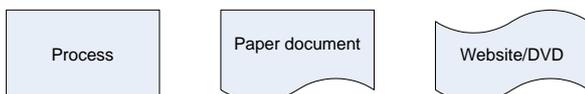# Great Ormond Street Hospital for Children NHS Foundation Trust

Information Pathway for Duchenne Muscular Dystrophy (DMD)

Patient journey stage/topic	Information for parents/carers	Information for children/young people	Information for professionals
Referral to service	GOSH essential information		Best practice guidelines
	Neuromuscular glossary		
Diagnostic investigations	Muscle biopsy		
Diagnosis counselling	New diagnosis booklet	Brainpop website DMD	What is Duchenne MD
	Steroids		
	Talking to your children		
	Behaviour management		
	DMD family guide		
Genetics	Carrier detection tests		
	Inheritance and the MDs		

Key

Process

Paper document

Website/DVD

Great Ormond Street Hospital for Children NHS Foundation Trust

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Patient journey stage/topic	Information for parents/carers	Information for children/young people	Information for professionals
School	Your child's SEN		Talking with children and parents (MDC)
	Inclusive education		DMD learning and behaviour (MDC)
	Learning and behaviour toolkit (PPUK)		Learning and behaviour toolkit (PPUK)
	Parents' Education Network		Schools – getting it right for the child
Family	Fathers and grandparents	Everybody's different	
	DMD aged 5 to 12 booklet	Hey there I'm here too	
	Booklist on the MDs	Same but different	
	Support groups		
	Hospice information		
	DMD the older child		

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Finances	DLA factsheet		
	A checklist for parents		
	Family Fund		
	GOSH CAB		
Housing/ adaptations	Adaptations guide		Adaptations guide
Respiratory monitoring	Making breathing easier		Respiratory letter for hospitals
	GOSH respiratory leaflet		
	Vaccination advice		
	GOSH respiratory letter		
Cardiac monitoring	Heart check		Cardiac protocol
Using a wheelchair	Wheelchair guidelines		Wheelchair guidelines

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Staring steroids	Steroid factsheet Bone protection Steroid booklet		Steroid protocol Steroid booklet Bone protection
Scoliosis monitoring	GOSH scoliosis booklet Surgical correction Questions to ask	Pt experience of spinal surgery Brainpop website scoliosis	Spinal pathway
Foot deformity			
Nutrition	Health eating booklet Nutrition and feeding factsheet MDC Gastrostomy factesheet GOSH Gastrostomy booklet	Pt experience of gastrostomy	Gastrostomy pathway

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Information Pathway for Duchenne Muscular Dystrophy (DMD)

Patient journey stage/topic	Information for parents/carers	Information for children/young people	Information for professionals
Transition	Your child's transition	Transition guide	Transition pathway
		Becoming a man	
		Becoming an adult	
	DMD teenage years	DMD teenage years	
		DMD on the ball	