

Figure 1

The different areas of care required at each stage of DMD

Stage 1: PRESYMPTOMATIC May be diagnosed at this stage if CK found to be elevated by chance or if positive family history May show developmental delay but no gait disturbance	Stage 2: EARLY AMBULATORY Gowers' maneuver Waddling gait May be toe-walking Can climb stairs	Stage 3: LATE AMBULATORY Increasingly labored gait Losing ability to climb stairs and rise from floor	Stage 4: EARLY NON-AMBULATORY May be able to self-propel for some time Able to maintain posture May develop scoliosis	Stage 5: LATE NON-AMBULATORY Upper limb function and postural maintenance is increasingly limited	
Requires diagnostic workup and genetic counselling		Likely to be diagnosed by this stage unless delayed for other reasons (e.g. concomitant pathology)			DIAGNOSIS
Anticipatory planning for future developments Ensure immunization schedule complete	Ongoing assessment to ensure course of disease is as expected in conjunction with interpretation of diagnostic testing At least six-monthly assessment of function, strength and range of movement to define phase of disease and determine need for intervention with steroids, ongoing management of steroid regime and side-effect management				NEUROMUSCULAR MANAGEMENT
Education and support Preventative measures to maintain muscle extensibility/minimize contracture Encouragement of appropriate exercise/activity Support of function & participation Provision of adaptive devices, as appropriate	Previous measures continued Provision of appropriate wheelchair and seating, and aids and adaptations to allow maximal independence in daily activities, function and participation				REHABILITATION MANAGEMENT
Orthopedic surgery rarely necessary	Consideration of surgical options for Achilles tendon contractures in certain situations		Monitoring for scoliosis: Intervention with posterior spinal fusion in defined situations Possible intervention for foot position for wheelchair positioning		ORTHOPEDIC MANAGEMENT
Normal respiratory function Ensure usual immunization schedule including 23-valent pneumococcal and influenza vaccines	Low risk of respiratory problems Monitor progress		Increasing risk of resp. impairment Trigger respiratory assessments	Increasing risk of resp. impairment Trigger respiratory investigations and interventions	PULMONARY MANAGEMENT
Echocardiogram at diagnosis or by 6 years	Maximum 24 months between investigations until age 10 years, annually thereafter	Assessment same as in the younger group Increasing risk of cardiac problems with age; requires intervention even if asymptomatic Use of standard heart failure interventions with deterioration of function			CARDIAC MANAGEMENT
Monitoring for normal weight gain for age Nutritional assessment for over/underweight				Attention to possible dysphagia	GASTROINTESTINAL MANAGEMENT
Family support, early assessment/intervention for development, learning and behavior	Assessment/intervention for learning, behavior and coping Promote independence and social development			Transition planning to adult services	PSYCHOSOCIAL MANAGEMENT