reduced. 57,61 Petronic et al<sup>36</sup> found that when treatment was initiated before 1 month of age, 99% of infants with CMT achieved excellent clinical outcomes (no head tilt, full passive cervical rotation) with an average treatment duration of 1.5 months, but if initiated between 1 and 3 months of age, only 89% of infants achieved excellent outcomes with treatment duration averaging 5.9 months. When initiated between 3 and 6 months of age, 62% of infants achieved excellent outcomes with treatment duration averaging 7.2 months.<sup>36</sup> When initiated between 6 and 12 months of age, 19% of infants achieved excellent outcomes with an average treatment duration of 8.9 months.<sup>36</sup> In contrast to recommendations to provide stretching instruction to the parents when CMT is identified at birth, and only refer to a PT at 2 months of age if the condition does not resolve,<sup>37</sup> recent studies suggest that early physical therapy reduces the time to resolution compared with parent-only stretching,<sup>64</sup> that infants become more difficult to stretch as they age and develop neck control,<sup>63</sup> and that earlier intervention can negate the need for later surgery.57,61

Physical therapists address a broad range of developmental and environmental factors that influence outcomes, such as parental ability to perform the home exercise programs, transportation distance from the clinical setting,<sup>38</sup> feeding positions, and the infant's motor and developmental progression.<sup>38,71</sup> Since developmental delays are detectable at 2 months in infants with CMT,<sup>54</sup> and the delays may be inversely related to time spent in the prone position,<sup>54</sup> instruction to parents and early modeling of prone playtime may help negate potential developmental lags that can occur with CMT.

#### R. Research Recommendations:

- Studies are needed to clarify the predictive baseline measures and characteristics of infants who benefit from immediate follow-up and to compare the cost-benefit of early physical therapy intervention and education versus parental instruction and monitoring by physicians.
- Longitudinal studies of infants with CMT are needed to clarify how the timing of referral and initiation of intervention impact body structure and functional outcomes, as well as overall costs of care.

# II. PHYSICAL THERAPY EXAMINATION AND EVALUATION OF INFANTS WITH ASYMMETRIES/CMT

**B** Action Statement 4: <u>Revised and updated</u>. DOC-UMENT INFANT HISTORY. Physical therapists should obtain and document a general medical and developmental history of the infant, including 9 specific health history factors, prior to an initial screening. (Evidence quality: II; Recommendation strength: Moderate)

#### **Action Statement Profile**

Aggregate Evidence Quality: Level II cohort and outcome studies.

#### Benefits:

• A complete history of the pregnancy, delivery, known medical conditions, developmental milestones, and daily management of the infant can provide information important to the physical therapy diagnosis, prognosis, and intervention.

Risk, Harm, Cost: None.

**Benefit-Harm Assessment:** Preponderance of benefit. **Value Judgments:** None.

Intentional Vagueness: None.

**Role of Patient/Parent Preferences:** Parents/caregivers can provide much of the history through interview and preadmission information packets; however, obtaining medical records may provide specifics that oral histories may not.

Exclusions: None.

#### Quality Improvement:

• Documentation of the 9 specific health history factors provides uniform data both for more effective communication among clinicians and settings and for uniform data entry in patient registries.

#### Implementation and Audit:

- Create parent/caregiver report forms that are completed prior to the initial examination to assist with collecting the 9 items.
- Documentation forms or electronic records may need revision to reflect the 9 specific health history factors.
- Audit the completeness of history documentation.

#### **Supporting Evidence and Clinical Interpretation**

In addition to documenting the standard intake information (eg, date of birth, date of examination, gender, birth rank, and reason for referral or parental concerns, general health of the infant, and other health care providers who are seeing the infant), the PT should specifically document the following 9 birth and health history factors:

- Chronological age (and corrected age if the infant was born preterm) at initial visit.<sup>41,61,71</sup>
- Age of onset of symptoms,<sup>26,71</sup> which may be aided by early photographs.

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- Pregnancy history including maternal sense of whether the baby was "stuck" in one position during the final 6 weeks of pregnancy.<sup>25</sup>
- Delivery history including birth presentation (cephalic or breech presentation)<sup>26,72,73</sup> and low birth weight.<sup>72</sup>
- $\bullet$  Use of assistance during delivery such as forceps or vacuum suction.  $^{29}$
- Head posture/preference<sup>20,27,74,75</sup> and asymmetries of the head/face.<sup>20,26,32,51,76</sup>
- Family history of torticollis or any other congenital or developmental conditions.<sup>77,78</sup>
- Other known or suspected medical conditions.<sup>22,75</sup>
- Developmental milestones.<sup>53,54,79</sup>

**R. Research Recommendation:** Studies are needed to clarify how the health history factors influence physical therapy diagnosis, prognosis, and intervention.

**B** Action Statement 5: Revised and updated. SCREEN **INFANTS** FOR NONMUSCULAR CAUSES OF ASYMMETRY AND CONDITIONS ASSOCIATED WITH CMT. When infants present with or without physician referral, and a professional, or the parent or caregiver, indicates concern about head or neck posture and/or developmental progression, PTs with infant experience should perform and document screens of the neurological, musculoskeletal, integumentary, and cardiopulmonary systems, including screens of vision, gastrointestinal history, postural preference, and the structural and movement symmetry of the neck, face and head, trunk, hips, and upper and lower extremities, consistent with state practice acts. (Evidence quality: II-IV; Recommendation strength: Moderate)

# Action Statement Profile

Aggregate Evidence Quality: Levels II to IV from cohort and outcome studies and expert clinical consensus.

# Benefits:

- Thorough screening can identify asymmetries and determine their consistency with CMT.
- Screening for other causes of asymmetry (eg, DDH, clavicle fracture, brachial plexus injury, neurological, congenital and/or genetic conditions) facilitates referral to specialists.
- For infants treated for other conditions (ie, brachial plexus injuries, reflux, and DDH) associated with higher risks for developing CMT, parents can receive preventive instruction for CMT.
- In states where PTs may screen and/or treat without physician referral, infants may receive services more quickly.

# Risk, Harm, Cost:

- The cost of a physical therapy screening if the infant is not already being treated for other conditions.
- The risk that PTs without infant experience may miss or misidentify nonmuscular causes of asymmetry.

# Benefit-Harm Assessment: Preponderance of benefit.

**Value Judgments:** In some geographic locations or practice settings, particularly where direct access to physical therapy is permitted, PTs may be the first to screen an infant for postural asymmetries. Infants may present for reasons other than head or neck postures, but observing overall symmetry is an element of a thorough physical therapy screen.

Intentional Vagueness: None.

Role of Patient/Parent Preferences: None.

# Exclusions: None.

**Note:** This action statement includes conditions for referral after examination that were in the 2013 CMT CPG Action Statement 14 but are more appropriate in this statement.

# Quality Improvement:

- Documentation of screens of the neurological, musculoskeletal, integumentary, and cardiopulmonary systems provides uniform data both for more effective communication among clinicians and settings and for uniform data entry in patient registries.
- Systematic screening ensures that nonmuscular causes of asymmetry or associated conditions are ruled out or that timely referral for additional testing occurs.

# Implementation and Audit:

- Documentation forms or electronic records may need revision to reflect the data collected from the screens.
- Clinicians may require training to enhance consistency and reliability of the system screens.
- Audit the incidences in which system screens are positive for potential nonmuscular causes of CMT or potential associated conditions.

# **Supporting Evidence and Clinical Interpretation**

It is within the scope of physical therapy practice to screen for nonmuscular causes of CMT in the neuromuscular and musculoskeletal systems, including testing for ocular cranial nerve integrity and coordination, abnormal tone, orthopedic alignment, and developmental delay.<sup>80</sup> The screen is performed to rule out nonmuscular causes of observed asymmetrical posturing<sup>22,74,75,80</sup> and to determine whether the PT should refer to or consult with the infant's physician immediately or continue with a detailed examination for CMT. The screen is conducted through parent report and observation of the infant in different positions. Elements of the screen to document include the following:

**History**: Per parent report as described in Action Statement 4.

**Systems Screen:** Per the APTA Guide to Physical Therapist Practice,<sup>80</sup> a systems screen traditionally examines the following 4 domains. For infants with CMT, a gastrointestinal history should be added.

**Musculoskeletal Screen:** Screen for symmetrical shape of the face, skull, and spine<sup>19,56</sup>; symmetrical alignment of the shoulder and hip girdles with particular attention to cervical

vertebral anomalies, rib cage symmetry,58 and DDH51; symmetrical PROM of the neck; and palpation for SCM masses or restricted movement.81

Neurological Screen: Screen for abnormal or asymmetrical tone, retention of primitive reflexes, resistance to movement, cranial nerve integrity, brachial plexus injury; temperament (irritability, alertness); and achievement of age-appropriate developmental milestones<sup>4,22,58,75,79,81</sup> inclusive of cognitive and social integration within the family setting.<sup>82</sup> Perform a visual screen comprising symmetrical eye tracking in all directions, noting visual field defects and nystagmus as potential ocular causes of asymmetrical postures.4,81,83

Integumentary Screen: Screen for skinfold symmetry of the hips<sup>25,75</sup> and cervical regions<sup>84,85</sup>; color and condition of the skin, with special attention to signs of pressure and trauma that might cause asymmetrical posturing.<sup>75</sup>

Cardiorespiratory Screen: Screen for symmetrical coloration, rib cage expansion, and clavicle movement to rule out conditions that might cause asymmetrical posturing (eg, brachial plexus injuries, Grisel syndrome)75,78; check for acute upper respiratory tract distress.<sup>24,86</sup> The infant should be alert and appropriately vocal, without wheezing.

Gastrointestinal History: Interview the parents for an infant history of reflux or constipation,<sup>24</sup> or preferential feeding from one side,<sup>27</sup> both of which can contribute to asymmetrical posturing.

Reasons for Consultation or Referral: The following are the basis for consultation with or referral to the infant's physician or other specialists.

- Cranial deformation and/or facial asymmetry, including plagiocephaly and brachycephaly.19,20,29
- Atypical presentations, such as tilt and turn to the same side, or plagiocephaly and tilt to the same side.
- Abnormal tone.<sup>24,75,81</sup>
- · Late-onset torticollis at 6 months or older, which can be associated with neurological conditions, tissue mass, inflammation, or acquired asymmetry.<sup>24,75</sup>
- Visual abnormalities including nystagmus, strabismus, limited or inconsistent visual tracking, and gaze aversion.75,81
- · History of acute onset, which is usually associated with trauma or acute illness.22,87
- Suspected DDH.<sup>21,52,75,88,89</sup>
- · Changes in the infant's color during screening of neck PROM.
- If the infant is older than 12 months on initial screening and either facial asymmetry and/or 10° to 15° of difference exist in active or passive cervical rotation or lateral flexion ROM; or the infant is older than 7 months on initial screening and an SCM mass is present.

R. Research Recommendation: Studies are needed to identify the precision of screening procedures specific to CMT.

**B** Action Statement 6: Revised and updated. REFER INFANTS FROM PHYSICAL THERAPISTS TO PHYSICIANS IF INDICATED BY SCREEN. Physical therapists should document referral of infants to their physicians for additional diagnostic testing when a screen identifies the following: nonmuscular causes of asymmetry (eg, poor visual tracking, abnormal muscle tone, extra-muscular masses); associated conditions (eg, CD); asymmetries inconsistent with CMT; or if the infant is older than 12 months and facial asymmetry and/or 10° to 15° of difference exists in passive or active cervical rotation or lateral flexion; or the infant is 7 months or older with an SCM mass; if the side of torticollis changes or the size or location of an SCM mass increases. (Evidence quality: II; Recommendation strength: Moderate)

#### **Action Statement Profile**

Aggregate Evidence Quality: Level II based on cohort follow-up studies of moderate sizes.

#### **Benefits**:

- Infants with positive screen results are identified and can be comanaged with the infant's physician and other specialists, for example, orthotists or surgeons.
- Early coordination of care may resolve CMT more quickly and with less cost, as well as initiate appropriate intervention for conditions other than CMT.
- Parent support starts earlier for effective home programming, parent education, and the balance of intervention with parental needs to enjoy and bond with their infant.

#### Risk, Harm, Cost:

- Cost of care is increased in the cases when there is a falsepositive from screening results.
- · Additional family stress due to concerns about the infant having more serious health conditions.

#### Benefit-Harm Assessment: Preponderance of benefit.

Value Judgments: Level II evidence demonstrates that earlier diagnosis of CMT is better, but there is no literature that documents the risks and consequences of a lack of immediate follow-up for the 18% of infants who have conditions other than CMT.<sup>22</sup> While the recommendation strength is categorized as "moderate" based on level II evidence, the GDG believes that referral to the infant's physician should be categorized as a MUST, when any nonmuscular causes of asymmetry are identified to collaborate in the comanagement of care of the infant who may have both CMT and other medical conditions.

Intentional Vagueness: In settings with direct access to physical therapy services, parents may seek evaluation services for an infant with postural asymmetry without referral from the infant's physician. In either case, a PT should consult with the infant's physician when any of the aforementioned conditions are present.

Role of Patient/Parent Preferences: None. Exclusions: None.

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#### Quality Improvement:

• Documentation of referral to the infant's physician when the PT suspects a nonmuscular cause of the asymmetry or associated medical conditions provides uniform data for communication across clinicians and settings and ensures an accurate record of care.

#### Implementation and Audit:

- Consultations or referrals to the physician should include the results of the examination and a rationale for concerns underlying the consult or referral.
- Documentation forms or electronic records may need revision with indicators for referrals and rationales for referral.
- Audit the incidences in which referrals helped identify nonmuscular causes of CMT and associated conditions.

#### Supporting Evidence and Clinical Interpretation

Up to 18% of cases with asymmetrical head posturing may be due to nonmuscular causes,<sup>22</sup> including Klippel-Feil syndrome,<sup>22</sup> neurological disorders,<sup>22,34</sup> ocular disorders,<sup>22,83,90,91</sup> brachial plexus injuries including clavicle fractures,<sup>22</sup> paroxysmal torticollis that alternates sides,<sup>24</sup> spinal abnormalities<sup>87,92</sup> and SCM neoplastic masses<sup>34,85</sup> such as rhabdomyosarcoma.<sup>93</sup> Identification of presentations atypical of CMT, including masses that change shape, location, or size, warrants immediate referral to or consultation with the infant's physician.

**R. Research Recommendations:** Studies are needed to clarify the incidence of nonmuscular causes of CMT and associated conditions and how early referral impacts ultimate outcome.

**B** Action Statement 7: <u>Revised and updated</u>. **REQUEST IMAGES AND REPORTS**. Physical therapists should request, review, and include in the medical record all images and interpretive reports, completed for the diagnostic workup of an infant with suspected or diagnosed CMT, to inform prognosis. (Evidence quality: II; Recommendation strength: Moderate)

#### **Action Statement Profile**

Aggregate Evidence Quality: Level II based on cohort and outcome studies.

#### Benefits:

- Images and imaging reports, when available, provide a comprehensive picture of the infant's medical status, including comorbidities.
- Images provide visualization of the SCM muscle fiber organization and the location and size of fibrotic tissue.
- Parents appreciate care that is coordinated and shared across disciplines.

Risk, Harm, Cost:

• Requesting reports may require additional time for the parents and/or the PTs.

#### Benefit-Harm Assessment: Preponderance of benefit.

**Value Judgments:** Per the APTA Guide to Physical Therapist Practice,<sup>80</sup> requesting relevant clinical reports on an infant's suspected or diagnosed condition is considered appropriate gathering of medical history.

Intentional Vagueness: None.

**Role of Patient/Parent Preferences:** Parents need to formally release information for reports to be forwarded to the PT; parents may arrive with reports and images in their possession.

#### Exclusions: None.

#### Quality Improvement:

• Document the request for and receipt of reports and images.

#### Implementation and Audit:

- Documentation forms or electronic records may need revision with indicators of requests for and receipt of images and reports.
- Audits the incidences in which a report or image helped inform the prognosis or intervention choices.

#### **Supporting Evidence and Clinical Interpretation**

The current standard of care does not include routine imaging of infants younger than 1 year with suspected or diagnosed CMT.<sup>94</sup> Rather, infants are typically referred for imaging when there is a specific sign or symptom that raises concern or there is a lack of progress despite close adherence to the intervention program. Reports and images from specialized examinations or laboratory tests can rule out ocular, neurological, skeletal, and oncological reasons for asymmetrical posturing.<sup>22,87</sup> In particular, there is a growing body of research using sonoelastography95 or ultrasound imaging to quantify the size, shape, organization, and location of fibrous bands or masses<sup>51,96-98</sup> and to assist with determining an appropriate plan of care and treatment duration.<sup>26,99-102</sup> Ultrasound imaging can also indicate the amount of muscle fiber realignment that occurs over time.<sup>96,98,103</sup> Emerging evidence suggests that infants with masses or abnormal fiber organization of the SCM are typically identified earlier but require longer episodes of care.<sup>73,102</sup>

**R. Research Recommendations:** Studies are needed to determine who would benefit from imaging, at what time in the management of CMT images are useful, and how images affect the plan of care.

**B** Action Statement 8: <u>Revised and updated</u>. EXAMINE BODY STRUCTURES. Physical therapists should perform and document the initial examination and evaluation of infants with suspected or diagnosed CMT for the following 7 body structures:

- Infant posture and tolerance to the supine, prone, sitting, and standing positions for body symmetry, with or without support, as appropriate for age. (Evidence quality: II; Recommendation strength: Moderate)
- Bilateral PROM into cervical rotation and lateral flexion.(Evidence quality: II; Recommendation strength: Moderate)
- Bilateral AROM into cervical rotation and lateral flexion. (Evidence quality: II; Recommendation strength: Moderate)
- PROM and AROM of the trunk and upper and lower extremities, inclusive of screening for possible DDH. (Evidence quality: II; Recommendation strength: Moderate)
- Pain or discomfort at rest and during passive and active movement. (Evidence quality: IV; Recommendation strength: Weak)
- Skin integrity, symmetry of neck and hip skinfolds, presence and location of a SCM mass, and size, shape, and elasticity of the SCM muscle and secondary muscles. (Evidence quality: II; Recommendation strength: Moderate)
- · Craniofacial asymmetries and head/skull shape. (Evidence quality: II; Recommendation strength: Moderate)

#### **Action Statement Profile**

Aggregate Evidence Quality: Preponderance of level II studies based on well-conducted prospective and retrospective cohort follow-up studies of small to moderate sample sizes.

#### Benefits:

- · Confirms the diagnosis of CMT and identifies other problems such as craniosynostosis, DDH, plagiocephaly, brachycephaly, scoliosis, or other orthopedic and medical conditions.
- · Determines the extent of primary and secondary muscle involvement to estimate prognosis.
- · Establishes baselines to measure progress of ROM, strength and alignment, and infant's ability to incorporate movement through available ranges.
- · Facilitates systematic linking of interventions to identified impairments.
- Standardizes measurement and documentation of body structure limitations from CMT to evaluate group outcomes across clinical settings.

#### Risk. Harm. Cost:

- Examination of passive cervical rotation may result in SCM snapping or a sense of "giving way" in approximately 8% of infants.35
- The infant may feel some discomfort or pain and/or may cry86,104 due to restricted movement, discomfort with ROM tests, or intolerance of general handling.

• In infants with undiagnosed orthopedic conditions (eg, osteogenesis imperfecta, hemivertebrae, or cervical instability), there is a risk that overly aggressive testing of PROM could cause secondary injury, though this has not been reported.

Value Judgments: The evidence for selected measurement approaches varies in strength; however, measures of PROM and AROM, strength, and posture must be documented as part of any physical therapy examination and are consistent with current standards of practice.<sup>80</sup> For ROM measurement, the GDG recognizes that clinical practicality has to be weighed against the desire for the most reliable measures. Use of photography, head markers, and other devices to increase measurement reliability may create undue burdens for the infant, the family, and the PT in daily clinical practice. While there is only moderate to weak evidence to justify the measurement of cervical spine AROM, AROM of the upper and lower extremities, pain or discomfort, condition of the skinfolds, condition of the SCM and cervical muscles, and head shape, a lack of evidence is not equated with a lack of clinical relevance. Furthermore, documentation of these initial examination findings sets the baseline for regularly scheduled objective reassessment and outcome measurement.

Intentional Vagueness: There is no vagueness as to what should be documented. There is variability as to how selected body structures should be measured because of the limited number of valid tools or methods.

Role of Patient/Parent Preferences: During testing, parents may perceive that the baby experiences discomfort or that testing positions could potentially harm the baby, resulting in requests to stop testing if the baby is crying. The clinician must be aware and responsive to the parents' perceptions; it is incumbent on the clinician to fully explain the importance of the measures and the safety precautions used so that parents and infants can comfortably and accurately complete the testing procedures. Clinicians may need to provide the infant breaks during testing to obtain the baby's best performance and most reliable measures. Including the parent in the test procedures may help elicit the infant's best performance, calm the infant if under stress, and generally assist with building trust between the PT and the infant.

Exclusions: None.

#### Quality Improvement:

• Documentation of the 7 elements provides uniform data both for more effective communication among clinicians and settings and for uniform data entry in patient registries.

#### Implementation and Audit:

- Documentation forms or electronic records may need revision to reflect the 7 body structure elements.
- Additional equipment, such as an arthrodial protractor, may need to be procured.

- Clinicians may require training to enhance consistency and reliability of the examination elements, specifically cervical PROM using an arthrodial protractor, cervical AROM using the Muscle Function Scale (MFS) and the rotating stool test, pain assessment using the Face, Legs, Activity, Crying and Consolability (FLACC) scale, and craniofacial asymmetries using the Argenta classification scales.
- Use of photographs may require consent and storage procedures for HIPAA compliance.
- Audit the incidences in which body structure elements informed intervention.

#### Supporting Evidence and Clinical Interpretation

Following a thorough history and screening to rule out asymmetries inconsistent with CMT, the PT conducts a more detailed examination of the infant. The following items appear as a checklist, but in practice, the PT simultaneously observes for asymmetries throughout all examination positions to reduce infant repositioning and increase infant cooperation.

• General Posture: Document infant's posture and tolerance to the supine, prone, sitting, and standing positions for body symmetry, with or without support, as appropriate for age. (Evidence quality: II; Recommendation strength: Moderate)

Observe the infant in all positions, documenting symmetrical alignment and preferred positioning or posturing.<sup>20,27,53,71,105</sup> In the supine position, document the side of torticollis,<sup>20,25,27,53</sup> asymmetrical hip positions,<sup>25,27,76,106</sup> facial and skull asymmetries, restricted AROM, and asymmetrical use of the trunk and extremities,<sup>20,25,27,53,107</sup> as these are all typical of CMT.

In the prone position, document asymmetry of the head relative to the trunk, the spine, and/or the presence of scoliosis,<sup>43</sup> asymmetrical use of the extremities, and the infant's tolerance to the position. In infants developing typically, greater time spent in the prone position while awake is positively correlated with higher Alberta Infant Motor Scale (AIMS) scores and fewer delays in achieving prone extension, rolling, unsupported sitting, and fine motor control.<sup>108,109</sup> In infants with CMT, positioning in the prone position at least 3 times per day is correlated with higher AIMS scores.<sup>54</sup>

In the sitting, supported sitting, and supported upright positions (eg, holding the infant vertically in the air or supported standing as age appropriate), document asymmetrical preferential postures and compensations in the shoulders, trunk, and hip.<sup>54,58,71,76</sup>

If feasible, digital photography may be a fast, reliable method of measuring the preferred supine position.<sup>110</sup> A baseline is drawn through the acromial processes and another is drawn through the midpoints of both eyes. The intersection angle of the eye line with the shoulder baseline provides an objective measure of preferred head tilt. Care needs to be taken not to record artifacts of the placement of the baby on the surface; photographs should represent the typical posture that the baby repeatedly reverts to during the examination session.

• **PROM:** Document the infant's bilateral PROM into cervical rotation and lateral flexion. (Evidence quality: II; Recommendation strength: Moderate)

Both passive cervical rotation and lateral flexion/side bending should be measured bilaterally with an arthrodial protractor as described by Öhman and Beckung.<sup>111</sup> The CMT severity grade is determined by the *difference* between the left and right PROM measures of cervical rotation. Cervical neutral<sup>112</sup> needs to be maintained for all measures but is easily compromised when the infant compensates with cervical rotation or extension movements at the end ranges. The PT visually checks the cervical neutral position, ensuring that the infant's nose, chin, and visual gaze are directed forward (neutral rotation), with the nose, mouth, and chin vertically aligned (neutral lateral flexion) and the ear lobes and base of the nares are horizontally level (neutral flexion-extension).<sup>112</sup>

Passive cervical rotation should be measured with the infant in the supine position, head in cervical neutral, and the nose aligned with the 90° vertical reference.<sup>32,111</sup> This approach with an arthrodial protractor is the most commonly referenced standard for measuring passive cervical rotation, <sup>20,25,26,31,32,70,111,113</sup> with a reported interrater intraclass correlation coefficient (ICC) of 0.71.114 The benefit of an arthrodial protractor is that the infant's head is supported beyond the edge of the supporting table, allowing full neck rotation and removing the table surface as a possible barrier to full range. Cervical rotation can be measured reliably by the same rater (ICC = 0.87-0.97) using a standard goniometer aligned along the support surface with the infant lying in the supine position or in the horizontal plane with children older than 2 years if they can independently sit and cooperate<sup>115</sup>; however, the values from the method used by Klackenberg et  $al^{115}$  of (49° to 67°)  $\pm$  (4° to 9°) are distinctly lower than the  $110^{\circ} \pm 6^{\circ}$  found by others.<sup>26,111</sup>

The clinical challenge of using either a goniometer or an arthrodial protractor is that they minimally require 2 adults, one to stabilize the infant's trunk on the support surface (and this can be the parent/caregiver) and one to rotate the head/neck while measuring range. A third person may be needed to hold the arthrodial protractor in place unless it can be attached to the support surface or stabilized in a stand and calibrated to be level. The GDG strongly values the objective measurement of cervical rotation as a means of establishing a baseline for future comparison. Practice surveys in New Zealand and Canada suggest that PTs often visually estimate, rather than measure rotation range with an instrument, the greatest barrier being the absence of a time-efficient and reliable tool.<sup>38,71</sup>

Cervical lateral flexion should be measured in the supine position with the infant's shoulders stabilized, using an arthrodial protractor for measurement. The PT can either place his or her hands on the side of the head if the parent stabilizes the trunk and shoulders or place one hand under the occiput and one hand diagonally across the baby's chest to palpate for trunk movement and to stabilize the shoulder on the side of the stretch. The head should start in cervical neutral, avoiding neck extension or flexion. The head is laterally flexed until the ear approaches or contacts the stabilized shoulder<sup>115</sup> while the opposite shoulder is stabilized; lateral flexion PROM typically reaches 70° ± 2.4°, with the limiting factor being cheek size.<sup>111</sup> This method is reliable (ICC = 0.94-0.98) when the measures are taken by the same person, using the same setup and procedure, and may be more accurate by 2° to 3° than photographs taken of the same end-range positions.<sup>115</sup>

When testing cervical PROM, known orthopedic conditions may require modification or avoidance of tests (eg, osteogenesis imperfecta, congenital hemivertebrae, or children with Down syndrome who have not been cleared for cervical instability). In these cases, the GDG recommends that testing for passive range use only very gentle guidance through the range, ending at the first palpable sign of resistance.

**R. Research Recommendation:** Reliable, valid, and timeefficient methods of measuring infant cervical PROM need to be developed, including lateral flexion, and large-scale normative data of PROM should be established by age in months.

• AROM: Document the infant's bilateral AROM into cervical rotation and lateral flexion. (Evidence quality: II; Recommendation strength: Moderate).

Cervical AROM is considered an important indicator of symmetrical development and neck strength<sup>70,76,111,116</sup> and the infant's integration of PROM for functional activities. Treatment to improve AROM is consistent with the goals of early intervention.<sup>82</sup> Asymmetrical movements and movement compensations can indicate muscle tightness, restrictions, or weakness.<sup>63,117</sup>

Active range is challenging to measure in infants due to behavior and movement variability, difficulty with isolating cervical movements, and a paucity of practical measurement tools that capture infant movements in the clinical setting in a timely manner.<sup>38,71</sup> Studies may list "active movement" as an outcome but do not describe how it is measured, and many PTs rely on visual estimation.<sup>71</sup>

Physical therapists should measure active cervical movement by using one of the following techniques, looking for active and full range in all planes, including diagonals, while the baby is enticed to follow toys, sounds, or other forms of stimulation to elicit full range:

- For the infant who is younger than 3 months, head rotation is tested in the supine position.<sup>118</sup>
- For the infant who is 3 months or older, test neck rotation while the infant sits in the clinician's lap who is on a rotating stool, named the rotating stool test. The parent entices the infant to maintain eye contact while the PT rotates the baby away from the parent. The PT observes

neck rotation from above using the baby's nose as a midline indicator as it approaches the shoulder.<sup>118</sup> In addition, neck flexion and extension can be screened in this sitting position.

• For infants 2 months and older, the MFS provides an objective categorization of active lateral flexion in developmentally appropriate positions.<sup>111,119</sup> By holding the infant vertically in front of a mirror and tipping the baby horizontally, the PT classifies the head righting position according to a 6-point scale.<sup>119</sup> Infants developing typically rarely have a difference between sides, and infants with CMT frequently have a difference of 2 to 3 points.<sup>119</sup> Clinicians should refer to Öhman et al<sup>119</sup> for specific reference values and procedures.

#### R. Research recommendations:

- Determine the sensitivity and specificity of the MFS to differentiate infants with clinically significant limitations from infants developing typically.
- Establish a clinically practical, objective method of measuring cervical rotation AROM in infants 0 to 3 months old and infants older than 3 months to assess baselines and changes over time.
- Determine what, if any, correlation between AROM and PROM should be used for discontinuation and/or discharge criteria.
- Trunk and Extremity ROM: Document the infant's PROM and AROM of the trunk and upper and lower extremities, inclusive of screening for possible DDH. (Evidence quality: II; Recommendation strength: Moderate)

The PT should examine PROM and AROM of the spine, shoulder and hip girdle, and arms and legs by observing the natural movements of the infant and by passively moving the arms and legs through all available range at each joint to rule out brachial plexus injuries, clavicle fractures, neurological impairments, hypermobility or central nervous system lesions.<sup>4,22,51,58,60,113</sup>

To rule out DDH, PTs should observe for symmetry and stability of the hip and symmetry of the leg lengths and gluteal skinfolds.<sup>106</sup> The incidence of DDH with CMT ranges from  $2.5\%^{53}$  to  $17\%^{21}$  depending on inclusion criteria, and it increases with the severity of neck rotation restriction.<sup>32</sup> While routine screening of all infants for DDH is controversial,<sup>120,121</sup> infants at risk for or those with a diagnosis of CMT may have a slightly higher incidence.<sup>21,89</sup> Factors such as a history of breech position (OR = 4.68; 95% CI, 1.66-13.03) or cesarean delivery (OR = 5.19; 95% CI, 2.06-12.04),<sup>88</sup> family history, maternal age less than 20 years, completion of the evaluation Apgar scores less than 8 at 1 minute,<sup>122</sup> and being female<sup>120</sup> have been associated with a greater risk of DDH. No single test or observation is sufficient to diagnose the presence of DDH, nor does the presence of DDH in young infants necessitate immediate treatment,

as symptoms in more than 90% of newborns with DDH confirmed by ultrasonography (US) may resolve on their own.<sup>123</sup> Conversely, a missed diagnosis of DDH may cause the infant more suffering if treated later with bracing or surgery; thus, the Ortolani and Barlow maneuvers and skinfold assessment are traditionally included in the evaluation of the infant younger than 3 months with CMT.<sup>106,124</sup> Although the sensitivity of the tests varies among studies,<sup>120,125</sup> the specificity for ruling out DDH is stronger.<sup>120,126</sup> After 3 months of age, the Ortolani and Barlow maneuvers may not be sensitive enough to pick up DDH as the joint capsules tighten.<sup>126</sup> For infants older than 3 months, the Galeazzi sign (asymmetrical shortening of the affected leg), asymmetrical posture of the legs and skinfolds, and restrictions in hip abduction PROM may be stronger indicators for DDH, especially since it would be expected to resolve by that time.<sup>126</sup>

#### Pain: Document the infant's pain or discomfort at rest and during passive and active movement (Evidence quality: IV; Recommendation strength: Weak)

Physical therapists should observe for behaviors reflective of body structure discomfort or pain in infants and children during examinations.<sup>85,105,127</sup> Pain is not typically associated with the initial presentation of CMT<sup>59</sup> but may be associated with passive stretching.<sup>43,128</sup> The infant may cry in response to stretching<sup>128</sup> or in response to handling from the therapist; children older than 2 years may be able to provide self-reports of pain.<sup>127</sup> Physical therapists should differentiate actual pain responses from discomfort or behavioral reactions to stretching, anxiety, or the stress of an unusual environment. Despite acknowledging the possibility of pain, no assessment tools for identifying or rating pain are reported in the CMT literature.

There are 3 clinician-rated pediatric pain scales that quantify infant pain-related behaviors and that do not rely on physiological monitoring (eg, heart rate, blood pressure, oxygen saturation, body temperature). The Children's and Infants' Postoperative Pain Scale (CHIPPS)<sup>129</sup> has been validated for newborns through 5 years of age for postsurgical pain and is available in English and Portuguese.<sup>130</sup> The FLACC scale is valid for children from 2 months to 7 years of age<sup>131,132</sup> and in children younger than 3 years before and after anesthesia.<sup>133</sup> The revised rFLACC<sup>134</sup> scale is valid for children 4 to 19 years old including those with cognitive impairments. Parent descriptions of their children's specific pain reactions are part of the rFLACC scale, and the clinician can observe for those specifically.

Since the FLACC scale is valid for the typical age range of infants and children treated for CMT, the GDG continues to recommend its use over the CHIPS or rFLACC scale. The FLACC scale is administered by having the clinician rate facial expressions, movement, and behavior state with a 3-point scale of "0" = no expression or a quiet state, "1" = occasional expression or movements, and "2" = inconsolable and large, frequent movements for a maximum of 10 points; lower scores indicate fewer pain-related behaviors, and higher scores indicate more behaviors. Training in the use of the FLACC scale is required to

achieve adequate reliability.<sup>133</sup> One method to differentiate pain from behavioral distress is to hand the inconsolable baby back to its parent/caregiver, observing how quickly the infant quiets. Another option is to have the caregiver do the handling with physical therapy instruction and observe the infant's reactions to differentiate true pain from discomfort or behavioral reactions.

R. Research Recommendation: Studies are needed to:

- Describe and differentiate signs of discomfort from the types of pain reactions typically observed in infants with CMT during specific testing or interventions.
- Determine the validity of the FLACC scale in rating true pain reactions during CMT examinations or interventions.
- Skin and Muscle: Document the infant's skin integrity, symmetry of neck and hip skinfolds, presence and location of an SCM mass, and size, shape, and elasticity of the SCM muscle and secondary muscles (Evidence quality: II; Recommendation strength: Moderate)

**Skin:** Physical therapists should observe the symmetry and condition of the skinfolds around the neck and hips. Typically, the neck skinfolds on the anterior affected side are deeper and reddened.<sup>81</sup> Infants with brachycephaly and limited cervical ROM in all directions may have deeper posterior folds.<sup>85</sup> Observe for symmetry of the hip skinfolds in the inguinal and upper thigh areas as an indicator of DDH.<sup>75,106</sup>

**Muscle:** Physical therapists should visually inspect and palpate both SCM muscles and document the side of tightness, the presence or absence of a fibrous band and/or mass, and, if a mass is present, note its size and location along the SCM muscle (inferior, middle, superior, or entire length).<sup>96</sup> The presence of a fibrous band and/or mass, particularly a mass that involves more than the distal one-third of the muscle, is correlated with greater severity of the condition.<sup>96,114</sup> These qualities are useful for determining the CMT severity and estimating the episode of care.<sup>26,32,35,51,63,96,102,114</sup>

Physical therapists should document the presence of secondary asymmetries, compensations, or atypical tone in the shoulders, trunk, hips, and distal extremities while the infant moves through positions during the examination. Typical compensations include tightness of the upper trapezius muscle,<sup>135</sup> imbalance of neck muscle strength,<sup>111</sup> hiking of the shoulder on the same side of the involved muscle,<sup>136</sup> asymmetrical preference for limb use,<sup>76,137</sup> asymmetrical and delayed protective and righting reactions of the head, neck, and trunk,<sup>79</sup> Trendelenburg's sign in children who are walking,<sup>106</sup> and scoliosis.<sup>76</sup> Secondary compensations and asymmetries of movement need to be continually monitored across the episode of care as they can develop and/or worsen over time.<sup>18,56,76,136</sup>

• Craniofacial: Document the infant's craniofacial asymmetries and head/skull shape. (Evidence quality: II; Recommendation strength: Moderate)

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Facial asymmetries involve the relative alignment of each side of the jaw, the cheekbones, eye orbits, and ear positions.<sup>19,20,25,29,37,56,138</sup> Cranial asymmetries or deformation (CD) refers to asymmetries of the skull, including the frontal, temporal, parietal, and occipital bones, presenting with posterior unilateral flatness (plagiocephaly), bilateral posterior flattening (brachycephaly), asymmetrical brachycephaly, or flattening on both sides of the skull (scaphocephaly).<sup>58,65,139</sup>

Peitsch et al<sup>65</sup> reported the incidence of localized cranial flattening as 13% in typical singleton infants and 55.6% in twins.<sup>65</sup> Cheng et al<sup>26</sup> reported a 90.1% prevalence of craniofacial asymmetry in children with CMT at initial evaluation. Untreated CMT can cause craniofacial asymmetries on the side of the torticollis, including reduced jaw or ramal height, a smaller and elevated eye with changes in the orbit (recession of the ipsilateral zygoma), recession of the ear on the affected side, a flat appearance of the jaw, malocclusion, and possible gum line asymmetry.<sup>19,20,56,138</sup>

Cranial deformation can either cause or be a result of CMT. Limited AROM from CMT may cause CD, as asymmetrical muscle tensions lead to an asymmetrical postural head preference and subsequent skull deformation.<sup>19,27,59,65,74,118,140</sup> Conversely, for infants with CD and no initial CMT, an asymmetrical resting position of the skull may cause persistent neck rotation that can lead to SCM tightness.<sup>25,59,74,118,140,141</sup>

Physical therapists should document asymmetries of the skull and face. One of the most clinically feasible tools is the classification scales by Argenta.<sup>139</sup> The method is clinically practical, does not require equipment other than a copy of the scales, includes pictures to assist with rating, and has moderate interrater (mean weighted  $\kappa$  score = 0.54) and substantial intrarater reliability (weighted  $\kappa$  scores ranged from 0.6 to 0.85).142 Other methods to quantify head shape asymmetries exist, and when more reliable or accurate methods for guantifying head shape are available and feasible, PTs should use them. Examples include plagiocephalometry,<sup>143,144</sup> the modified Severity Scale for Assessment of Plagiocephaly,145 a craniometer with a headband,146 molding a flexible ruler to the infant's head shape and tracing the shape,147 3-dimensional computerized scanning,148 plaster of Paris molds of the infant's head,149 and the Children's Healthcare of Atlanta Plagiocephaly Severity Scale.<sup>150</sup> These alternative methods may not be available in physical therapy clinics or tolerated well by the infant.

Physical therapists should document when CD or facial asymmetry are inconsistent with deformational plagiocephaly or brachycephaly and refer back to the infant's physician to assess for craniosynostosis.<sup>151</sup>

# **B** Action Statement 9: Upgraded with new evidence. CLASSIFY THE LEVEL OF SEVERITY. Physical therapists and other health care providers should classify and document the level of CMT severity, choosing 1 of 8 proposed grades (see Figure 2, also SDC 2, available at: http://links.lww.com/PPT/A222), based on infant's age at

examination, the presence of an SCM mass, and the difference in cervical rotation PROM between the left and right sides. (Evidence quality: II; Recommendation strength: Moderate)

#### **Action Statement Profile**

Aggregate Evidence Quality: A level II cohort reliability study.

#### Benefits:

- Classifying levels of severity may assist with prognosis and parent education.
- The 8 grades integrate 2 of the strongest factors related to outcome: the infant's age at which treatment is initiated and the type of CMT the infant presents with.
- More precise classification grades are needed to compare outcomes across research samples.

#### Risk, Harm, Cost:

• Minimal costs to update electronic health records to add grade 8 and to retrain staff on its use.

#### Benefit-Harm Assessment: Preponderance of benefit.

**Value Judgments:** The GDG recommends the use of its updated CMT Severity Classification System. Clinician feedback and its uptake into practice<sup>7</sup> suggest that the grades assist with educating families about the estimated episode of care.

**Intentional Vagueness:** There is no evidence as to whether the chronological or corrected age should be used for infants born preterm to determine the severity grade. Clinicians should document both ages in their practice setting. The GDG recommends using corrected age when determining the severity grade.

Role of Patient/Parent Preferences: None.

#### Exclusions: None.

#### Quality Improvement:

- Documentation of a severity grade provides a common taxonomy both for clinical and research communication and for uniform data entry in patient registries.
- The severity grades are a tool for communicating with parents about the estimated episode of care.

#### Implementation and Audit:

- Documentation forms or electronic records may need revision to reflect the CMT Severity Classification grades, including the addition of grade 8.
- Clinicians may require training to enhance consistency and reliability of the CMT Severity Classification System.
- Audit the frequency of documentation of the CMT Severity Classification grades and the accuracy of prognoses with respect to episode of care and functional outcomes.
- While there are no studies that correlate the severity of cervical lateral flexion to the severity of CMT or the episode of care, PTs should document objective measures of lateral flexion as a type of asymmetry.
- For infants who change service providers to treat CMT, CMT severity should be classified on the basis of the

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#### CMT Classification Grades and Decision Tree for 0-12 months

To use this chart: The vertically aligned ovals on the left, list the factors that are most relevant to the classification process (age asymmetry noted, age of referral and PT evaluation, type of CMT); the diamonds below describe the cycle of PT examination, intervention and reassessment. Begin in the larger rectangle with age at evaluation and type of CMT to choose a grade in the ovals below. Abbreviations: PT, physical therapy; TX, treatment; SCM, sternocleidomastoid; L/R, left/right.

Fig. 2. 2018 Classification of Severity and Management of CMT.

infant's current age and initial examination findings by the new provider.

#### Supporting Evidence and Clinical Interpretation

Multiple taxonomies of CMT classification recur in the literature: age of treatment initiation,<sup>36,57</sup> type of CMT (postural, muscular, or SCM mass),<sup>26,57,113,114</sup> severity of ROM limitations,<sup>26,32</sup> presence of plagiocephaly,<sup>58,60</sup> and muscle fiber appearance by US.<sup>23,96,152</sup> In most studies, these taxonomies are detailed enough to answer the research questions about incidence of various types, incidence of surgical outcomes, and usefulness of US as a diagnostic tool or classification process. The use of US to determine a CMT classification is beyond the scope of typical pediatric physical therapy practice.

When looking for guidance on intervention effectiveness for CMT, study samples typically analyze outcomes according to the type of CMT (postural, muscular, or SCM mass), the age of presentation,<sup>41</sup> or cervical rotation PROM.<sup>62,114,153</sup> These 3 factors are considered strongly correlated with outcomes such that the earlier one is treated and the milder the form of CMT, the shorter the episode of care and the higher the probability of complete resolution.<sup>36</sup> No studies were found using passive lateral flexion as a factor for categorizing CMT outcomes.

The 2013 CMT CPG proposed a 7-grade CMT Severity Classification System that combined the 3 factors (ie, age, PROM, mass) to add clarity to research and aid communication among clinicians. The original 7 grades have good interrater reliability (ICC (2,1) = 0.83; 95% CI, 0.74-0.91) and good intrarater reliability (ICC (3,1) = 0.81; 95% CI, 0.66-0.91).<sup>9</sup> In a survey of 282 PTs who treat children with CMT, only 3% classified severity with any scale prior to the 2013 CMT CPG; following its publication, the 7-grade CMT Severity Classification System was implemented by 57%.<sup>7</sup> This 2018 CMT CPG updates the original 7 grades to 8, based on clinician confusion as to how to grade toddlers older than 12 months<sup>9</sup> and because the majority of the evidence estimating episodes of care is based on infants younger than 12 months.

Figure 2 (also SDC 2, available at: http://links.lww. com/PPT/A222) presents the updated diagram to include grade 8 for children who are referred for physical therapy at the age of 12 months or older, regardless of the type of CMT (postural, muscle tightness, or SCM mass). The diagram is best viewed in the color version available at https://pediatricapta.org/clinical-practice-guidelines; however, to aid clarity with noncolor copies, the lines from conditions to grades are patterned. An additional line was added to classify 4to 6-month-olds with only postural preferences as grade 1. The vertically aligned ovals, at the leftmost edge of the diagram, list the factors that are most relevant to the classification process (age asymmetry noted, age of referral and physical therapy evaluation, type of CMT), followed by diamonds that describe the cycle of physical therapy examination, intervention, and reassessment. To the right are the range of conditions and actions that link the classification with physical therapy management.

#### **SEVERITY GRADE DEFINITIONS**

Grade 1—Early mild: Infants between 0 and 6 months of age with only postural preference or a difference between sides in passive cervical rotation of less than 15°.

Grade 2—Early moderate: Infants between 0 and 6 months of age with a difference between sides in passive cervical rotation of 15° to 30°.

Grade 3—Early severe: Infants between 0 and 6 months of age with a difference between sides in passive cervical rotation of more than 30° or an SCM mass.

Grade 4—Later mild: Infants between 7 and 9 months of age with only postural preference or a difference between sides in passive cervical rotation of less than 15°.

Grade 5—Later moderate: Infants between 10 and 12 months of age with only postural preference or a difference between sides in passive cervical rotation of less than 15°.

Grade 6—Later severe: Infants between 7 and 9 months of age with a difference between sides in passive cervical rotation of more than  $15^{\circ}$  or between 10 and 12 months of age with a difference of  $15^{\circ}$  to  $30^{\circ}$ .

Grade 7—Later extreme: Infants between 7 and 12 months with an SCM mass or between 10 and 12 months of age with

a difference between sides in passive cervical rotation of more than  $30^{\circ}$ .

Grade 8—Very late: Infants and children older than 12 months of age with any asymmetry, including postural preference, any difference between sides in passive cervical rotation, or an SCM mass.

The classification process begins at the top of the diagram. Document the age that asymmetry is first noted by a parent or health care professional; this may be informed by early infant photographs. This age provides history of the condition and may impact the prognosis for the episode of care; however, it does not directly factor into the choice of severity grades. The age of referral for physical therapy evaluation is documented to understand the timeliness between referral and the initial physical therapy evaluation. The age of initial physical therapy evaluation is documented and used in combination with the difference in cervical rotation PROM and/or the presence of an SCM mass to determine a severity grade. Classifications are first grouped as "early," "later," or "very late." "Early" and "later" have a range of severity within the categories. For example, CMT Severity Classification grade 2-Early moderate is assigned to an infant evaluated by a PT either between 0 and 3 months or between 4 and 6 months, with a difference between sides in cervical rotation PROM of 15° to 30°. The estimated episode of care is based on a constellation of factors including environmental and family resources and would be estimated at a shorter period for the younger infant. A CMT Severity Classification grade 7-Later extreme is assigned to an infant evaluated by a PT between 7 and 9 months of age with an SCM mass or between 10 and 12 months of age with a difference between sides in cervical rotation PROM of more than 30° or an SCM mass. Although it would be convenient to assume that there is a linear relationship between the severity grades and the episode of care, there are many factors that may influence an overlap in time frames, with unexpected reductions or extensions in the episode of care. A study by van Vlimmeren et al<sup>154</sup> illustrates how the grades can describe study samples more accurately.

Decisions regarding intervention intensity, frequency, and duration take into consideration each of the factors within the large central oval: Severity Classification Grade, Access to Services & Clinician Knowledge and Skill, Patient/Caregiver CMT Knowledge and Program Adherence, Muscle Tissue Characteristics, Infant's Developmental Stage, and Comorbidities. Action Statement 12 regarding prognosis supports the idea that the earlier and more intense the intervention, the shorter the episode of care and the more complete the resolution of symptoms. No specific recommendation of intensity of intervention is appropriate for all cases. Regardless of severity, when physical therapy intervention is initiated, the first-choice intervention should be performed frequently throughout each day, with responses to intervention regularly reassessed for effectiveness. While a minimum of 1.5 months<sup>36</sup> and a maximum of 36 months<sup>63</sup> of conservative intervention are reported, the majority of studies cite a range of 4 to 6 months' duration for intervention.

Copyright © 2018 Academy of Pediatric Physical Therapy of the American Physical Therapy Association. Unauthorized reproduction of this article is prohibited. **R. Research Recommendation:** Studies are needed to determine a reliable, valid, and clinically practical method of measuring cervical lateral flexion and then to determine how the severity of lateral flexion may relate to the CMT Severity Classification grades.

**B** Action Statement 10: <u>Revised and updated</u>. EXAMINE ACTIVITY AND DEVELOPMENTAL STATUS. During the initial and subsequent examinations of infants with suspected or diagnosed CMT, PTs should examine and document the types of and tolerance to position changes, and motor development for movement symmetry and milestones, using an age-appropriate, valid, and reliable standardized test. (Evidence quality: II; Recommendation strength: Moderate)

#### **Action Statement Profile**

Aggregate Evidence Quality: Level II from cohort and outcome studies.

Benefits:

- Early detection of developmental delays, neurological impairments, movement capabilities, muscle function in developmental positions, and infant preferences help direct the plan of care.
- Provides opportunities for parent education on typical development, importance of prone playtime, alternative positioning, and reinforcement of parent adherence to home programs.
- Standardizes measurement and documentation of motor activity to evaluate group outcomes across clinical settings for infants with CMT.

#### Risk, Harm, Cost:

- No risks or harms.
- Norm-referenced developmental standardized tests are proprietary and thus have associated costs for the forms, test manuals, and test items. Proficiency in administering the tests may require training.

#### Benefit-Harm Assessment: Preponderance of benefit.

**Value Judgments:** Measures of the infant's activity, symmetry of movements, and developmental progression *must* be documented as part of any physical therapy examination. These are consistent with professional standards of practice<sup>80</sup> and clinical practice specific to CMT.<sup>38,71</sup>

#### Intentional Vagueness: None.

**Role of Patient/Parent Preferences:** Parents may perceive that the baby experiences discomfort from the testing positions or that the prone position is harmful and may request that testing not continue if the baby is crying. The clinician should fully explain the importance of varying the infant's positions, including use of prone positioning, which may be avoided by parents because of misinterpretation of *Back to Sleep* instructions.<sup>54</sup>

Exclusions: None.

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#### Quality Improvement:

• Routine assessment of development ensures that infants with CMT are achieving age-appropriate milestones, and if not, those delays are addressed as they are identified.

#### Implementation and Audit:

- Documentation forms and electronic records may need revision to include the recommended standardized developmental tests and documentation of asymmetries during developmental activities.
- Clinicians may require training to enhance consistency and reliability to administer standardized developmental tests.
- Audit the incidences in which the standardized developmental tests are completed and inform intervention.

#### **Supporting Evidence and Clinical Interpretation**

Infants with CMT have a higher prevalence of gross motor delay at 2 and 6 months of age.<sup>53,54</sup> The motor delay of most infants undergoing physical therapy for CMT resolves by 8 to 15 months of age, 53,54 but similar to the general population, some will continue to demonstrate a gross motor delay.<sup>53</sup> Physical therapists should use a standardized test with established predictive validity to monitor infants with CMT for potential developmental delays and, if identified, should address remediation of those delays in their plans of care. The GDG recommends using age-appropriate, reliable, and valid standardized tests, such as the Test of Infant Motor Performance (TIMP) through 4 months of corrected age (http://thetimp.com/), the AIMS from 1 to 18 months of corrected age or until walking,<sup>155</sup> or the Gross Motor subtest of the Peabody Developmental Motor Scales, 2nd edition (PDMS-2) from 1 to 72 months of age,<sup>156</sup> during the initial evaluation and reassessments. While certification is not required to administer these tests, the validity of the scores and test-retest reliability may be improved following formal training. In addition, the PT should observe and document asymmetries of age-appropriate developmental activity, movement, and upper- and lower-limb use throughout all examination positions.<sup>76</sup>

**R. Research Recommendation:** Studies are needed to identify the best developmental tests to use for infants with suspected or diagnosed CMT, from birth through 12 months, so that the same measures can be documented on all infants, enabling comparison of outcomes across studies.

# **B** Action Statement 11: Revised and updated. EXAMINE PARTICIPATION STATUS. The PT should obtain and document the parent/caregiver responses regarding:

- Positioning when awake and asleep. (Evidence quality: II; Recommendation strength: Moderate).
- Infant time spent in the prone position. (Evidence quality: II; Recommendation strength: Moderate)

- Whether the parent is alternating sides when breast- or bottle-feeding the infant. (Evidence quality: II; Recommendation strength: Moderate)
- Infant time spent in equipment/positioning devices, such as strollers, car seats, or swings. (Evidence quality: II; Recommendation strength: Moderate)

#### **Action Statement Profile**

**Aggregate Evidence Quality:** Predominance of level II prospective cohort follow-up studies with small sample sizes.

# Benefits:

- Identifies routine passive positioning that facilitates asymmetrical positions of the head, neck, and trunk.
- Provides information about the general developmental activities and position preferences of the infant.
- Provides opportunities for parent/caregiver education and counseling about positioning and activities that facilitate symmetrical development, including successful breast-feeding.

#### Risk, Harm, Cost: None.

**Benefit-Harm Assessment:** Preponderance of benefit. **Value Judgments:** None.

Intentional Vagueness: None.

Role of Parent or Patient Preferences: Parents and caregivers must accurately describe the infant's daily care routines so that positioning and home exercise programs can be tailored to maximize implementation opportunities and enhance the success of early parent roles. Fear of blame for the infant's condition may lead parents/caregivers to provide inaccurate descriptions. Clinicians should be sensitive to this and may need to build a level of trust with the parents/caregivers before an accurate description can be obtained.

Exclusions: None.

#### Quality Improvement:

• Routine examination of participation ensures that parentinfant dyads are appropriately and successfully interacting during daily routines in ways that optimize motor development.

#### Implementation and Audit:

- Documentation forms and electronic records may need revision to reflect the 4 participation elements listed earlier.
- Clinicians may require training to enhance consistency and reliability for assessing participation.
- Audit the incidences in which the participation elements are documented and inform intervention.

#### **Supporting Evidence and Clinical Interpretation**

There is consensus about the need to assess across all the domains of the ICF, including infant participation in daily routines, to develop a comprehensive plan of care.<sup>38,71,79</sup> Moderately strong evidence suggests that specific activities are either preludes for possible asymmetrical development or the consequences of existing asymmetries.

**Positioning When Awake and Asleep, Including Time Spent in the Prone Position**: Documentation should address positioning when awake and asleep, during feeding, and while using positioning devices (eg, car seats, changing tables, cribs). The purpose of asking parents/caregivers about positioning is to *prevent* deformational plagiocephaly that may be associated with CMT,<sup>60</sup> to *correct* postural preference that can lead to CMT and plagiocephaly,<sup>20,58,74,157</sup> and to *treat* CMT if present. Three aspects of positioning support an interaction effect with CMT resolution: use of prone positioning, asymmetrical handling to activate weak neck musculature, and AROM toward the limited side, including feeding from alternate sides.

Prone positioning while awake for greater than 1 cumulative hour per day, with no minimum amounts of time per opportunity, appears to offset the transient effects of supine sleep positions on motor skill acquisition.<sup>158,159</sup> Supine positioning is associated with postural preference and consequently may facilitate asymmetrical neck ROM and secondary development of plagiocephaly.<sup>27,141</sup> Infants who spend more time in the prone and side-lying positions reduce the effect of preferred positioning<sup>27</sup> and achieve motor milestones sooner.<sup>54,160</sup> Although prone sleeping position is counter to the *Back to Sleep* recommendations<sup>161</sup> and is not recommended by the GDG, it has been associated with faster achievement of developmental milestones.<sup>162</sup>

The conscientious use of positioning during wakeful activities (eg, play, feeding, and dressing) facilitates symmetrical development of head shape,<sup>60,163</sup> active and passive neck motion,<sup>60,104</sup> tolerance of prone positioning,<sup>159</sup> and achievement of motor milestones.<sup>70,164</sup> Conscientious positioning means that the parent actively places the infant in positions during play, on changing tables, or in cribs, or carries the infant in ways that require head righting, rotation toward the restricted side, neck and upper-body extension,<sup>70</sup> or visual attraction toward the affected side. Active movement toward the affected side<sup>37</sup> and alternation of trunk and limb movements<sup>165</sup> help counteract asymmetries and prevent potential ones. For the infant with postural preference, these activities may reduce the preference and avoid consequential tightness.

Parents are reported to avoid prone positioning with infants developing typically because the infant does not tolerate the position or because the infant has already achieved independent sitting.<sup>159</sup> Education about the importance of prone play-time is critical for infants with suspected or diagnosed CMT, as they have multiple risks of asymmetrical development and delayed motor milestones. Physical therapists should evaluate each parent's ability to carry out exercises and home program positioning.

**Feeding:** Physical therapists should document the infant's feeding positions and difficulties as reported by the parent/caregiver during the initial and periodic evaluations.

Feeding problems have been identified in infants with CMT and/or plagiocephaly as asymmetrical jaw positioning,166 preference for side of nursing,<sup>74,141</sup> and/or side of bottle-feeding.<sup>62,141</sup> As many as 44% of infants with CMT may demonstrate a feeding preference to one side,<sup>62</sup> and as many as 2.4% are described as having additional feeding problems.<sup>51</sup> In conjunction with infant preference, the parent's preferred side or hand dominance may also bias positioning to bottle-feed from the same side.<sup>27</sup> Conversely, infants who breastfeed from both sides have a lower incidence of CD and CMT, possibly due to frequency of position changes as compared with infants who are bottle-fed on the same side at each feeding.<sup>167</sup> Intervention that addresses alternating sides and alternative positions<sup>168</sup> for feeding can effectively increase symmetrical positioning, reduce preferred positioning by the infant, and improve parent self-efficacy with feeding. Interviewing parents/caregivers about their comfort with alternating feeding positions is common practice,38,71 is consistent with family-centered care,82 and provides an opportunity to suggest positioning strategies.

Equipment/Positioning Devices: Physical therapists should document the amount of time the infant spends in positioning equipment as reported by the parents (eg, positioning/seating devices, strollers, car seats, cribs, or swings).<sup>118</sup> Persistent use of supportive equipment, in lieu of time spent playing in the prone or side-lying position, may facilitate the deformation of the developing skull due to gravitational forces, which increases the risk of CMT and other asymmetrical developmental movement patterns. The PT should discuss practical strategies with the parents/caregivers regarding positioning and movement facilitation, including alternating positioning of toys and placement in cribs,76,167 and ensuring frequent opportunities to play in the prone position from an early age.<sup>54,85,164</sup> Avoidance of prone placement by parents can occur if the infant does not tolerate it well; the discussion offers an opportunity to assess parent/caregiver comfort and provide graded strategies for prone positioning that build on the infant's tolerance.

**R. Research Recommendations:** Studies are needed to quantify changes in participation and clarify how the participation elements inform the plan of care.

**B** Action Statement 12: Reaffirmed and updated. DETERMINE PROGNOSIS. Physical therapists should determine and document the prognosis for resolution of CMT and the episode of care after completion of the evaluation and communicate it to the parents/caregivers. Prognoses for the extent of symptom resolution, the episode of care, and/or the need to refer for more invasive interventions are related to: the age of initiation of treatment, classification of severity (see Figure 2, also SDC 2, available at: http://links.lww.com/PPT/A222), intensity of intervention, presence of comorbidities, rate of change, and adherence with home programming. (Evidence quality: II; Recommendation strength: Moderate)

#### **Action Statement Profile**

**Aggregate Evidence Quality:** Level II-IV cohort studies and case reports with long-term follow-up.

#### Benefits:

- Links the examination results and CMT Severity Classification grade to interventions and/or referrals.
- Provides guidance on the frequency and dosage of intervention(s) across episodes of care.
- Allows parents/caregivers to psychologically prepare for what to expect from physical therapy and the range of possible outcomes for their infant.
- Assists parents with understanding and implementing the plan of care.
- Articulates the relationship of examination results to expected outcomes for documentation, including letters of medical necessity.

#### Risk, Harm, Cost:

Lack of a prognosis by either the referring physician or the PT may lead to underestimation of the CMT severity, resulting in inadequate or untimely delivery of care and/or parent/caregiver confusion about what to expect.

Benefit-Harm Assessment: Preponderance of benefit.

Value Judgments: The GDG supports the need to document the potential for improvement of CMT before initiating intervention. The physical therapy prognosis is the bridge between the evaluation of initial examination results and classification of severity with the associated interventions within an expected time frame; thus, it should include both objective outcomes to achieve and time frames to achieve them. Articulating the prognosis for physical therapy management ensures clear communication of expectations for the parents/caregivers and sets objective milestones as a basis for referral back to the primary physician if outcomes are not met. Prognosis is a continual process that occurs throughout the episode of care.

#### Intentional Vagueness: None.

**Role of Patient/Parent Preferences:** The prognosis for improvement, or the time to achieve change, may need to be corrected on the basis of the parent/caregiver ability to perform the exercises and adhere to a home program designed by the PT. Parents should participate in shared decision-making with the PT to design a home program that addresses both the infant's limitations and other parental responsibilities.

Exclusions: None.

#### Quality Improvement:

• Determining a prognosis provides the family and caregivers, health care providers, and payers an estimate of the episode of care.

#### Implementation and Audit:

• Educate parents and caregivers about the estimated episode of care and the importance of consistently implementing the home program to maximize outcomes.

- Update documentation forms or electronic records to include prognosis based on uniform collection of age of initiation of treatment, CMT Severity Classification grade, intensity of interventions, presence of comorbidities, rate of change, and adherence to the home program.
- Include the prognosis and estimate of the episode of care on the initial evaluation document and in all professional communications.
- Audit the frequency of documentation of prognoses and the accuracy of prognoses with respect to episode of care and functional outcomes.

#### **Supporting Evidence and Clinical Interpretation**

A PT is responsible for determining a prognosis following the patient evaluation.<sup>80</sup> A prognostic statement should include the expected outcome in objective measurable terms, the time frame for intervention to achieve the outcomes, and a description of the potential courses of the condition if treated or not. For CMT, the earlier and more intense the intervention, the shorter the episode of care and the more complete the resolution of symptoms.<sup>32,36,37,43,103,169</sup>

Demirbilek and Atayurt<sup>57</sup> found the prognosis for full resolution of CMT, treated conservatively prior to 3 months of age, was 100% and lower (75%) when treated after 3 months of age. Five factors have been associated with full or more complete symptom resolution including the infant's: (1) participation in physical therapy intervention,<sup>170</sup> (2) younger age at initiation of treatment,<sup>36,41,43,62-64</sup> (3) decreased difference in cervical rotation PROM between sides,<sup>153</sup> (4) decreased difference in SCM muscle thickness between sides,<sup>171</sup> and (5) the caregiver's ability to frequently implement a home program of active positioning and passive stretching.<sup>64</sup>

The episode of care has been associated with the severity of the CMT, with mildest forms requiring an average of 2 to 3 months of treatment and more severe forms requiring up to 5 to 6 months of treatment.<sup>32</sup> Infants who receive surgical interventions may require an additional 4 months<sup>26</sup> to 11 months<sup>18,172</sup> of treatment. Seven factors have been associated with a longer episode of care including: (1) older age at initiation of treatment,<sup>72</sup> (2) increased restriction of neck rotation PROM,<sup>63</sup> (3) increased severity of head tilt,<sup>173</sup> (4) motor asymmetry,<sup>107</sup> (5) increased thickness<sup>72</sup> or stiffness<sup>174</sup> of the involved SCM or higher thickness ratio between the involved and uninvolved SCM,<sup>72,173</sup> (6) the presence of an SCM mass or lesion,<sup>63,73,102,175</sup> and (7) delivery history including infants with lower birth weight<sup>72</sup> and breech, compared with cephalic, presentation.<sup>72</sup>

There is no consensus on the intensity, frequency, or delivery of intervention that is appropriate for all cases except that more frequent stretching and strengthening throughout the day are more effective than the less frequent ones.<sup>176</sup> Öhman et al<sup>64</sup> provide preliminary evidence of better outcomes when infants are treated by a PT versus parents, but the combination of physical therapy and home program is the more frequent intervention plan.<sup>31,63,103,114</sup> Individual intervention is the most commonly provided delivery model, but a single observational study of group CMT intervention (each group consisted of 6 infantparent dyads and 2 PTs) suggests that this model may be an alternative to individual intervention.<sup>177</sup> Additional research is needed to determine the equivalency of outcomes and the costeffectiveness of group compared with individual intervention.

R. Research Recommendations: Studies are needed to:

- Clarify the interaction between the factors associated with full symptom resolution and episode of care.
- Clarify the accuracy of prognosis with respect to full symptom resolution and episode of care.
- Describe and clarify the efficacy of different delivery models, for example, individual versus group or clinic versus home.

#### III. PHYSICAL THERAPY INTERVENTION FOR INFANTS WITH CMT

The literature continues to support the following 5 components as the first-choice intervention for CMT: neck PROM; neck and trunk AROM; development of symmetrical movement; environmental adaptations; and parent/caregiver education. The provision of interventions allows for continuous evaluation of progress along all ICF domains, including body structure and function, activities, and participation. Moreover, repeated objective measurements of progress can focus intervention choices to achieve goals more quickly.<sup>8</sup> It is incumbent on the PT to educate the parents on the importance of the home program<sup>178</sup> and to partner with them to incorporate a reasonable and effective program into the home and family schedule. Care should be taken to balance the full scope of the family demands and resources on a case-by-case basis.

It is important to look beyond the infant's body structure limitations to include perceptual-motor experiences within the context of the infant's social environment and gross and fine motor exploration as contributing to the development of cognition.<sup>82</sup> Infants with limited or asymmetrical exploration, as seen in CMT and CD,<sup>53,79,164</sup> have demonstrated delays in early motor development that may affect the development of early perceptual-motor skills and, by inference, cognition.<sup>82</sup> Thus, pediatric PTs should treat beyond the body structure level to design and provide interventions that incorporate the infant's available functional range into activities that promote age-appropriate participation and that promote current and future development and learning across domains.<sup>82</sup>

**B** Action Statement 13: <u>Revised and updated</u>. PRO-VIDE THESE 5 COMPONENTS AS THE FIRST-CHOICE INTERVENTION. Physical therapists should provide and document these 5 components as the first-choice intervention for infants with CMT:

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- Neck PROM. (Evidence quality: II; Recommendation strength: Moderate)
- Neck and trunk AROM. (Evidence quality: II; Recommendation strength: Moderate)
- Development of symmetrical movement. (Evidence quality: II; Recommendation strength: Moderate)
- Environmental adaptations. (Evidence quality: II; Recommendation strength: Moderate)
- Parent/caregiver education. (Evidence quality: II; Recommendation strength: Moderate)

#### **Action Statement Profile**

Aggregate Evidence Quality: Level II randomized controlled trials (RCTs), cohort, and outcome studies.

#### Benefits to the Infant

- Increases infant's AROM and PROM.
- Facilitates normal and prevents, reduces, or eliminates asymmetrical postural, gross motor, skeletal, cognitive, sensory, and visual development.
- Reduces use of environmental supports/equipment that may increase asymmetry.
- Avoids or minimizes need for future, more invasive procedures.

#### Benefits to the Parent

- Enables parents to be active and effective caregivers.
- Education and early intervention provide assurances that they did not cause the CMT.
- Education empowers parents to implement interventions between physical therapy appointments.
- Education provides parents with information about typical developmental milestones and the factors that contribute to asymmetry.
- Balances the use of the supine position as a frequent infant position with activities in the prone, side-lying, and sitting positions during supervised, wakeful activities.
- Reduces potential overall cost of care for CMT with early, intense treatment.

# Risk, Harm, Cost:

- Stretching of the SCM can result in muscle snapping, which may or may not cause momentary infant discomfort; however, the documented long-term outcomes are positive.<sup>35</sup>
- Cost of care may be a burden for families.
- Parents/caregivers may apply interventions incorrectly.
- Parents may decrease the intensity of home exercises if they perceive that the PT is implementing the treatment.<sup>70</sup>

#### Value Judgments: None.

**Intentional Vagueness:** The GDG supports that stretching should be frequent through the day, every day; however, there is no dosage standard linking technique and duration of stretches, repetitions within each treatment session, frequency of treat-

ment sessions per day, overall duration of care, and frequency of clinic visits, including tapering schedules, to specific CMT severity classifications.

**Role of Parent/Caregiver or Patient Preferences:** Parental perceptions of the effect of CMT on their infant's function and the importance of the intervention program on their infant's future function are strong factors related to adherence to appointments and home exercises.<sup>178</sup> Parent/caregiver adherence to the plan of care under a PT's guidance<sup>64,176</sup> is optimal for achieving early intense treatment dosages.

# Exclusions: None.

# Quality Improvement:

• This recommendation may reduce unwarranted variation in practice and provides consumers with guidance for evidence-based interventions.

#### Implementation and Audit:

- Develop home exercise program materials, including online demonstrations of the 5 components of the first-choice intervention.
- Update documentation forms and electronic records to include the education provided to parents and their understanding and adherence to the exercises.
- While there are no studies that correlate the severity of lateral cervical flexion to the severity of CMT or the episode of care, PTs should document objective measures of lateral flexion and treat until resolved.
- Physical therapists should consider the corrected age of infants born preterm when designing a plan of care.
- Audit PT adherence to providing the 5 components of the first-choice intervention or reasons for deviating from the recommendation.

# **Supporting Evidence and Clinical Interpretation**

Neck PROM: Manual stretching remains the most commonly reported form of intervention for CMT, 37,57,103,105 with one new randomized controlled study comparing 2 stretching frequencies with infants younger than 3 months with CMT and PROM limitations.<sup>176</sup> One group received 10 sessions per day of 10 stretches each (100 stretches), and the other group received 5 sessions per day of 10 stretches each (50 stretches), with all other stretching parameters held constant. Both groups had significant improvements in head tilt and cervical rotation at 4 and 8 weeks, but the group receiving 100 stretches per day showed greater improvement than the 50 stretches per day group. While this one study provides support for an increased stretching frequency, there is no consensus on the techniques to perform the stretches, the number of repetitions, the duration of stretches and rest periods, and the number of individuals required for the stretches.

Stretching as an intervention should not be painful; stretches should be stopped if the infant resists<sup>59,104</sup> or the parent perceives changes in breathing or circulation.<sup>176</sup>

Low-intensity, sustained, pain-free stretches are recommended to avoid micro trauma of the muscle tissue.<sup>59</sup>

The 2-person technique for stretching has one person stabilizing the infant in the supine position with the head held beyond the support surface and the second person holding the head to guide it through the available range of cervical rotation and side bending.37,63,179 Alternatively, the single-person technique has the infant in the supine position on the caregiver's lap with one hand stabilizing the chest and shoulders and the other guiding the head through the range.<sup>25</sup> Hand placement is important when using either the 1- or 2-person stretch to properly stabilize the infant, to minimize compensatory movements, and to guide the infant's head through the available range.<sup>25,63,179</sup> The choice of technique may depend on the size and age of the infant when stretching is initiated, with younger, smaller infants more easily managed by a single-person technique whereas larger or more active infants may require 2 people to provide adequate positioning support.

Cervical PROM can also be achieved through positioning and handling,<sup>70,76,104</sup> including carrying or placing the infant in the side-lying position to gently stretch the shortened SCM<sup>37,59,76,104</sup> and while lying in the prone position with the face turned to the shortened SCM.<sup>31,37,104,180</sup> Passive cervical stretching can also be achieved during feeding<sup>141,167</sup> by encouraging turning toward the shortened side to pursue a bottle or breast, through the use of alternative feeding positions<sup>168</sup> and, when necessary, through positioning in car seats and infant carriers.<sup>25,104,118,140</sup>

Neck and Trunk AROM: Active ROM continues to be the standard of care in combination with other interventions.<sup>180,181</sup> Strengthening cervical and trunk muscles can be achieved through AROM during positioning,<sup>104</sup> handling,<sup>63,70,86</sup> carrying the infant,<sup>70,76,86,141</sup> while feeding,<sup>141,167,168</sup> and through exercises isolating the weaker muscles.<sup>63,70,76,104</sup> Incorporating righting reactions in upright, rolling, side-lying, or sitting postures has been used effectively during treatment and daily care routines to strengthen muscles opposite of the affected muscles.31,104,182 The affected side of CMT is placed downward, elongating the tighter muscles and encouraging activity of the weaker, nonaffected side.<sup>70,76,104</sup> Positioning the infant in the prone position encourages bilateral neck flexor elongation and strengthens neck and spine extensors.<sup>63,81</sup> Using visual and auditory tracking to elicit head turning in supported sitting toward the affected muscle<sup>37,76</sup> can strengthen cervical rotation.

**Development of Symmetrical Movement.** Observational data (n = 173) suggest that up to 25% (n = 44) of infants with postural CMT may have transient motor asymmetry; two-thirds of the 33 infants with follow-up data had no asymmetries by the age of 2 years.<sup>107</sup> Developmental exercises should be incorporated into physical therapy interventions and home programs to promote symmetrical movement in weight-bearing postures and to prevent the development of asymmetrical move-

ment patterns in the prone, sitting, crawling, and walking positions.  $^{76,86,107,141}$ 

**Environmental Adaptations**. Adaptations to the infant's environment can be incorporated into the home exercise program. Alternating the infant's position in the crib and changing table encourages head turning in the desired direction.<sup>25,65,141</sup> Adapting the car seat position to promote desired AROM,<sup>104,160,167</sup> minimizing the amount of time in a car seat and an infant carrier,<sup>118,140</sup> and placing toys on the affected side for the infant to turn the head toward the tighter side<sup>104</sup> have been recommended as part of home programming but not studied.

**Parent/Caregiver Education.** Parents and caregivers should be educated about the importance of "tummy time" or prone play,<sup>54,59,67,159,162,164</sup> positioning and handling to encourage symmetry,<sup>25,59,70,81,141</sup> minimizing the time spent in car seats and carriers to avoid CD as a precursor to CMT,<sup>25,27,118</sup> and alternating feedings to each side.<sup>167,168</sup> These strategies should be integrated into daily routines and home programs to enhance adherence.

Parents and caregivers may be inclined to seek advice from Internet sites and support groups. These sources can provide an array of information, but the veracity of information can vary, and the sites cannot tailor interventions to an individual child's body structures and activity limitations. Information on the use of prone positioning for play varies widely on when to start, how often, and for how long a session.<sup>67</sup> Parents should be encouraged to review information with their infant's physician and/or PT regarding exercises or interventions they are considering. Identification of evidence-based, reputable Internet resources would assist both clinicians and families in keeping up with current and valid management approaches.

R. Research Recommendation: Studies are needed to:

- Identify intervention techniques and dosages, including accurate descriptions of active exercises, with links to the CMT Severity Classification grades.
- Identify the components of optimal home programs.
- Evaluate the benefits of individual versus group therapy conditions.

C Action Statement 14: <u>Revised and updated</u>. PROVIDE SUPPLEMENTAL <u>INTERVENTION(S)</u>, AFTER APPRAISING APPROPRIATENESS FOR THE INFANT, TO AUGMENT THE FIRST-CHOICE INTERVENTION. Physical therapists may provide and document supplemental interventions, after evaluating their appropriateness for treating CMT or postural asymmetries, as adjuncts to the first-choice intervention when the first-choice intervention has not adequately improved range or postural alignment, and/or when access to services is limited, and/or when the infant is unable to tolerate the intensity of the first-choice intervention, and if the PT has the appropriate training to administer the intervention. (Evidence quality: I-IV; Recommendation strength: Weak)

Pediatric Physical Therapy

#### **Action Statement Profile**

Aggregate Evidence Quality: Level I-IV studies; 2 new level I studies on microcurrent (MC) and kinesiology tape (KT).  $^{180,181}$ 

**Benefits:** On an individual basis, combining supplemental interventions supported by limited evidence with the first-choice intervention:

- May be effective in improving outcomes or shortening treatment duration.
- May accommodate an infant's temperament or tolerance to treatment.
- May avoid or minimize the need for future, more invasive procedures.
- May increase parent/caregiver ability to implement home program.

#### Risk, Harm, Cost:

- Selected supplemental interventions should only be applied by clinicians skilled in that specific technique or modality and who understand the potential risks or side effects.
- There may be an added burden to the parent(s)/caregivers to learn additional intervention techniques.
- Some interventions may not be covered by insurance.
- Some approaches may increase the cost of care.

**Benefit-Harm Assessment:** Preponderance of benefit for MC and equal benefits and harms/costs for other supplemental interventions.

Value Judgments: Clinicians who are seeking to augment their first-choice interventions should choose those supplemental interventions with the strongest evidence first. Thus, if trained, clinicians should choose to use MC before choosing among the others of lesser strength.

**Intentional Vagueness:** While evidence supporting the use of MC is increasing, it is not known when it is best to add it to a plan of care.

**Role of Parent/Caregiver or Patient Preferences:** Parents may inquire about different interventions for the treatment of CMT.

Exclusions: None. Quality Improvement:

• Providing supplementary interventions may accelerate the resolution of CMT in infants whose progress has slowed.

#### Implementation and Audit:

- Document the application and dosage of supplemental interventions to accurately measure their effect on infants with CMT.
- Audit the types and documentation of supplemental interventions to determine their overall benefit to patients.

#### Supporting Evidence and Clinical Interpretation

The following interventions may be added as supplements to the first-choice intervention described in Action Statement 13 and are presented in descending order of evidence strength. In addition to experimental intervention studies, several studies have used a combination of the first-choice intervention with soft tissue mobilization (STM),173 massage,41,153,173,174 and therapeutic US.<sup>41,153,173,180</sup> While these studies are designed to look at prediction of outcomes or efficacy of other interventions, they provide preliminary evidence that a multimodal approach is effective; additional research is needed to study their individual effects. Finally, there are some interventions described in the common press for which there are no peer-reviewed publications to explain their effect on CMT and/or support their effectiveness. Departures from this guideline should be documented in the patient's record at the time the relevant clinical decisions are made; clinicians are strongly encouraged to publish the clinical reasoning and results of these alternative approaches.

#### Interventions With New Evidence: Level I Evidence:

**Microcurrent** is a low-intensity, single-channel alternating current applied superficially at a level that is not perceived by the patient. Two studies demonstrate reduced treatment duration and improved ROM with the addition of MC to physical therapy intervention. In a 2013 level I RCT,<sup>180</sup> all 20 infants received a home program, 20 minutes of exercises, 5 minutes of US, and 30 minutes with the MC unit setup, but only 10 infants received active MC. Treatment sessions were 3 times per week until PROM resolved or there were no improvements after 6 months of ongoing care. Those receiving the active MC had significantly shorter treatment durations (2.6 months) than those who did not (6.3 months). The results are consistent with a prior RCT<sup>128</sup> when 30 minutes of MC was applied to the involved SCM of infants with CMT, 3 times per week for 2 weeks, resulting in improved head tilt angle, neck rotation toward the affected side, and less crying during therapy when compared with a control group of infants with CMT who received traditional stretching and exercises. The sample groups were small (n = 7 experimental vs n = 8 control) and there was no long-term follow-up, but the average infant age was 7 months, and many had already been treated with stretching programs.

**Kinesiological taping (KT)** refers to the use of stretchable tape to support muscles and to provide sensory feedback. In contrast to the 2013 CMT CPG recommendation that KT could be a supplemental intervention, a 2016 level I study suggests that there is no added value to KT when provided for 3 weeks in conjunction with other conservative methods.<sup>181</sup> This was a small, prospective, single-blinded RCT with 3 infant groups who had KT applied 6 days per week for 3 weeks; all groups also received an exercise program and physical therapy intervention. Group 1 had exercise-only, group 2 had KT applied to the involved SCM for inhibition and the uninvolved SCM for facilitation, and group 3 had KT applied only to the involved

SCM for inhibition. While there were within-group changes in neck PROM, MFS scores, and head shape symmetry from their baselines, there were no significant differences between treatment groups immediately after treatment, at 1 month, or at 3 months posttreatment. This suggests that there is no added value of KT beyond exercise even over a 3-week treatment period. Öhman<sup>183</sup> reported an immediate effect of KT on MFS scores while the tape is on; however, it is not clear whether the change lasts beyond the immediate effect when KT is removed. Additional studies of alternative methods of applying KT may further clarify when and whether this approach is supported for use with CMT.

Soft Tissue Mobilization, as described by Keklicek and Uygur,<sup>12</sup> was applied in 3 phases: a passive mobilization phase, mobilization with stretching, and mobilization with active cervical rotation. For infants with CMT, a home program with STM 3 days a week for 12 weeks, compared with only a home program, resulted in improved cervical rotation PROM and head tilt after 6 weeks of intervention but not after 12 weeks of intervention or 18 weeks after the start of the study. Between groups, there was no difference in lateral flexion PROM or AROM throughout the study. It is not clear whether the improvements at 6 weeks are due to the treatment technique or intensity of treatment since the intervention for the control group was not dose equivalent and parents performed an unspecified home program of stretching and handling. Physical therapists may choose this approach if an infant is not progressing or is resisting passive stretching.

# Interventions With No New Evidence:

Level I Evidence:

Myokinetic stretching as described by Chon et al<sup>103</sup> consists of sustained 2-finger overpressure on the taut SCM muscle; 60 repetitions were delivered over 30 minutes, 5 times per week for an average of 1.7 months. Pre- and posttreatment measures of the SCM thickness in infants with either muscular or SCM mass torticollis were made by US. Results describe significant reductions in SCM thickness and improved cervical rotation and head symmetry with retention at the 1-year reassessment by parent reports. The study had no control group and the average age of the sample was 50 days (range, 30-70 days). In addition, the parents performed an unspecified home program of stretching and handling, so it is not clear whether the improvements are due to the treatment technique, intensity of treatment, and/or age of the infants. Most studies demonstrate that symptoms of infants younger than 2 months will resolve with traditional stretching approaches delivered at frequencies of less than 5 days per week. Physical therapists may choose this approach if an infant is not progressing or is resisting passive stretching.

#### Level IV Evidence:

The **Tscharnuter Akademie for Motor Organization** (**TAMO**) approach promotes problem solving and movement exploration during treatment, emphasizing light touch and the

infant's responses to gravity and support surfaces. A single case study of TAMO describes the treatment plan for an infant with CMT.<sup>86</sup> The subject is a twin born prematurely, hospitalized in the neonatal intensive care unit for 5.5 weeks and for other medical conditions during which he appeared to develop asymmetrical posturing. Despite home programming of position changes, encouragement of AROM, and use of prone positioning, SCM tightness developed and the infant was referred for treatment at 6.5 months of age (4.5 months corrected age). The application of TAMO is mixed with AROM activities, STM, parent instruction for use of home positioning to facilitate muscle lengthening, and carrying techniques that facilitate head righting opposite of the tightness. While the changes across time are well documented, it is not clear what contribution the TAMO approach provides separate from the positioning and handling approaches that others have shown to be effective except for the noticeable absence of passive stretching. This approach may be a useful addition for PTs who have received postgraduate training in the TAMO approach, particularly for infants who are resistant to stretching; however, without any other studies to demonstrate its application, generalizability is limited.

#### Level V Evidence:

The **Tubular Orthosis for Torticollis** (TOT) collar has been described in the literature<sup>63,84</sup> and online (www.symmetric-designs.com) as a neck orthotic designed to prevent movement toward and stimulate active movement away from the tilted head position. The collars are used as an adjunct to conservative treatment of infants with CMT who demonstrate adequate head control in supported sitting position and more than 5° to 6° of head tilt.<sup>84,179</sup> Although noted as part of routine intervention in the treatment of infants with CMT who meet criteria for their use,<sup>63,81,105,182</sup> there are no studies that isolate the outcomes of the TOT collar compared with other interventions. Pilot data reported by Karmel-Ross<sup>84</sup> suggested that infants treated with the TOT collar achieve 89.5°/90° vertical head position as compared with 84.8°/90° for those who did not.

**Soft foam collars** have been described by Jacques & Karmel-Ross<sup>84</sup> and have been used postsurgery,<sup>78</sup> postsurgery in conjunction with physical therapy,<sup>184-188</sup> and post-botulinum toxin<sup>44</sup> without specific rationales provided. They may be useful as passive support for the lengthened muscle, to protect incisions from curious hands, or to facilitate active movement away from the previously shortened side. Binder et al<sup>76</sup> describe the use of a soft felt and stockinette collar for infants presenting with less than 45° passive cervical rotation and a constant tilt. In all cases, no studies have been found that isolate the effect of foam or soft collars on the outcomes of conservative care.

**Custom fabricated cervical orthoses** have been described for postsurgical management of CMT in children<sup>186,189</sup> or young adults.<sup>190</sup> They reportedly provide greater stabilization of the spine and less mobility than the softer foam collars or semirigid cervical orthoses,<sup>191,192</sup> but their use with infants has not been reported in the literature.

Interventions Without Published Evidence of Efficacy:

The following approaches have either not been studied systematically or shown not to provide any additional benefit. Additional approaches have been found on the Internet and in the common press for which no peer-reviewed literature was found.

Cervical manipulation of the infant in the supine position has been compared with standard stretching alone in a small double-blind randomized trial (n = 32). Results indicated no differences between the groups, with many confounding variables. The study sample was underpowered, both groups received stretching and home programs, the infants were young (3-6 months of age when stretching alone is known to be effective), and selected measures are reported as unreliable due to infant cooperation. The actual technique used for cervical manipulation is not well described in the study. Others have concluded that the use of cervical manipulation in infants has no sufficient evidence of benefits and may be associated with higher risks of apnea and possible death.<sup>193,194</sup> In weighing the potential risks against the benefits of other approaches, the GDG does not recommend cervical manipulation as an intervention for infants with CMT.

The following interventions appear in print, online, in continuing education brochures, and parent support groups for infants with torticollis and deformational plagiocephaly, but no peer-reviewed studies have been found that describe the specific approaches or their effectiveness for resolving CMT: soft tissue massage as a single modality,<sup>81,84,86,103</sup> craniosacral therapy,<sup>84</sup> Total Motion Release, and Feldenkrais method.<sup>84</sup> Physicians, therapists, and parents should be aware that these approaches have no peer-reviewed publications that describe or study their effect on CMT, and their clinical application, risks, and anticipated outcomes may only be anecdotally reported. Because of a lack of studies, the GDG cannot recommend these approaches for management of CMT at this time. Clinicians who choose to use these approaches should document departures from this guideline in patient records at the time the relevant clinical decisions are made, obtain consent to treat from parents that acknowledges the lack of published evidence, carefully document objective measures of change, and consider publication of their outcomes.

**R. Research Recommendation:** Studies are needed to describe and clarify the efficacy of all supplementary interventions, including determinants for their choice, principles of application, dosage, and outcomes measures.

**B** Action Statement 15: <u>Revised and updated</u>. INI-TIATE CONSULTATION WHEN THE INFANT IS NOT PROGRESSING AS ANTICIPATED. Physical therapists who are treating infants with CMT or postural asymmetries should initiate consultation with the infant's physician and/or specialists about other interventions when the infant is not progressing as anticipated. These conditions might include when asymmetries of the head, neck, and trunk are not starting to resolve after 4 to 6 weeks of comprehensive intervention or after 6 months of intervention with a plateau in resolution. (Evidence quality: II; Recommendation strength: Moderate)

# **Action Statement Profile**

Aggregate Evidence Quality: Level II based on cohort follow-up studies.

Benefits:

- Other interventions (eg, botulinum neurotoxin therapy or surgery) can be considered to resolve the current asymmetries and prevent further progression of deformities and compensations.
- Provides the family/caregivers with alternative management strategies to help resolve asymmetries.

#### Risk, Harm, Cost:

• The consultations and possible subsequent interventions may add to the cost of care.

#### Benefit-Harm Assessment: Preponderance of benefit

**Value Judgments:** Collaborative and coordinated care is in the best interest of the infant and family-centered care.

**Intentional Vagueness:** The GDG is intentionally vague about the range of 4 to 6 weeks as the amount of time that a PT should treat an infant who is not responding to intervention. Since younger infants typically change more quickly than older infants, the GDG recommends that infants younger than 2 months who are not responding to intervention should be referred to their physician sooner than infants older than 2 months, who may require more time to respond to intervention.

**Role of Patient/Parent Preferences:** The age of the infant, severity of the CMT, rate of changes, needs of the family, cooperation and developmental needs of the infant, and available resources of the family/caregivers should help determine the episode of care before an infant is referred back to the infant's physician for consideration of alternative interventions.

# Exclusions: None.

**Note:** The 2013 CMT CPG conditions of referral when an infant presents at older ages with ROM limitations and/or facial asymmetry were incorporated into Action Statement 5 on Screening.

#### Quality Improvement:

• Referral back to the physician when the infant is not progressing as anticipated enhances coordinated communication about the infant, enables the infant to receive additional or specialized interventions, and promotes stronger professional relationships.

# Implementation and Audit:

• Documentation should include information supporting the reason for referral, the PT's hypotheses about other factors that might need attention, and the treatment types and intensities that were used.

- Survey referral sources for how they would like to receive communication about their patients (eg, digital vs hard copy reports or letters).
- Audit the number of infants whose symptoms are fully resolved as compared with those who require referral for interventions other than physical therapy.

#### **Supporting Evidence and Clinical Interpretation**

The literature supports a wide range of treatment durations for conservative care, so the question of when to refer an infant who is not progressing as anticipated has no clear answer. The duration of care will vary depending on the age of diagnosis and referral of the infant for services and the severity grade. Infants who are referred within the first 3 months with severity grades of 1 to 3 (see Figure 2, also SDC 2, available at: http://links.lww. com/PPT/A222) will most likely NOT require 6 months of conservative intervention if the interventions appropriately address the impairments and there is adherence with home programming. Infants who present with severity grades of 4 to 7 will more likely require the full 6 months of care, or more, depending on the number of comorbidities. Factors that might extend treatment duration include the presence of motor asymmetries,<sup>107</sup> an older age at initiation of treatment,<sup>36,41</sup> the presence or absence of an SCM mass,<sup>63,73,102,175</sup> the amount of head tilt,<sup>26,36,63,114,173</sup> the quality of the SCM fibers,<sup>72,102,173,174</sup> the presence of facial asymmetry or CD,<sup>36</sup> parental preference for conservative care, inconsistent home program adherence by parents/caregivers, and infant health conditions that may interfere with CMT interventions. Throughout the episode of care, the PT should collaborate with the infant's physician and the family to make a judgment about when to increase the intensity of direct physical therapy treatment or consider alternative approaches. This decision should be based on the rate of change, the persisting impairments, the age of the infant, and the needs and values of the family. The literature supports that if infants have treatment initiated before 3 months of age, 98% to 100% will respond to conservative treatment within a 6-month period of time, 37, 57, 61, 63 though full resolution may require longer durations. The determining factors should be documented measures of progressive improvement, with referral triggered by plateaus at or after 6 months of consistent and intensive intervention.

**Invasive Interventions:** There are 2 conditions for which a child may be referred for consideration of more invasive interventions: (1) if after 6 months of conservative intervention there is a lack of progress, or (2) if the child first begins intervention after 1 year of age and presents with significant restrictions and/or an SCM mass. Under these conditions, the PT should consult with the infant's physician or referring physician about other approaches; the 2 most reported are botulinum toxin injections and surgical lengthening of the SCM. The following brief descriptions are provided for information but are not exhaustive reviews of these approaches. Clinicians and fam-

ilies should discuss these options with their infants' physicians when conservative care has not been successful.

Botulinum toxin is a neurotoxin that is postulated to act on the tight SCM in 2 ways: as a neuromuscular block that inhibits acetylcholine release, thus reducing stimulation of an already tight muscle, and as a neurotoxin causing muscle atrophy and weakening that allows for easier stretching.<sup>135,195</sup> While it is not formally approved for use with infants, it is approved for adults with cervical dystonia.<sup>195</sup> Three retrospective studies<sup>44,135,136</sup> describe the effectiveness of botulinum toxin in increasing ROM in infants with CMT as varying from 25%<sup>136</sup> to 74%<sup>135</sup> to 93%.<sup>44</sup> Adverse effects include pain and bruising,<sup>44</sup> temporary dysphagia,<sup>135</sup> and neck weakness,<sup>135</sup> all of which are reported to resolve.

Surgical release of the SCM is the more traditional alternative for treating recalcitrant CMT.<sup>184,188,196</sup> It is beyond the scope of this CPG to describe the variety of surgical approaches, which generally fall into 3 categories: tendon lengthening, unipolar release of the distal SCM attachment, or bipolar release of both SCM muscle attachments.<sup>197,198</sup> There is emerging evidence that use of acellular dermal matrix may yield better postsurgical cervical ROM for corrections after 8 years of age.<sup>199</sup> Criteria that have been used to determine the timing for surgery include persisting limitations in cervical ROM more than 15°, <sup>114,169</sup> progressing limitations, <sup>59</sup> having an SCM mass and being older than 12 months combined with late-age diagnosis,<sup>114</sup> persistent visible head tilt,<sup>26,114,169</sup> not responding to intervention after 6 months,<sup>26,114</sup> and reaching the age of 1 year without resolution<sup>169</sup>; surgery before 8 years of age appears to yield better outcomes than after 8 years of age.<sup>200</sup> The postoperative management of CMT is similar to the preoperative one and can range from 4 to 6 weeks<sup>201</sup> up to 11 months<sup>172,202</sup> to work on scar management, muscle strength, and ROM

**R. Research Recommendations:** Studies are needed to describe the incidence of infants that require invasive care, their history of interventions, the best time for referral, and any associated physical therapy outcomes.

#### IV. PHYSICAL THERAPY DISCONTINUATION, REASSESSMENT, AND DISCHARGE OF INFANTS WITH CMT

**B** Action Statement 16: Revised and updated. DIS-CONTINUE DIRECT SERVICES WHEN THESE 5 CRITERIA ARE ACHIEVED. Physical therapists should discontinue direct physical therapy services and document outcomes when these 5 criteria are met: PROM within 5° of the nonaffected side; symmetrical active movement patterns; ageappropriate motor development; no visible head tilt; and the parents/caregivers understand what to monitor as the child grows. (Evidence quality: II-III; Recommendation strength: Moderate)

#### **Action Statement Profile**

**Aggregate Evidence Quality:** Levels II-III based on long-term follow-up studies.<sup>37,203</sup>

#### Benefits:

Use of these criteria for discontinuation from direct physical therapy reasonably ensures that:

- The CMT has resolved within accepted ranges of measurement error.
- There are no lingering secondary compensations or developmental delays.
- The parents/caregivers know how to assess for regression as the infant grows and when to contact their infant's physician and/or PT for reassessment.
- Discontinuation documentation reflects the expected outcomes for the episode of care relative to the baseline measures taken at the initial examination.

**Risk, Harm, Cost:** There is an unknown amount of risk that discontinuation from physical therapy services with 5° of residual asymmetry will progress to other anatomical areas (cervical scoliosis, craniofacial) or return as the infant grows.

Benefit-Harm Assessment: Preponderance of benefit.

**Value Judgments:** The GDG defines cervical rotation and cervical lateral flexion motions as included in PROM. Furthermore, it includes full active cervical rotation and lateral flexion in the phrase "symmetrical active movement."

#### Intentional Vagueness: None.

**Role of Patient/Parent Preferences:** Parents/caregivers need to be educated about the importance of screening for asymmetries as the child grows and becomes more active against gravity. They should be advised that preferential positioning is often observed during times of fatigue or illness and that reevaluation is only warranted if it persists.

Exclusions: None.

#### Quality Improvement:

- Complete documentation of baseline and discontinuation measures will support more accurate physical therapy outcomes.
- Measurements taken at each treatment session provide feedback to parents about the child's progress and support fine-tuning of the interventions that can shorten the duration of care.<sup>8</sup>

#### Implementation and Audit:

- Physical therapists should follow up with families that discontinue direct physical therapy services before achieving resolution of asymmetries or formal discharge to determine the reason for discontinuation.
- Physical therapists should educate parents/caregivers on signs of recurring CMT when changing from direct physical therapy to monitoring with a reassessment at 3 to 12 months of age or when the infant starts walking.

#### **Supporting Evidence and Clinical Interpretation**

The 2018 CMT CPG uses the phrase *discontinuation of direct services* to mean when the infant has achieved the 5 criteria and direct intervention is no longer warranted. *Discharge* is defined as occurring 3 to 12 months after the discontinuation of direct services when physical therapy reassessment for potential residual CMT or other developmental concerns is negative.

While the duration of intervention for the individual infant will vary depending on the constellation of factors identified in Figure 2 (also SDC 2, available at: http://links.lww.com/PPT/ A222), the criteria for discontinuing direct physical therapy services are based on norms for infant growth and development,<sup>111</sup> known risk of early delays,<sup>53,54,203</sup> and the emerging evidence of possible long-term sequelae.<sup>43,113</sup> Functionally, it is critical that the infant who has achieved full PROM can actively use the available range, so physical therapy criteria for discontinuation should address developmental activity rather than focus solely on biomechanical measures of change.<sup>79</sup> Persistent functional limitations or developmental delays, after achievement of full PROM, are reasons to extend or initiate a new episode of care. Finally, these criteria are common across the literature and thus are in keeping with current practice norms.

**R. Research Recommendation:** Longitudinal studies are needed to understand the best criteria and/or timing for discontinuing infants from direct physical therapy intervention and the final discharge from the episode of care.

**B** Action Statement 17: <u>Revised and updated</u>. REASSESS INFANTS 3 TO 12 MONTHS AFTER DISCONTINUATION OF DIRECT SERVICES AND THEN DISCHARGE IF APPROPRIATE. Three to 12 months following discontinuation from direct physical therapy intervention *or* when the child initiates walking, PTs who treat infants with CMT should examine postural preference, the structural and movement symmetry of the neck, face and head, trunk, hips, upper and lower extremities, and developmental milestones to assess for reoccurrence of CMT and evidence of atypical development. (Evidence quality: II; Recommendation strength: Moderate)

#### **Action Statement Profile**

Aggregate Evidence Quality: Level II based on longitudinal follow-up studies with moderately large samples, reasonable follow-up periods, and reliable outcome measures.

**Benefits**:

- Detection of postures and movement consistent with relapsing CMT, particularly as infants initiate walking and move against gravity.
- Detection of developmental delays.
- Ability to restart home exercise programs if asymmetry is identified.

• Screening identifies other causes of asymmetry, other than CMT, if asymmetries reappear.

#### Risk, Harm, Cost:

• A single follow-up visit will minimally add to the cost of care.

#### Benefit-Harm Assessment: Preponderance of benefit.

**Value Judgments:** A single follow-up physical therapy visit for infants with a history of CMT is consistent with the APTA Guide to Physical Therapist Practice that describes the roles of a PT as including prevention of recidivism and preservation of optimal function.<sup>80</sup>

Intentional Vagueness: The recommended time at which follow-up is scheduled (3-12 months) is wide because the age of the infant at discontinuation from direct physical therapy intervention will vary. Reassessment of younger infants, discontinued from direct intervention between 4 and 6 months, may need to occur sooner when the infants are initiating standing and walking. It is not known how far out into early childhood that reassessment should occur. Literature suggests that by 8 to 15 months, infants with delays at 2 to 6 months catch up with their peers<sup>53,54</sup> and they continue to demonstrate age-appropriate motor development at preschool age.<sup>203</sup> However, a single follow-up study suggests that some infants are at a greater risk for persistent neurodevelopmental conditions, such as developmental coordination disorder and attentiondeficit/hyperactivity disorder, which may not become evident until the early school years.113

**Role of Patient/Parent Preferences:** Parents/caregivers may choose to forego a physical therapy reassessment if it places undue burden on the family for travel, time, or finances. Parents should be advised at discontinuation of direct physical therapy intervention of the small chance that developmental conditions may evidence themselves when the child enters school, and parents should be educated to observe for persistent asymmetry.

Exclusions: None.

#### **Quality Improvement:**

• Long-term follow-up reassessments will provide data to understand the incidence of residual asymmetries or functional deficits, and parental satisfaction.

#### Implementation and Audit:

- Provide education to clinicians and families about this recommendation to improve adherence to reassessment.
- Determine a method, based on location and health care coverage processes, to facilitate a cost-effective physical therapy reassessment. This may require PTs to educate administrators, service coordinators, and nonmedical professionals about the importance of a comprehensive reassessment for infants with CMT. Physical therapists should collaborate with their administrative and health care providers to develop pathways for parents to obtain

this reassessment, either internally or by referral to other services.

- Provide clear instructions to parents about the signs of unresolved or returning CMT.
- After reassessment, document:
  - That parents were instructed to notify the PT if there is a persistent return of head tilt or asymmetry in active rotation or lateral flexion ROM.
  - The PT's recommendation to the physician to check the infant's cervical ROM and presence of head tilt in well-child visits.
  - The PT's recommendation for a physical therapy reassessment to check the condition of the infant's CMT and general development at 12 months of age or when walking begins.
- Have the parent complete a reminder postcard for a physical therapy reassessment that can be mailed to the family at the appropriate time.
- Audit the number of reassessments completed versus the reasons for no reassessment, or premature discontinuation of services.

#### Supporting Evidence and Clinical Interpretation

The long-term consequences of CMT are implied from studies of older children and adults who require surgical procedures for correction of unresolved asymmetry<sup>43,47,197</sup> and from long-term follow-up studies.<sup>37,203</sup> While the short-term outcomes of conservative management are well documented, there is little direct evidence of the long-term effectiveness of early physical therapy intervention, nor the rate of recidivism following early intervention. Studies report an "excellent" resolution of CMT as having less than 5° of passive rotation asymmetry with the opposite side<sup>26,32,46,175</sup> and a "good" resolution with as much as  $10^{\circ32,46}$  residual. It is not known whether the last 5° to  $10^{\circ}$  spontaneously resolves or in whom a mild limitation remains, whether achieving cervical rotation PROM equates to full active use of the available range, or whether residual asymmetry influences normal development.

Öhman and Beckung<sup>203</sup> found that although infants with a history of CMT did not exhibit motor delays at preschool age, 7% exhibited a head tilt and 26% had some degree of PROM asymmetry.<sup>204</sup> The clinical significance of asymmetric neck PROM is uncertain because only children with CMT were followed. All had 85° or more of rotation PROM to each side, and 7 children had a lateral flexion PROM differences between sides of only 5° to 10°; it is not clear whether age-matched children without CMT would present with similar results. In this study, asymmetric cervical PROM at preschool age was associated with the degree of asymmetric cervical rotation PROM as an infant.<sup>204</sup>

The documented potential for increasing muscle fibrosis,<sup>98</sup> developmental delays,<sup>113</sup> and hemisyndrome<sup>76</sup> supports that a single physical therapy reassessment is prudent to determine whether the resolution of CMT achieved at an earlier age is

maintained as the infant continues to develop and to assess for potential developmental delays or biased limb use. Physicians should be cognizant of the risk for asymmetries and/or motor delays during routine physical examinations as infants with a history of CMT are followed through to their teen years.

The length of time after discontinuation that a physical therapy reassessment should be conducted is supported by level IV evidence. Wei et al<sup>51</sup> proposed following infants until complete resolution or a minimum of 12 months. Ultrasound images suggest that while clinical indicators of ROM may improve, they are not correlated with SCM fibrous changes and these fibrous changes can continue until at least 3 years of age.<sup>98</sup> Finally, the potential for developmental delays may not become evident until early school age,<sup>113</sup> so a reexamination when the child enters elementary school may be warranted if a parent or teacher reports or the child presents with residual asymmetries, developmental delays, or preferential positioning. Regional differences as to when a child is seen for his or her final direct service appointment may differ from the criteria for discharge, when the episode of care for CMT is considered closed.

R. Research Recommendations: Studies are needed to:

- Determine the most reasonable physical therapy reassessment times after discontinuation of direct physical therapy intervention, based on initial presentations.
- Establish the level of risk of developing asymmetries following an episode of intervention.

- Describe parent/caregiver experiences and/or satisfaction with physical therapy intervention and infant outcomes. Limited mentions of parent and/or patient satisfaction are available postsurgery<sup>46,198</sup> and post–botulinum toxin use,<sup>44</sup> but none were found specific to physical therapy management.
- Determine the validity and reliability of using telemedicine or virtual meetings as compared with in-person physical therapy reassessment for the 3- to 12-month reassessment.

#### SUMMARY

A review of the literature, including a focused systematic review, resulted in 17 graded action statements with varying levels of obligation that address education, referral, screening, examination and evaluation, classification, prognosis, firstchoice and supplementary physical therapy interventions, interprofessional consultations, discontinuation, reassessment, and discharge, with suggestions for quality improvement, implementation, and audits. Flow sheets for referral paths and classification of CMT severity have been updated. Evidence tables are available as supplemental files. Research recommendations are made for 17 practice issues and summarized at the end of the document. There is a growing body of evidence on implementing research into practice. The following suggestions are provided as general strategies for clinicians to implement the action statements of this CPG but are not an exhaustive review. Many variables impact the successful translation of evidence into practice; clinicians will need to assess their own practice structures, cultures, and clinical skills to determine how to best implement the action statements as individuals and how to facilitate implementation by others.

The GDG recommends that:

- Education about the 2018 CMT CPG should be included in physical therapy curricula.
- Continuing education programs are provided to PTs on the updates in the 2018 CMT CPG.
- Physical therapists distribute brochures developed by the APPT (https://pediatricapta.org/ clinical-practice-guidelines/) to parents, physicians, midwives, and other health care providers that summarize the applicable key points of the 2018 CMT CPG.

#### **Strategies for Individual Implementation**

- Seek training in the use of the recommended standardized measures and/or intervention approaches.<sup>205</sup>
- Build relationships with referral sources to encourage early referral of infants.
- Measure individual service outcomes of care (eg, patient impact across the ICF domains, costs, parent/caregiver satisfaction).<sup>206,207</sup>

# Strategies for Facilitating CPG Implementation in Other Clinicians

- Recognize that adoption of the recommendations by others may require time for learning about the 2018 CMT CPG content, developing a positive attitude toward adopting the action statements, comparing what is already done with the recommended actions, trialing selected changes in practice to determine their efficacy, and, finally, routine integration of the tested changes.<sup>206,208</sup>
- Identify early adopting clinicians as opinion leaders to introduce the guideline via journal clubs or staff presentations.<sup>206,208</sup>
- Identify gaps in knowledge and skills following content presentations to determine staff needs to implement recommendations.<sup>208</sup>
- Use documentation templates to facilitate standardized collection and implementation of the recommended measures and actions.<sup>5,209,210</sup>
- Institute quality assurance processes to monitor the routine collection of recommended data and implementation of recommendations and to identify barriers to complete collection.<sup>206,211</sup>
- Measure structural outcomes (eg, dates of referral, equipment availability), process outcomes (eg, use of tests and measures, breadth of plan of care), and service outcomes (eg, patient impact across the ICF domains, costs, parent/caregiver satisfaction)<sup>206,207</sup> to describe service delivery patterns and publish results.

Action Statement 1: Educate Expectant Parents and Parents of Newborns to Prevent Asymmetries/CMT. Studies are needed on the effect of education of:

- Health care providers and their knowledge of pediatric PTs' roles in managing postural preference.
- Parents/caregivers about the parental experience of receiving this education.

Action Statement 2: Assess Newborn Infants for Asymmetries/CMT. Studies are needed to determine:

- Whether routine screening at birth increases the rate of CMT identification or increases false-positives.
- The barriers to early referral of infants with CMT to physical therapy.

Action Statement 3: Refer Infants With Asymmetries/CMT to Physicians and Physical Therapists.

- Studies are needed to clarify the predictive baseline measures and characteristics of infants who benefit from immediate follow-up and to compare the cost-benefit of early physical therapy intervention and education versus parental instruction and monitoring by physicians.
- Longitudinal studies of infants with CMT are needed to clarify how the timing of referral and initiation of intervention impact body structure and functional outcomes, and overall costs of care.

Action Statement 4: Document Infant History.

• Studies are needed to clarify how the health history factors influence physical therapy diagnosis, prognosis, and intervention.

**Action Statement 5:** Screen Infants for Nonmuscular Causes of Asymmetry and Conditions Associated With CMT.

• Studies are needed to identify the precision of screening procedures specific to CMT.

Action Statement 6: Refer Infants From Physical Therapists to Physicians if Indicated by Screen.

• Studies are needed to clarify the incidence of nonmuscular causes of CMT and associated conditions and how early referral impacts ultimate outcome.

Action Statement 7: Request Images and Reports.

• Studies are needed to determine who would benefit from imaging, at what time in the management of CMT images are useful, and how images affect the plan of care.

Action Statement 8: Examine Body Structures.

- Reliable, valid, and time-efficient methods of measuring infant cervical PROM need to be developed, including lateral flexion, and large-scale normative data of PROM should be established by age in months.
- Determine the sensitivity and specificity of the MFS to differentiate infants with clinically significant limitations from infants developing typically.

- Establish a clinically practical, objective method of measuring cervical rotation AROM in infants 0 to 3 months and infants older than 3 months to assess baseline and change over time.
- Determine what, if any, correlation between AROM and PROM should be used for discontinuation and/or discharge criteria.
- Studies are needed to describe and differentiate signs of discomfort from the types of pain reactions typically observed in infants with CMT during specific testing or interventions.
- Determine the validity of the FLACC scale in rating true pain reactions during CMT examinations or interventions.

Action Statement 9: Classify the Level of Severity.

• Studies are needed to determine a reliable, valid, and clinically practical method of measuring cervical lateral flexion and then to determine how the severity of lateral flexion may relate to the CMT Severity Classification grades.

Action Statement 10: Examine Activity and Developmental Status.

• Studies are needed to identify the best developmental tests to use for infants with suspected or diagnosed CMT, from birth through 12 months, so that the same measures can be documented on all infants, enabling comparison of outcomes across studies.

Action Statement 11: Examine Participation Status.

• Studies are needed to quantify changes in participation and clarify how the participation elements inform the plan of care.

Action Statement 12: Determine Prognosis. Studies are needed to:

- Clarify the interaction between the factors associated with full symptom resolution and episode of care.
- Clarify the accuracy of prognosis with respect to full symptom resolution and episode of care.
- Describe and clarify the efficacy of different delivery models, for example, individual versus group or clinic versus home.

Action Statement 13: Provide These 5 Components as the First-Choice Intervention. Studies are needed to:

- Identify intervention techniques and dosages, including accurate descriptions of active exercises, with links to the CMT Severity Classification grades.
- Identify the components of optimal home programs.
- Evaluate the benefits of individual versus group therapy conditions.

Action Statement 14: Provide Supplemental Intervention(s), After Appraising Appropriateness for the Infant, to Augment the First-Choice Intervention.

• Studies are needed to describe and clarify the efficacy of all supplementary interventions, including determinants for their choice, principles of application, dosage, and outcomes measures.

Action Statement 15: Initiate Consultation When the Infant Is Not Progressing as Anticipated.

• Studies are needed to describe the incidence of infants who require invasive care, their history of interventions, the best time for referral, and any associated physical therapy outcomes.

Action Statement 16: Discontinue Direct Services When These 5 Criteria Are Achieved.

• Longitudinal studies are needed to understand the best criteria and/or timing for discontinuing infants from direct physical therapy intervention and the final discharge from the episode of care.

Action Statement 17: Reassess Infants 3 to 12 Months After Discontinuation of Direct Services and Then Discharge if Appropriate.

- Determine the most reasonable reassessment times after discontinuation of direct physical therapy intervention based on initial presentations.
- Establish the level of risk of developing asymmetries following an episode of intervention.
- Describe parent/caregiver experiences and/or satisfaction with physical therapy intervention and infant outcomes. Limited mentions of parent and/or patient satisfaction are available postsurgery<sup>46,198</sup> and post–botulinum toxin use,<sup>44</sup> but none were found specific to physical therapy management.
- Determine the validity and reliability of using telemedicine or virtual meetings as compared with in-person physical therapy reassessment for the 3- to 12-month reassessment.

#### **DEVELOPMENT OF THE GUIDELINE**

This CPG is the product of many people's work and support. At each phase of the update, the GDG has benefitted from the work and advice of clinicians, methodologists, and the families with whom we work. The following outlines the phases of this update and formally acknowledges the contributors in each phase. Contributors are listed alphabetically.

Phase 1: Organization and manuscript development, including determination of scope.

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Phase 2: Literature search and abstract review.

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Emily Heidenreich, PT, DPT, PCS

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Phase 3: Literature review, appraiser reliability training, and critical appraisal ratings.

Emily Heidenreich, PT, DPT, PCS

Barbara Sargent, PT, PhD, PCS

Phase 4: Action statement generation and literature summarization.

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Phase 5: First round review by content experts.

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All first round reviewers declared an absence of conflicts of interest with the topic, process, and/or financial relationships.

Phase 6: External review of the revised CPG by the public and AGREE II ratings.

Following edits based on the first round review, a revised CPG draft was posted for public comment on the APTA APPT Web site. Notices were sent through the APPT electronic newsletter, posted on a physical and occupational therapy social media Web site, and sent individually to any clinicians who had inquired about the CPG during its update regarding the opportunity for comments. Comments were and may be submitted to torticolliscpg@gmail.com.

#### AGREE II Reviewers

This CPG was evaluated by the following reviewers using the AGREE II,<sup>15</sup> an established instrument designed to assess the quality of CPGs:

Lisa Selby-Silverstein, PT, PhD, NCS, Professor, Program in Physical Therapy, Neumann University, Aston, Pennsylvania

Catherine R. Smith, PT, DPT, PhD, PCS, CNT, Associate Professor, Physical Therapy; Vanderbilt Pediatric Professorship, University of Tennessee, Chattanooga, Tennessee

Phase 7: Submission for publication to *Pediatric Physical Therapy*.

Colleen P. Coulter, PT, DPT, PhD, PCS

Sandra L. Kaplan, PT, DPT, PhD

Barbara Sargent, PT, PhD, PCS

Linda Fetters, PT, PhD, FAPTA, Pediatric Physical Therapy, Editor-in-Chief

Phase 8: Dissemination of guideline.

APTA APPT Web page.

PEDro Submission—Sandra L. Kaplan, PT, DPT, PhD

Presentations scheduled at the APPT Annual Conference

(2018) and the APTA Combined Sections Meeting (2019).

Phase 9: Plan for revision. The GDG recommends that the CPG be reviewed for updating in 5 years, as the body of evidence expands.<sup>11</sup> The guideline revision will be organized by Barbara Sargent, PT, PhD, PCS. Similar to the 2018 CMT CPG, a systematic review to inform an update will be initiated in 2021 and completed in 2023; if warranted, the 2023 CMT CPG update will begin in 2022 and be completed in 2023.

Phase 10: Plan for monitoring guideline uptake. The GDG recommends a survey of pediatric PTs in 2021, similar to Kaplan et al,<sup>7</sup> to assess implementation of the 2018 CMT CPG guideline.

#### ACKNOWLEDGMENTS

Pam Corley, Reference librarian, USC 2013 CMT CPG; Robert Johnson, MLIS, Reference librarian, USC, 2018 CMT Systematic Review; Richard Shiffman, MD, BridgeWIZ developer; Melanie McKinney, PT, DPT, PCS, liaison to APPT Knowledge Translation and KBNet working groups.

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Appendix 1:

ICF and ICD-10 Codes

ICF Codes	CMT Presentation	
Impairments of body structures and functions		
B7108: Mobility of joint functions, other specified	Cervical PROM and AROM	
B7300: Power of isolated muscles and muscle groups	Strength of lateral neck flexion and cervical rotation; strength of neck and back extensors in the prone position; symmetrical strength of SCM in pull to sit.	
B7350: Tone of isolated muscles and muscle groups	Hyper- or hypotonia; spasm	
B7600: Control of simple voluntary movements	Active visual pursuit toward the shortened side; symmetrical movements of trunk; UEs and LEs in developmental positions	
S7103: Joints of head and neck region	Cervical AROM, PROM	
S7104: Muscles of head and neck region	Presence of an SCM mass	
S7108: Structure of head and neck region, other specified	Facial and skull symmetry	
S7401/S5001: Hip joint	Hip dysplasia	
Activity limitations		
D110: Watching	TIMP, AIMS, AROM, ocular torticollis	
D440: Fine hand use	Hands to midline; hemisyndrome	
D445: Hand and arm use	Hands to midline; hemisyndrome; AIMS, AROM	
Participation restrictions		
D7600: Parent-child relationships	Parent comfort and knowledge with positioning and home programming	
D7601: Child-parent relationships	Infant engagement with parent during feeding and play	
D920: Recreation and leisure	AIMS, attention to toys	

Abbreviations: AROM, active range of motion; AIMS, Alberta Infant Motor Scales; CMT, congenital muscular torticollis; ICD, International Statistical Classification of Diseases and Related Health Problems; ICF, International Classification of Functioning, Disability, and Health; LEs, lower extremities; PROM, passive range of motion; ROM, range of motion; SCM, sternocleidomastoid; TIMP, Test of Infant Motor Performance; UE, upper extremities.

#### **ICD-10 Codes**

The following codes may be used by a variety of health care professionals and are offered for reference; they are not intended to be directional for billing purposes.

Q67.0	Facial asymmetry
Q67.3	Plagiocephaly
Q68.0	Congenital deformity of sternocleidomastoid muscle
Q79.8	Other congenital malformations of the musculoskeletal
	system
P15.2	Sternomastoid injury due to birth injury
M43.6	Torticollis

#### **Appendix 2:**

**Operational Definitions** 

**Brachycephaly:** Cranial deformation with flattening of the entire posterior surface of the head.<sup>209</sup>

**Cervical rotation**: Movement in the transverse plane such that the chin turns toward or past the ipsilateral shoulder.

**Congenital muscular torticollis (CMT):** Congenital muscular torticollis is a common pediatric orthopedic condition, described as a postural deformity of the neck evident at birth or shortly thereafter. It is typically characterized by a head tilt to one side and the neck rotated to the opposite side, due to unilateral shortening or fibrosis of the sternocleidomastoid muscle. It may be accompanied by cranial deformation or developmental dysplasia of the hip (DDH), and less frequently, atypically present as a head tilt and neck twisting to the same side.<sup>29,110,210</sup> Congenital muscular torticollis has been associated with DDH,<sup>49</sup> brachial plexus injury,<sup>20–22</sup> lower extremity deformities,<sup>23–25</sup> early developmental delay,<sup>20,50</sup> persistent developmental delays,<sup>109</sup> facial asymmetry, which may impact function and cosmesis,<sup>52</sup> and temporomandibular joint dysfunction.<sup>53</sup>

**Cranial deformation:** A distortion of the shape of the skull resulting from mechanical forces that occur pre- or postnatally.<sup>209</sup> This term includes plagiocephaly and brachycephaly.

**Lateral cervical flexion, side bending, or head tilt:** Movement in the coronal plane such that the infant's ear approaches the ipsilateral shoulder.

**Plagiocephaly:** Cranial deformation with flattening of one posterior side of the head.<sup>139</sup>

**Postural preference** (synonymous with positional preference): It refers to the preferred head and neck asymmetry that an infant gravitates to in all positions.

**Sternocleidomastoid mass** (synonymous with fibromatosis colli, tumor, pseudotumor, or node): A condition in which the sternocleidomastoid muscle is enlarged because of fibrosing of muscle cells with identifiable histological changes.<sup>93</sup> It is referred to as a "mass" throughout this document.