DM1 HEALTH SUPERVISION CHECKLIST

Reprinted from Neuromuscular Disorders, Health supervision and anticipatory guidance in adult myotonic dystrophy type 1, 20(12), Gagnon, C, Chouinard, M.C., Laberge, L., Veillette, S., Bégin, P., Breton, R., Jean, S., Brisson, D., Gaudet, D., Mathieu, J. Appendix 1.

	CONCERNS	INTERVENTIONS
Central nervous system concerns		
Cognitive impairments	☐ Normal IQ ☐ Low IQ ☐ Intellectual Disability ☐ Evaluation required	
Depression	☐ Absent ☐ Evaluation/treatment required	
Excessive daytime sleepiness	☐ Absent ☐ Mild symptoms ☐ Evaluation/treatment required	
Fatigue	☐ Absent ☐ Mild symptoms ☐ Evaluation/treatment required	
Visual concerns		
Ptosis	☐ Absent ☐ Mild, reassess at follow-up ☐ Moderate ☐ Evaluation required	
Cataracts	☐ Absent or aphaky ☐ Present ☐ Evaluation required	
Respiratory concerns		
Pneumonia	☐ Absent ☐ One or more in the last 6 months	
Chronic respiratory failure	☐ Absent ☐ Arterial blood gaz and spirometry required	
Sleep disturbances	☐ Absent ☐ Insomnia ☐ Sleep apnea symptoms ☐ Oxymetry/PSG required	
Vaccination	☐ Annual influenza vaccine ☐ Pneumovax vaccine ☐ year	
Anesthetic risks	☐ Information provided	
Cardiovascular concerns		
Conduction defects	☐ Absent ☐ Asympto. ECG abnormalities ☐ Evaluation in cardiology needed	
	☐ Pacemaker ☐ year ☐ Pacemaker/defibrillator ☐ year	
Arterial hypotension	☐ Absent ☐ Asymptomatic ☐ Symptomatic AT /	
Muscular concerns		
Myotonia	☐ Absent ☐ Mild, no disturbance ☐ Intervention required	
Muscular weakness	MIRS grade	
Walking limitations	☐ No risk of falls ☐ Physiotherapist evaluation/equipment required	
Transfer difficulties	☐ No difficulties ☐ Occupational therapist evaluation/technicals aids required	
Wheelchair dependence	☐ Not required ☐ Already provided ☐ Intervention required	
Gastrointestinal concerns		
Dysphagia	☐ Absent ☐ Present but no intervention needed ☐ Intervention required	
Gastroparesis	☐ Absent ☐ Mild/occasional N/V ☐ Intervention required	
Gall-bladder problems	☐ Absent/cholecystectomy ☐ Evaluation required ☐ Intervention required	
Abdominal pain	☐ Absent ☐ Mild/occasional pain ☐ Intervention required	
Constipation/diarrhea	☐ Absent ☐ Mild/occasional constipation or diarrhea ☐ Intervention required	
Anal incontinence	☐ Absent ☐ Mild/occasional incontinence ☐ Intervention required	
Malnutrition	☐ Absent ☐ Mild loss of weight ☐ Intervention required	
Genitourinary and sexual concerns		
Urinary incontinence	☐ Absent ☐ Incontinence ≤ once/month ☐ Intervention required	
Erectil dysfunction	☐ Absent/NA ☐ Presence but no disturbance ☐ Intervention required	
Male infertility	☐ Absent/NA ☐ Intervention required	
Gynecologic problems	☐ Absent/NA ☐ Mild menstrual pain/dysmenorrhea ☐ Intervention required	
Metabolic and endocrine concerns		
Obesity	☐ Absent ☐ BMI ≥30 ☐ BMI >45 ☐ Weight (kg) ☐ WC(cm)	
Diabetes	☐ Absent ☐ Present ☐ Last check/year	
Hypothyroidism	☐ Absent ☐ Present ☐ Last check/year	
Hypogonadism	☐ Absent ☐ Present ☐ Last check/year	
Dyslipidemia	☐ Absent ☐ Present ☐ Last check/year	
Chronic hepatic dysfunction	☐ Absent ☐ Present	
Genetic concerns		
Genetic counselling	☐ Information provided ☐ Family tree completed	
Family planning	☐ NA ☐ Appropriate contraception ☐ Genetic counselling required	
Risk for family members	☐ NA ☐ Genetic counselling required	
Other health concerns		
Inappropriate use of medication	☐ Absent ☐ Doubt ☐ Supervision needed	
Drug abuse	☐ Absent ☐ Occasional user ☐ Drug abuse interfering with ADL	
Smoking	☐ No smoking ☐ ≤ 40 packs/years ☐ > 40 packs year	
Personal care deficiency	☐ No difficulty ☐ With difficulty but no assistance ☐ Evaluation required	
Pain	☐ Absent ☐ Investigation and treatment required	
End of life issues	☐ Not appropriate ☐ Discussion done on advance directives	
Information needs	☐ Information provided about the disease, researchs and support groups	
Social concerns		
Education	Education grade	
Employment	☐ Never worked ☐ Currently working ☐ Used to work/assistance required	
Income and financial assistance	☐ No problem ☐ Assistance needed	
Home maintenance	☐ No difficulty /NA ☐ Badly kept but acceptable ☐ Intervention required	
Familial and social network	☐ Normal social environment ☐ Unsatisfied by social life ☐ Social deprivation	
Parental care deficiency	☐ Absent/NA ☐ Doubt ☐ Evaluation required	
Car driving	☐ NA ☐ No difficulties ☐ Evaluation required	
Leisure activities	☐ Normal hobbies ☐ Unsatisfied ☐ Appropriate services required	