CLINICAL PRACTICE GUIDELINE

IN PHYSIOTHERAPY TO PROMOTE SEXUALITY IN ADULTS WITH A NEUROMUSCULAR DISEASE

(Short version)

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This guide is a summary of the recommendations in the **"Clinical practice guideline on roles and interventions in physiotherapy to promote sexuality in adults with a neuromuscular disease (2022)".** It is recommended to consult the long version for more detailed information.

The guide is based on a literature review as well as the clinical experience of physiotherapists with expertise in neuromuscular diseases or sexuality. The guide was reviewed by a multidisciplinary team, which includes a physiotherapist, an occupational therapist, a social worker, a nurse, and a neurologist.

ABBREVIATIONS

NMD	Neuromuscular disease
PFPT	Pelvic floor physiotherapy/ physical therapy

What is a neuromuscular disease (NMD)?

NMDs refer to any disease that affects muscle function with alterations to the muscle itself or to the peripheral nerves. There are over 200 different diagnoses, which creates a wide variety of impairments [1].

Why adress sexuality in physiotherapy?

Impairments present in NMD can directly or indirectly interfere with the ability to participate in various sexual activities:

- Loss of strength
- Fatigue
- Loss of mobility
- Dysfunction of pelvic floor muscles.

Sexuality is an aspect of people's lives that tends to be relegated to the background [3]. However, it is **the responsibility of the healthcare professional** to initiate the discussion [4]. It has been demonstrated that 70% of people with chronic diseases have problems with sexual activity, and only 18% of them are able to overcome them independently [5]. Being rehabilitation professionals, physiotherapists should take a holistic approach and include sexuality in their rehabilitation plan in order to address this important aspect of life [6].

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EX-PLISSIT model - How to approach sexuality

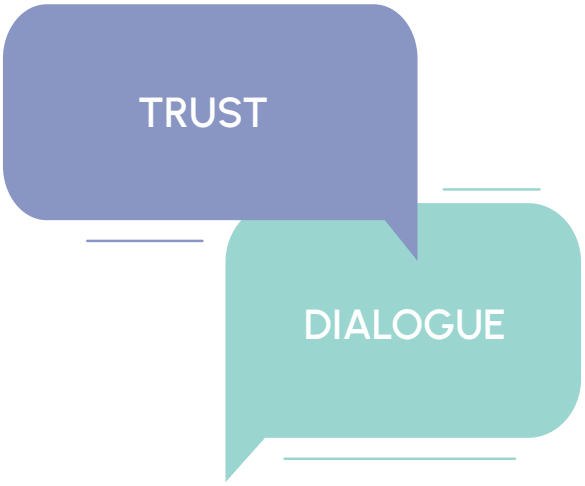
The EX-PLISSIT model [7, 8] serves as a guide for professionals who address or wish to address the subject of sexuality with a client and to determine the level of interventions.

- **EX**tended ;
- **P**ermission ;
- **L**imited **I**nformation ;
- **S**pecific **S**uggestion ;
- **I**ntensive **T**herapy.

EX-PLISSIT LEVELS OF INTERVENTION	
Ex	The purpose of the permission-giving feedback loop is to reassess each person's comfort level (the client's and the healthcare professional's) at each step or regularly during the intervention. It is important to check regularly if the client is still willing to discuss the subject further or in greater depth and to make appropriate changes by moving to the next step or back to previous steps.
P	Permission is granted to discuss sexuality, either through indirect or direct strategies. The physiotherapist must ensure that the client is ready and comfortable before initiating the discussion [4, 9, 10]. The discussion about sexuality can be introduced at different times during the intervention, but it is recommended to introduce it at the beginning and wait until the therapeutic relationship is more established before going into detail. Here are some strategies for discussing sexuality: · Explaining the physiotherapist's role by including sexuality throughout the explanation · Displaying leaflets or posters on sexuality in the waiting room or office [7, 11] · Including sexuality in the assessment form or supply self-administered questionnaires on sexuality [12] · Address sexuality by presenting a fact before a question [4].
LI	The physiotherapist must begin by providing limited information. The information should be addressed to a group and not to a particular individual. Appropriate terminology should be used to help normalize sexuality.
SS	Once specific issues or concerns have been identified, the physiotherapist can offer an individualized intervention to the client. The specific suggestions are based on the client's needs, problems, and preferences. It is important to clarify expectations and outline the client's treatment priorities [13].
IT	Intensive therapy may be provided by a physiotherapist with expertise in pelvic floor physiotherapy/physical therapy (PFPT) or a referral to another healthcare professional (sexologist, doctor, nurse, etc.) may be required. Collaboration with other professionals is encouraged in order to adopt a multidisciplinary approach [10, 13, 14].

VULNERABILITY TO ABUSE

People with disabilities are at greater risk of being victims of sexual assault. The rate of assault is about **twice as high** among women with a disability compared to women without a disability [2]. It is therefore necessary to remain on the lookout for this problem and discuss this subject if the physiotherapist has doubts that the client is a victim of abuse.



ASSESSMENT

History and subjective assessment

The assessment may take the form of an open discussion, an interview or self-administered questionnaires.

Aspects that can be explored in the subjective assessment include [15-17] :

- Interpersonal relationships (marital status, relationship)
- Frequency, type, positioning, penetration associated with sexual activity
- Whether or not assistance is needed during sexual activities
- Urinary, vaginal, or anorectal symptoms associated with sexual activity
- Desire, erectile, or orgasmic disorder
- Pain during sexual intercourse
- Fatigue
- Impact of the disease on sexuality
- The client's and the partner's objectives.

Objective assessment

Some deficiencies and limitations might be noticed during this evaluation and could have an impact on sexual function and activities. Therefore, it is important to remain on the lookout for these issues.

SPECIFICATIONS FOR THE OBJECTIVE ASSESSMENT	
Muscle strength and control	- Important for holding various positions and ability to change positions [18] - Check strength of the upper limbs (plank position, all fours position), trunk (sitting, standing) and lower limbs (hip movements, kneeling, standing) - Assess grip and dexterity (caresses, masturbation, ability to hold a sexual device)
Range of motion and flexibility	- Check the mobility of the hand and upper limbs (grip, undressing, putting on a condom, caresses, ability to hold a plank position, all fours position) - Check the mobility of the lower limbs (flexibility of the adductors, hamstrings)
Coordination	- Assess coordination as needed, mainly for the upper limbs (masturbation, caresses)
Musculoskeletal pain	- Assess hip, sacroiliac, coccyx, back, abdominal, and pelvic pain by palpation and specific tests* - Assess the lumbo-pelvic complex and posture [18] - Tension and pain in the abdominal and hip region may be involved in perineal pain. An old perineal scar with adhesions could cause pain [18]
Cardiorespiratory exam	- Since sexual activities are considered to be physical activities, it is sometimes necessary to assess the cardiorespiratory system - Assess vital signs, breathing patterns and response to exertion (dyspnea, desaturation, signs of intolerance, Borg scale) [18]
Neurological exam	- Check the reflexes and tone of the lower limbs (spasticity of the adductors) - Assess sensation in the L5-S1-S2 lumbosacral dermatomes in the periphery of the genital area. For a more in-depth assessment, a referral for PFPT can be made

*Some physiotherapists have advanced training in PFPT. The expertise of these physiotherapists is required for certain conditions such as incontinence, pain, prolapse and sensitivity disorders. More information on the different reasons for referral in PFPT is covered in the long version.

SOME DEFICIENCIES AND LIMITATIONS MIGHT BE NOTICED DURING THIS EVALUATION AND COULD HAVE AN IMPACT ON SEXUAL FUNCTION AND ACTIVITIES. THEREFORE, IT IS IMPORTANT TO REMAIN ON THE LOOKOUT FOR THESE ISSUES.

INTERVENTIONS

Physical activity

Physical activity improves mental and physical well-being as well as sexual function in people living with a disability [19-22] by having direct and indirect impacts on sexuality. Therefore, it is very important to encourage physical activity among clients.

Positioning

- The physiotherapist can help with positioning, for example by making recommendations, by testing various positions in the therapy room, or by prescribing an adapted exercise program.
- It is important to opt for positions and sexual activities that respect the physical capacities of both partners, specifically taking into consideration balance, muscle strength, endurance and dexterity.
- Some couples will opt for sexual activities without penetration in a position that is comfortable for them, which allows them to better manage their energy [23].
- The next pages present recommended positions [23-25].

Muscle weakness

- A training program should be taught to prevent deconditioning in this population [26]. However, it is preferable to adapt the activities if muscle weakness directly leads to limitations in sexual activities [27].
- Diverse accessory or sexual devices can be proposed in order to compensate for muscle weakness or fatigue by reducing the energy required during sexual activities, or it can allow activities that would not be possible without their use. Some erotic stores offer adapted sexual devices, cushions and furniture.

Fatigue

- The physiotherapist can give advice about energy management and determine with the client the times when their energy level is the highest so that they can plan their sexual activities at these times [23, 28].
- Transfers require a lot of energy for people with NMD, this is why efficient positioning techniques are highly important [13].
- Breaks and rest before and after sexual activity are encouraged [23].

Position	Indications	Advantages	Recommendations
On the back - Middle of the bed - Edge of the bed **Possible activities:** caresses, masturbation, oral sex, vaginal or anal penetration  	- Muscle weakness - Fatigue - Pain - Hypotonia - Ataxia/chorea	- For women or men - Less effort - Better support	- Put cushions under the lower back, under the pelvis and/or under the knees for more support or to change the angle of the pelvis. - A wedge cushion under the knees can also reduce spasms, relieve low back pain and allow easier access to the genitals. - To facilitate penetration, a woman with stiff legs can position herself on the edge of the bed and put one leg out of the bed. Another technique is to flex one or both legs and place them against her partner's torso or, if flexibility allows, on their shoulders.

Position	Indications	Advantages	Recommendations
On the side, face to face **Possible activities:** caresses, masturbation, vaginal penetration, oral sex in inverted position (69)	- Fatigue - Muscle weakness - Hypotonia	- Allows both partners to participate - Less effort - Interesting position if both have limitations	Put cushions behind the back for more support
On the stomach - Middle of the bed - Edge of the bed **Possible activities:** masturbation, vaginal or anal penetration 	- Spasticity - Low back pain	- For women or men (anal penetration) - Facilitates sexual intercourse with penetration	- Put a pillow under the hips or stomach. - More complex position; avoid if unable to turn onto the back, severe upper limb weakness, respiratory problems.

Position	Indications	Advantages	Recommendations
On the side, spoon or perpendicular **Possible activities:** caresses, masturbation, vaginal or anal penetration  	- Urinary catheter - Fatigue - Muscle weakness - Hypotonia - Spasticity (hip adductors)	- For women or men - Less effort	- A cushion between the legs can ease hip discomfort and facilitate penetration. - Put cushions to provide back support for the partner who is behind (spoon) or for both partners (perpendicular).

Position	Indications	Advantages	Recommendations
Sitting - In bed - In a wheelchair **Possible activities:** caresses, masturbation, oral sex, vaginal penetration **Man sitting:** face to face, facing away or to the side **Woman sitting:** possibility of moving the buttocks to the edge of the chair for penetration or oral sex, but this decreases support. 	- Muscle weakness - Fatigue - Poor trunk balance	- Passive position for the person who is sitting - Reduces the number of transfers	- Removing the armrests and lateral supports can increase the number of possible positions, but decreases support. - Use the bed or a fixed piece of furniture as a support for the partner who is on top when they are facing away during intercourse in a wheelchair. - To be seated in bed, the incline of the head of the mattress can be adjusted/ raised (electric bed) or a support cushion can be put behind the back to hold the position.

Decreased range of motion, contractures and spasticity

- These impairments are common among people with NMD, and it is important to address them. Spasticity can be decreased by specific stretching, optimal anti-spastic positioning, and thermal modalities [13, 29].
- Passive stretching or continuous stretching positions before sexual activity can help reduce tension and movement limitations [28].
- If it is difficult to spread the legs, clients can prioritize the spooning position or ask their partner to massage them and slightly stretch them to allow opening [26].

Erectile dysfunction

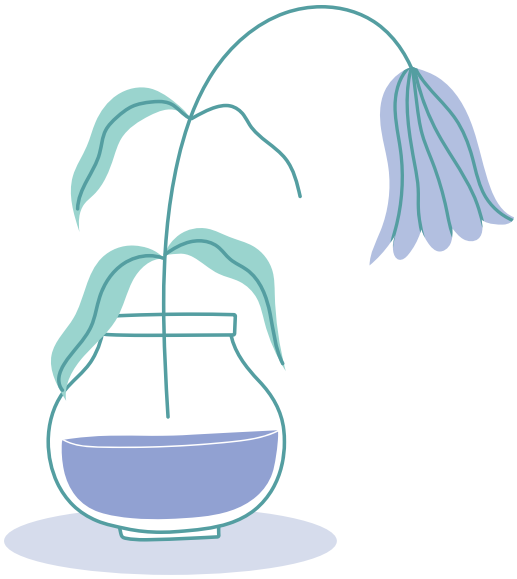
- Contraction of the pelvic floor muscles can help facilitate penetration and maintain erection. It is possible to teach the contraction of the pelvic floor muscles by self-palpation (see long version) or by referring the client in PFPT for specific interventions [30, 31].
- The pelvic floor muscles can also be contracted around the penis by the partner during sex to exert pressure and promote erection.
- The physiotherapist can advise the client to explore alternative techniques to satisfy his or her partner [15].
- If erectile dysfunction is newly reported by the client, it is best to refer them to their physician for evaluation and to receive the necessary medical care.

Sensitivity disorders

- In the case of hyposensitivity, various erogenous zones (e.g., the edges of the anus, nipples, groin, neck and ears) can cause orgasm or increase sexual desire when there is reduced sensation in the genitals [28, 32].
- Using a vibrator, other sex toys, or oral sex may help achieve orgasm in people with less sensation [13, 28], but caution should be taken when using sex toys due to reduced sensation (e.g., overheating, wounds, irritation).
- In people with hypersensitivity, it is possible to provide sensory rehabilitation [33]. As for sex toys, it is preferable to use manual sexual devices in order to have greater control over sensation and promote painless sexual activity.

Decrease in female lubrication

- Different types of lubricants are available, and it is important to know them in order to be able to recommend the most suitable type (water-based, silicone-based and oil-based lubricants). More information on lubricants is available in the long version of the guide.
- Given the role of the pelvic floor muscles in sexual function (clitoral arousal, vaginal tone and orgasm), PFPT interventions may be relevant to increase female lubrication.



Pain

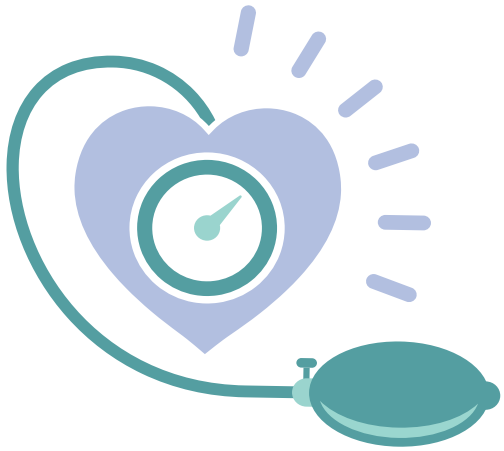
- It is crucial to assess the cause of the pain and specifically treat it according to its type and source (e.g., muscle tension, neurogenic pain, dryness, central sensitization).
- Proper positioning can reduce overload on painful joints or limbs [28].
- Relaxation and rest after sex are encouraged when pain is present [36].
- Sexual activities can be planned for times when the pain is less intense by synchronizing them with the effect of medications, and the client's level of fatigue and stress.

Incontinence

- Education is essential and can cover different subjects: anatomy of the bladder and pelvic floor, the pathophysiology of incontinence, catheter management, the influence of diet, hydration, and medication on urinary symptoms and stool consistency.
- Certain lifestyle habits can influence urinary function. Recommendations can be provided on weight loss, increased physical activity, quitting smoking and decreasing caffeine consumption [30].
- Bladder training with the use of a bladder diary can be taught to people with urge urinary incontinence.
- Pelvic floor muscle exercises to strengthen the muscles could be offered to certain clients and would help decrease stress and coital incontinence.
- For coital incontinence, it may be recommended to empty the bladder before sexual activity and to put a protective pad on the bed to limit soiling and reduce anxiety associated with leakage.

Respiratory or cardiac involvement

- Sexual activity should be performed when the client is well-rested.



- It is recommended to avoid sexual activity for one hour after eating and not to drink alcohol for three hours before, as this may increase shortness of breath.
- Strategies can be taught for managing dyspnea (e.g., positioning, pursed lip breathing, diaphragmatic breathing) [18].
- Environments that are too hot, humid, or cold should be avoided during sexual activity.
- People on ventilation can also have sexual intercourse [32]. If the medical prescription recommends increasing the O_2 flow rate during physical activity, people are encouraged to adjust O_2 flow rate during sexual activity as needed.

TAKE-HOME MESSAGE

Clients expect healthcare professionals to discuss sexuality with them [8, 37, 38] and many do not mention their difficulties on their own, due to the intimate and private nature of the topic.

It is imperative to recognize that the difficulties present in NMD can have an impact on sexuality. These issues are important in the lives of clients, and the rehabilitation team, including the physiotherapist, must find ways to ensure that sexuality becomes and remains an integral aspect of their practice.

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