



Guide for Healthcare Professional Roles in a Multidisciplinary Team (MDT) for Spinal Muscular Atrophy (SMA) Care

There are a number of healthcare professionals that support and manage SMA. The following is a list to understand their roles and responsibilities in guiding your care. Some of these individuals may require a referral from your physician.

Healthcare Professionals:

- **Assistive technology team:** is a team made up of different specialists (Occupational Therapy, Speech Therapy, and Engineering). They assess the child's need for technology that will help them participate effectively in their daily life. This can promote greater independence.
- **Child Life Specialist:** help children, youth and families cope with the stress and anxiety of being in hospital. They use interventions such as therapeutic play and education to reduce fear, pain and anxiety.
- **Child Psychologist:** provides counseling, support and guidance on social and psychological concerns related to emotions, development, stress of living with SMA.
- **Dietitian:** works with an individual with SMA to support health nutrition related to growth and motor function.
- **Electromyography (EMG) Technician:** assess the health of muscles and nerve cells that control them with various tests.
- **Equipment Therapist:** is a health professional (usually Occupational Therapist or Physiotherapist) that will assess the need for and provide specialized equipment to assist with sitting, standing and moving.

- **General Physician (GP):** A GP or family doctor provides primary care and helps coordinate referrals to specialists such as a neurologist.
- **Genetic Counselor:** provides information on the genetic basis of SMA. They explain the likelihood of transmitting the condition and being a genetic carrier.
- **Neurologist:** a physician specialized in the diagnosis and treatment of conditions related to the nervous system. This includes the brain, spinal cord, muscles, and nerves. Neurologists typically diagnose SMA, and they coordinate the care team and perform tests for motor function.
- **Nurse:** assist patients with education about treatment options, administration of treatment, and provide supportive care.
- **Occupational Therapist:** helps increase independence in daily activities by improving the physical function of an individual. This includes the ability to walk, get dressed, write, use a computer, or to eat.
- **Orthopedic specialist:** specializes in the surgical and non-surgical treatment of the bones, joints and soft tissue. An orthopedic specialist assesses spinal curvature and recommends a course of action.
- **Orthotist:** designs, makes and fits the child for devices (braces and supports) that help promote function and maintain musculoskeletal fitness.
- **Pediatrician:** is trained to diagnose and treat a broad range of childhood illnesses, and manage care for children until the age of 18.
- **Pharmacist:** is responsible for dispensing and educating patients on medications and treatment.
- **Physiatrist:** is a physician who specializes in Physical Medicine and Rehabilitation and focuses on whole body treatment for the musculoskeletal system and its pain-causing disorder.
- **Physiotherapist:** is a health professional that provides stretching, strength training and exercise recommendations for someone living with SMA. They also assess a patient's ability to breathe effectively and help optimize airway clearance and ventilation strategies.
- **Recreational Therapist:** are health professionals that help adapt activities to meet the needs of the child, encouraging active, healthy lifestyles.
- **Respiratory Therapists (RT):** work with the pulmonologists to assess and optimize a patient's lung function, ability to breathe effectively, airway clearance and ventilation techniques.
- **Respirologist:** also known as respiratory doctors, they are specialized in breathing and the respiratory system. They assess a patient's ability to breathe effectively and test lung function, airway clearance and ventilation techniques.
- **Social Workers:** are professionals trained to support children, teens, young adults and families regarding the impact of illness, disability and complex health needs. They care for the social, emotional and service needs for these individuals. They aim to support families in navigating the healthcare system and community resources.
- **Speech Therapist:** are specialized in different aspects of speech, language and vocal quality. They help improve the ability to communicate.
- **Vocational Rehabilitation specialist:** they help navigate employment and schooling as the youth nears adulthood.

Multidisciplinary Centers for SMA Care

Alberta			
Alberta Children's Hospital			
28 Oki Drive NW, Calgary, AB T3B 6A8	https://www.albertahealthservices.ca/ach/ach.aspx	Phone: 403- 955 5437. Fax : 403-955-7609	
South Health Campus Neuromuscular Clinic			
Outpatient Neurosciences Clinics, South Health Campus 4448 Front St. SE Calgary, AB T3M 1M4	https://cumming.ucalgary.ca/departments/dcms/programs/the-neuromuscular-program	shc.neuromuscularclinic@alberta-healthservices.ca	1- 403- 956- 3454
New Brunswick			
Stan Cassidy Centre for Rehabilitation-Horizon Health Network			
800 Priestman St, Fredericton, NB E3B 0C7	www.horizonnb.ca/horizon-services/provincial-program/stan-cassidy-centre-for-rehabilitation	Horizon@HorizonNB.ca	506-452-5225
Ontario			
Children's Hospital of Eastern Ontario (CHEO)			
401 Smyth Road Ottawa, ON K1H 8L1	www.cheo.on.ca	webmaster@cheo.on.ca	613-737-7600
Hamilton Health Sciences, McMaster Children's Hospital			
1200 Main St W, Hamilton, ON L8N 3Z5	www.hamiltonhealthsciences.ca/mcmaster-childrens-hospital/	patientexperience@hhsc.ca	905-521-2100
The Hospital for Sick Children			
555 University Ave, Toronto, ON M5G 1X8	www.sickkids.ca	patient.experience@sickkids.ca	416-813-1500
Hôtel Dieu Hospital, Kingston Health Sciences Centre			
166 Brock St, Kingston, ON K7L 5G2	www.kingstonhsc.ca/	PatientRelations@KingstonHSC.ca	613-544-3310
Kingston General Hospital, Kingston Health Sciences Centre			
76 Stuart St, Kingston (Ontario) K7L 2V7	www.kingstonhsc.ca/	PatientRelations@KingstonHSC.ca	613-548-3232
London Health Sciences, University Site			
339 Windermere Rd, London, ON N6A 5A5	www.lhsc.on.ca	patientrelations@lhsc.on.ca	519-685-8500
London Health Sciences Centre Victoria Hospital			
800 Commissioners Rd E, London (Ontario) N6A 5W9	www.lhsc.on.ca	patientrelations@lhsc.on.ca	519-685-8500

Multidisciplinary Centers for SMA Care (continued)

Ontario (continued)			
The Ottawa Hospital, Civic Campus			
1053 Carling Ave, Ottawa, ON K1Y 4E9	www.ottawahospital.on.ca	info@ohri.ca	613-722-7000
Sunnybrook Health Sciences Centre			
2075 Bayview Ave, Toronto, ON M4N 3M5	www.sunnybrook.ca	questions@sunnybrook.ca	416-480-6100
University Health Network, Toronto General Hospital			
200 Elizabeth St, Toronto, ON M5G 2C4	www.uhn.ca/OurHospitals/TGH	patientrelations@uhn.ca	416-340-3111
Quebec			
Centre de réadaptation en déficience physique Lucie-Bruneau			
2275, avenue Laurier Est Montréal QC H2H 2N8	https://ciusss-centresudmtl.gouv.qc.ca/etablissement/centre-de-re-adaptation-en-deficience-physique-lucie-bruneau		514 527-4527
IRD PQ			
525 Wilfrid-Hamel Blvd, Québec City, Quebec G1M 2S8	https://www.crdp.ca/en/partners/institut-de-readaptation-en-deficience-de-quebec	nathalie.parent@irdpq.qc.ca	418-529-9141
Saskatchewan			
ALS/MND Clinic Saskatoon City Hospital			
ALS/MND Clinic, Saskatoon City Hospital 701 Queen Street, Saskatoon, SK S7K 0M7	https://www.saskhealthauthority.ca		306-655-7742