POSITION STATEMENT:

Recommendations for establishing and providing hypertonicity / spasticity services in Queensland - 2024

Queensland Hypertonicity / Spasticity Special Interest Group

The Special Interest Group was established in 2018 to bring together a representative group of health professionals from a range of rehabilitation services across Queensland, who work with clients experiencing hypertonicity / spasticity, in order to:

- *Provide support and advice to Queensland clinicians managing clients with hypertonicity / spasticity.*
- *Share hypertonicity / spasticity knowledge, expertise and resources*
- *Develop hypertonicity / spasticity educational resources for therapists and clients*
- *Maximize access to specialised hypertonicity / spasticity services for clients across the state*
- *Build a sustainable workforce of clinicians across Queensland working in hypertonicity / spasticity management*
- *Collaborate and coordinate statewide evaluation strategies, education and research opportunities in hypertonicity / spasticity management.*

Recommendations for establishing and providing hypertonicity / spasticity services in Queensland.

Summary statement

To provide a high quality, evidence-based service to people experiencing hypertonicity/spasticity, clinicians need to implement an individualised, person and family-centred, comprehensive and multidisciplinary approach to their practice.

Purpose of position statement

The purpose of this position statement is to provide an outline of the principles considered to be minimum standards for best practice in the service provision for people experiencing hypertonicity/spasticity.

It is intended to inform clinicians, health service managers, professional associations and policy developers at a local level.

It aims to promote consistency in an individualised and collaborative approach to working with people with hypertonicity/spasticity.

The purpose of this statement is not to provide a comprehensive and updated review of current literature regarding hypertonicity/spasticity management. However, it has been developed according to current international practice guidelines and is regularly reviewed with reference to such guidelines.

Definitions and Background

Terminology

There are multiple terms used in the literature to describe the **muscle overactivity** observed in some clients with a **central nervous system disorder.** These include ‘increased tone’, ‘hypertonicity’, and ‘spasticity’.

In addition to muscle overactivity, adaptive changes to the biomechanical and contractile elements of muscle and connective tissue also contribute to the stiffness observed clinically (Esquenazi et al 2010). The broad term of ‘hypertonicity’ is used in this document to encompass all aspects of the resistance to movement observed in those with an upper motor neuron syndrome (Copley & Kuipers, 2014).

- **Hypertonicity** is the increased resistance to movement experienced by some people with upper motor neuron conditions (e.g. stroke, traumatic brain injury, cerebral palsy, spinal cord injury).

The term hypertonicity is also used in the international literature as an umbrella term that includes spasticity, dystonia and rigidity.

- **Spasticity** is 'a disorder of sensorimotor control resulting from an upper motor neurone lesion, presenting as an intermittent or sustained involuntary activation of muscles' (Pandyan et al 2005).

- **Dystonia** is a movement disorder in which involuntary sustained or intermittent muscle contractions cause twisting and repetitive movements, abnormal postures or both. Spasticity and dystonia may co-occur.
- **Rigidity** is a state of hypertonia where muscle resistance occurs throughout the entire range of motion of the affected joint independent of velocity.

Note that medical treatment approaches may differ for spasticity, dystonia, rigidity, and secondary muscle/soft tissue biomechanical changes.

Importance of managing hypertonicity / spasticity

Hypertonicity / spasticity and its impact on daily life can create a considerable burden for those affected, their carers and the health care system.

Prevalence: A recent systematic review reported the pooled prevalence of spasticity to be 26.7 per cent for first ever stroke and 39.5 per cent for those stroke patients with paresis. Pooled prevalence for stroke patients along the continuum was 4-48 per cent during acute and post-acute care, 7-63 per cent at 3-6 months post event, and 8-49 per cent beyond 9 months (Zeng et al (2021). High prevalence has also been reported with other neurological conditions including traumatic brain injury, spinal injury, cerebral palsy and multiple sclerosis (Gupta et al 2024; Diong et al 2012).

Economic Cost: A 2010 study demonstrated that the medical costs of managing a stroke survivor in the first year was four times higher if spasticity was present than stroke survivors without spasticity (Lundstrom et al. 2010). The presence of hypertonicity / spasticity is typically indicative of a severe motor disorder and associated with substantial disability (Wissel et al 2013; Zorowitz et al. 2013). There is limited data regarding the direct cost burden of hypertonicity/ spasticity. However, a recent study demonstrated significant reductions in healthcare resource utilization and costs, for stroke patients after 1 year of post stroke spasticity management (Esquenazi et al 2023).

Early treatment of problematic hypertonicity/spasticity is recommended, as treating established complications is often more challenging that preventing or treating hypertonicity/spasticity early in its course (Lindsay et al, 2021; Wissel et al, 2020).

Potential complications of hypertonicity/spasticity include:

- pain
- contractures
- pressure areas and other skin issues (such as fungal infections)
- difficulty with self-care and other daily tasks such as transfers
- impaired balance and mobility, resulting in increased risk of falls
- poor self-esteem and body image, reduced mood
- poor sleep
- inability to participate in valued recreational activities and employment
- reduced quality of life
- increased carer burden.

These difficulties often negatively impact on a person's recovery and outcomes, increasing the cost of both health care utilisation and long-term care (Brainin et al. 2011; Esquenazi et al. 2023; Finnerup. 2017; Zorowitz et al. 2013).

Recommendations for Establishing and Providing a Hypertonicity / Spasticity Service

Service Infrastructure

Staffing and Collaborative Practice

- Services should ideally be provided by a **multidisciplinary team**, either within the same facility or via referral to appropriate individual clinicians, teams or organisations.

- **Clear referral pathways and regular communication among clinicians** is essential to coordinated care. It is important to communicate with the client's **general practitioner** as their primary medical care provider and coordinator of their care. To service needs across the state, this communication may occur via online platforms.

- Key staff should include an **occupational therapist**, a **physiotherapist,** and a medical practitioner (preferably a **rehabilitation physician**), **all with neurological rehabilitation and hypertonicity/spasticity management experience**. In relation to therapy services, where the focus is on upper limb management, best practice would involve an occupational therapist (at minimum), and where the focus is on the trunk and lower limb management, best practice would involve a physiotherapist (at minimum). Where access to these therapists is difficult, for example in rural services, it is recommended that consultation with the relevant profession in another region is considered.

- Other disciplines who may contribute to the service provision include, but are not limited to: **General practitioner, nursing, orthotics/prosthetics, exercise physiology, pharmacy and speech pathology, and other medical/surgical specialities such as neurology, orthopaedic surgery and neurosurgery**. The staffing specialty indicated will depend on the individual client's needs.

- **Dedicated positions for key staff** are recommended, with these positions held by clinicians with **expertise** in spasticity/hypertonicity management. Specific, ongoing professional development **training and/or peer mentoring** in spasticity/hypertonicity management is highly recommended.

- **Staffing** should be considered in relation to:
    - the average time required for an assessment or intervention session (60-90 minutes on average)
    - the follow up frequency required (both in the short-term post intervention, and in the longer term)
    - whether rehabilitation is offered individually or in a group context.

- **Administrative support** is recommended due to the need for frequent ordering of consumables, client scheduling and frequent client communication.

- Services should consider implementing strategies, including allocation of appropriate staffing, that promote **early recognition and management of spasticity** in people with neurological conditions, in line with best practice (Lindsay et al, 2021; Wissel et al, 2020).

- Liaison with relevant public and private sector **services that can promote optimal outcomes** is recommended. This may include services that target, for example, the client's seating or other equipment needs, caregiver training and support, and capacity building through achievement of daily life goals in activities of daily living and/or community participation. Liaison should routinely involve the general practitioner and community-based physiotherapists and occupational therapists involved with the client.

Resources

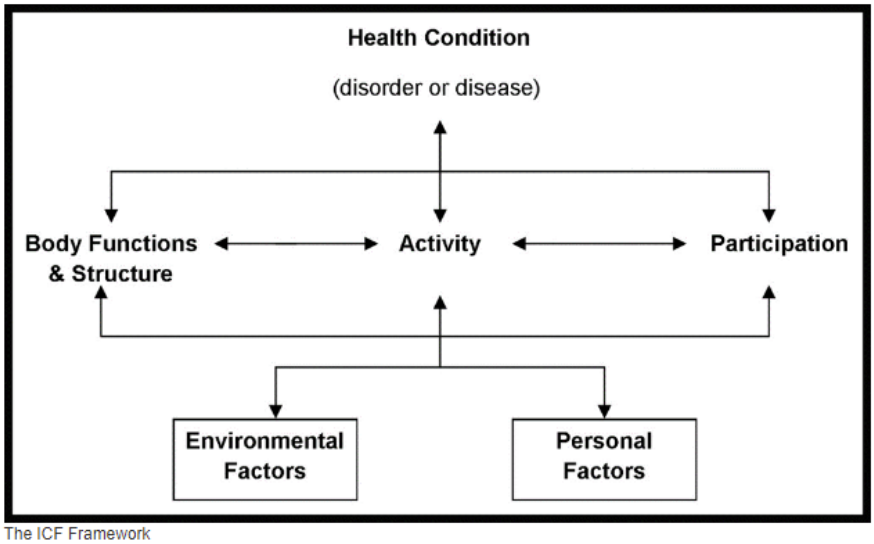
- **Location of service provision** may include hospitals, clinics, community venues or the client's home setting. The location of service provision should be individualised according to client preference and resources where possible.

- The location of service provision should be fully **accessible**, with **sufficient space** for activities such as assessment, injections, splinting, casting and gait analysis.

- As required, access to **relevant and safe equipment, materials and consumables** to allow best practice assessment and intervention provision, including, for example, a wide, height-adjustable electric plinth or appropriate bed to aid transfers, manual handling and positioning, access to hoist equipment, goniometers to measure joint range of motion, splint and cast fabrication and removal equipment and materials, and equipment to support injections such electromyography (EMG)/nerve stimulator and/or ultrasound devices, and intrathecal baclofen (ITB) delivery.

General Principles

- The International Classification of Functioning (**ICF**) (WHO, 2001) is recommended as a framework to guide focused service provision for hypertonicity/spasticity management, with clinicians taking the time to collaboratively identify with the client their intervention priorities. Clinicians should consider whether they are targeting body impairment, activity performance and/or daily life participation.



The ICF Framework

(WHO, 2001)

Goal Setting

- Broadly speaking, the goal of management is to **prevent / minimise** the complications and negative repercussions of hypertonicity/spasticity, however, to do so effectively the approach needs to be individualised**. Collaborating with clients and their caregivers/significant others** in goal setting and intervention decision-making is essential to support meaningful outcomes and long-term management. Shared decision-making and education should be provided at each stage of service provision.

- At minimum, **thorough discussion** with the client and caregivers/significant others **regarding the client's context and daily activities** is essential to establish goals that target meaningful outcomes from the client's perspective. A **formal goal setting tool** (e.g. Canadian Occupational Performance Measure – COPM; Goal Attainment Scaling – GAS light) could be considered. Goals should be SMART (Specific, Measurable, Achievable, Realistic and Timely).

- Goals may target outcomes related to **active function** (such as use of the arms and legs in daily activities such as eating, dressing, cooking, transferring and walking), or **passive function** (such as ease of care for the caregiver during hygiene, self-catheterisation or dressing tasks).

- Goals should be formally **documented** and may target any/all levels of the ICF but should ideally be linked to **current or future activity and/or participation.**

- **Priorities for intervention** should be set **collaboratively** with the client and caregivers/significant others.

- Goals should be **reviewed on a regular basis** and adjusted to reflect changes in client status and priorities.

Assessment and Evaluation of Outcomes

- Assessment requires an adequate understanding of the underlying **central nervous system diagnosis**, and examination should include confirmation and documentation of the resulting **upper motor neuron syndrome**. Assessment should identify any reversible factors.
- Assessment/evaluation should include relevant **formal and informal assessments** that relate to the client's goals. It is recommended that assessment targets **body impairment as well as activity performance and/or daily life participation levels** of the ICF.

- The **most valid and reliable assessments available** should be used, and a **consistent assessment process** agreed upon within each service.

  Assessment may include (but is not limited to):

  - **Body impairment** – passive and active joint range of motion, muscle strength, severity of pain, severity of hypertonicity/spasticity (Modified Ashworth Scale, Modified Tardieu Scale), analysis of movement patterns and impact of spasticity/hypertonicity on this movement, presence of contractures, skin integrity and joint changes.
  - **Activity capacity and performance** – e.g. observational analysis (including videos where possible) of daily tasks in which clients participate such as transfers, walking, and reach, grasp/manipulation or stabilisation of relevant items.
  - **Participation** – e.g. goal achievement, caregiver assistance scales, caregiver burden scales and quality of life measures.

- Assessment information for each client should be formally **documented at multiple points** during service provision. Usually, **repeated assessments over time** are required to determine if spasticity and its complications are developing or worsening, to assess the impact of any intervention, and to adapt the ongoing treatment approach to best fit the individual patient and their goals.

  At minimum, assessment/evaluation should occur **prior to intervention** and **soon after** (e.g within 4-6 weeks) intervention. Where possible, **short-term follow up** evaluation (e.g 3-6 months post intervention) and **long-term follow up** evaluation (e.g nine months or longer after intervention) is recommended.

- Scheduling of assessment sessions should allow an average of **60-90 minutes** per session.

Interventions

"Achieving optimal care requires a strong understanding of the pathophysiological concepts underpinning involuntary muscle overactivity, structural and functional anatomy, the available interventions (conservative, pharmacological and/or surgical) and knowledge of how these interventions can best be applied to achieve individualised patient-centric goals." Statement of the Rehabilitation Medicine Society of Australia and New Zealand, 2024.

- Spasticity can be exacerbated by any health conditions or factors that impact on the person's comfort (for example urinary tract infection, constipation, pressure sore, poor wheelchair seating) so any **exacerbating factors should be appropriately managed**. In the case of progressive conditions, it is important to ensure optimal management of the underlying condition that is causing the upper motor neuron syndrome.

- A **range of interventions** should be offered or be able to be accessed through referral to other services, to allow an individualised package of intervention.

- **Intensive, goal focused, blocks of therapeutic intervention** (e.g. 1-2 times a week for 4-6 weeks, depending on the goal of intervention) should be considered, as well as less frequent long-term **monitoring/review services** (e.g. every 3-6 months).

Interventions offered (either by the service or by referral to another practitioner with relevant expertise) should include a range of the following:

- **Education** about spasticity/hypertonicity and its lifetime management, including how to reduce its impact on day-to-day activities, exacerbating factors and how to minimise complications.

- **Therapy interventions** – These should target both the impacts of hypertonicity/spasticity, and optimisation of movement, function and comfort as relevant to the individual client. Examples include but are not limited to: development of a stretching program, splinting/orthotics, electrical stimulation, casting, task practice, and other interventions aimed at developing movement control, balance, independence or participation in daily activities, and/or comfort. Scheduling of therapy interventions should allow an average **of 60-90 minutes per session.**

- **Medical and surgical interventions** – for example, pharmacotherapy treatment options, Botulinum toxin A injections, intrathecal baclofen, surgical procedures (such as tendon transfer or joint arthrodesis). **Medical and surgical interventions** should be **linked to client goals**.

- **Involvement of allied health professionals** (occupational therapists and/or physiotherapists at minimum) should be considered both before and after medical and surgical interventions to ensure that there are no less invasive options available, and that optimal outcomes can be achieved.

Information Resources

The purpose of this position statement is to provide recommendations for establishing and providing hypertonicity / spasticity services in Queensland. Service providers are encouraged to continue to access up-to-date resources and evidence, and network with other practitioners working in the field to collaborate and learn from each other.

Resources include, but are not limited to:

- Statement of the Rehabilitation Medicine Society of Australia and New Zealand for the therapeutic use of botulinum toxin A in spasticity management (2024) Link
- Spasticity in adults: management using botulinum toxin –UK National Guidelines 2018
- Networking via membership of the Qld Rehabilitation Clinical Network- Qld Hypertonicity / Spasticity Special Interest Group: Email Hypertonicity.SIG@health.qld.gov.au
- UL Hypertonicity Education Package on ilearn: iLearn - Hypertonicity Education Package
- Resources created by the Qld Rehabilitation Clinical Network: Goal-setting in Rehabilitation Services | Improvement Exchange | Clinical Excellence Queensland | Queensland Health

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Version control

Version	Date	Author	Changes	Proposed review date
1.0	April 2022	Qld HT/SP SIG Co-chairs & working group	First draft	
1.1	June 2022	Qld HT/SP SIG members review	Edits of first draft	
1.2	July 2022	QRbCN steering committee review	Edits	
1.3	Aug 2022	Co-Chairs & working group review of QRbCN feedback	Edits	
1.4	Sept 2022	Qld HT/SP SIG, endorsed by QRbCN Co-Chairs & steering committee	Final version published	Sept 2023
2.0	May to June 2024	Review by Co-Chairs & working group	Edits following review, updated references.	March 2026
2.1	September 2024	Reviewed & endorsed by QRbCN Co-Chairs & steering committee	Added version control, final version published	October 2026