Consensus-Based Care Recommendations for Children with Myotonic Dystrophy Type 1 (DM1)

A guideline created by the **Myotonic Dystrophy Foundation**, in collaboration with NMD4C investigator, **Dr Campbell**

MYOTONIC DYSTROPHY TYPE 1

Inherited dominant neuromuscular disease

Phenotypes depending of age of onset and severity of symptoms

Multisystemic (mostly muscular and central nervous systems)

Estimated worldwide prevalence of **1:20 000**

Shortened life expectancy related to respiratory-cardiac involvements

THE GUIDELINE

AUDIENCE

Aimed towards **physicians** but useful for all healthcare professionals (i.e., physiotherapists, nurses, etc.)

POPULATION

Pediatric population, more specifically children living with DM1 with either the congenital or childhood phenotype

CONTENT

General care considerations, such as diagnosis, genetic counseling and neonatal care; and recommendations from a **system-based approach**

FIVE THINGS TO KNOW

1. **Diagnosis** should be considered not only in children with classic motor features but with other system issues such as gastrointestinal disorders, cardiac arrythmias and developmental disorders
2. **Referral to genetic counseling** is recommended for all patients with congenital and childhood onset and their parents
3. Do not use CTG repeat numbers for **prognostication**; it may be an indicator of severity, but it does not provide sufficient information alone to predict mortality or ventilation dependence
4. A high-risk obstetrician should provide **prenatal obstetric care** for mothers known or suspected to carry a child with DM1 and a pediatric/neonatal specialist should be present at delivery
5. A child should be followed in a **multidisciplinary clinic** with monitoring for the manifold issues associated with DM1

Dr Craig Campbell is a pediatric neurologist and the medical director of the multidisciplinary neuromuscular clinic based at Children's Hospital London Health Sciences Centre

To access the **complete** guideline, click here or scan this QR code!

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Neuromuscular Disease Network for Canada (NMD4C)
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