

# HAP-PEE - study II

## “Going when you have to” – problems in urinating when away from home as a woman with NMD

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### Aim

To investigate whether women with NMD experience problems in going to the toilet when away from home and how this impacts social activities and participation, and to assess to which extent women with NMD experience bladder health problems.

### Conclusion

Going to the toilet when away from home is a major problem for women with NMD. The consequences have a negative impact on QoL and all levels of functioning.

There is a major need to address this in the clinic, to find solutions, and prevent problems with bladder health.

### Results

692 women (43 %) responded to the survey; mean age was 52 years (range 12-89 years); 58% of participants were ≥ 51 years; 21% were non-ambulant. Diagnosis and age are illustrated in Figure 1.

**When at home, 16% of responders needed assistance with toilet visits. When away from home, the number increased to 27%.** In general, time for toilet visits increased when away from home.

Half of the participants needed support from armrests or a fixed piece of furniture; 23% needed support from another person; 39% of responders found it problematic to go to the toilet when away from home.

**One third of the participants experienced an impact on their social life.** Limitations in activities were experienced in all age groups (p= 0.280) and across all levels of mobility, but mostly by those with impaired gait and/or by non-ambulant persons. Impacts on social activities and participation are illustrated in Figure 2.

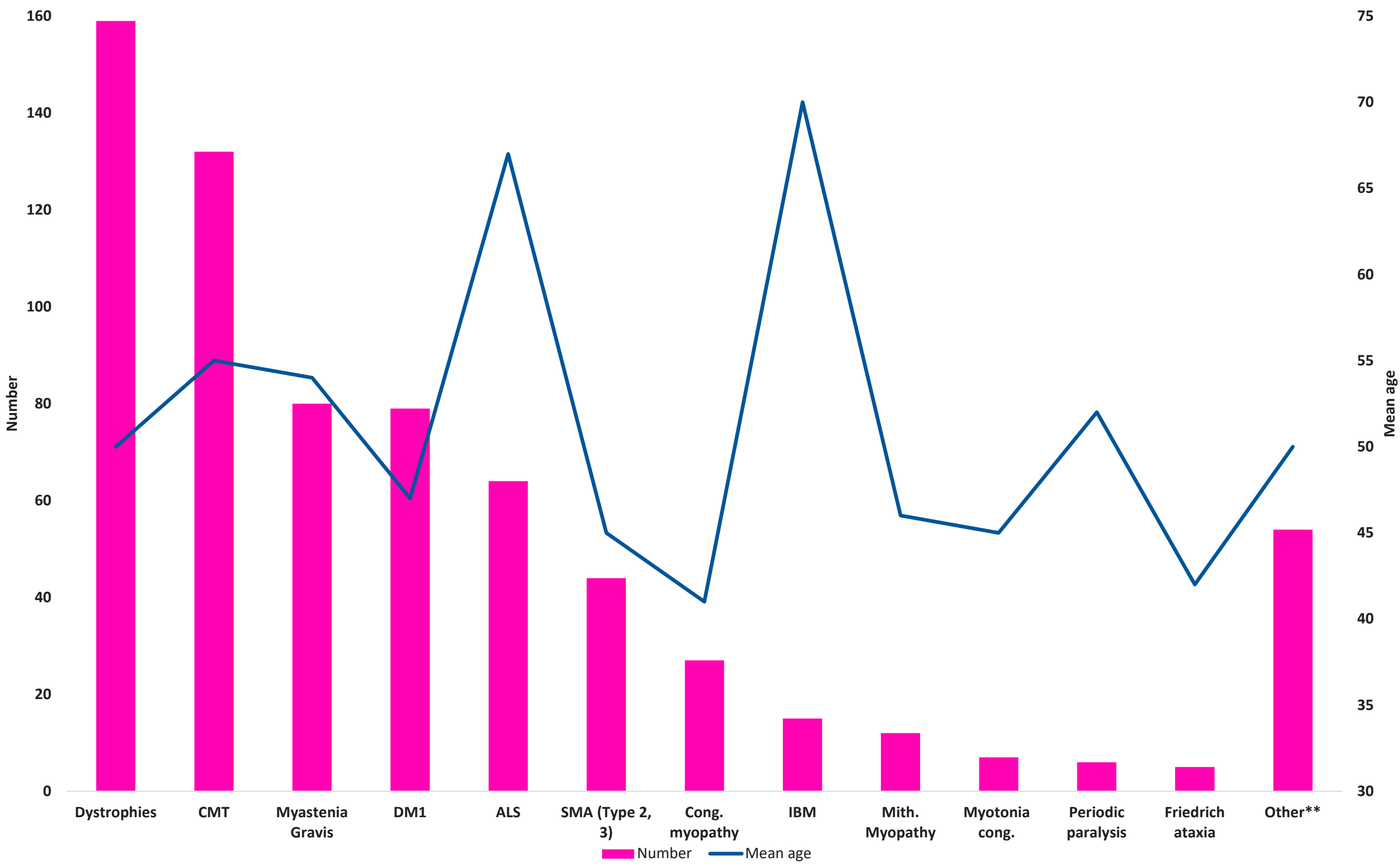
**Refraining from drinking fluids was a strategy to avoid urinating in almost 40% of the women.** Median time for not urinating was four hours but some could avoid urinating for up til 22 hours. Although holding in urine was related to level of mobility (p=0.000), more than 25% of the respondents who could walk independently also refrained from peeing when not at home.

**Recurrent urinary tract infections were reported by 17% of the participants,** mainly by women with lower mobility (p<0.005). Urge to urinate was associated with reduced level of mobility (p=0.001), but not with age or NMD subtype.

**Episodes with incontinence was reported by 56% (stress) and 60% (urge).** Both types of incontinence were associated with increasing age (p=0.002) and mobility level (P=0.001) but not with NMD subtype.

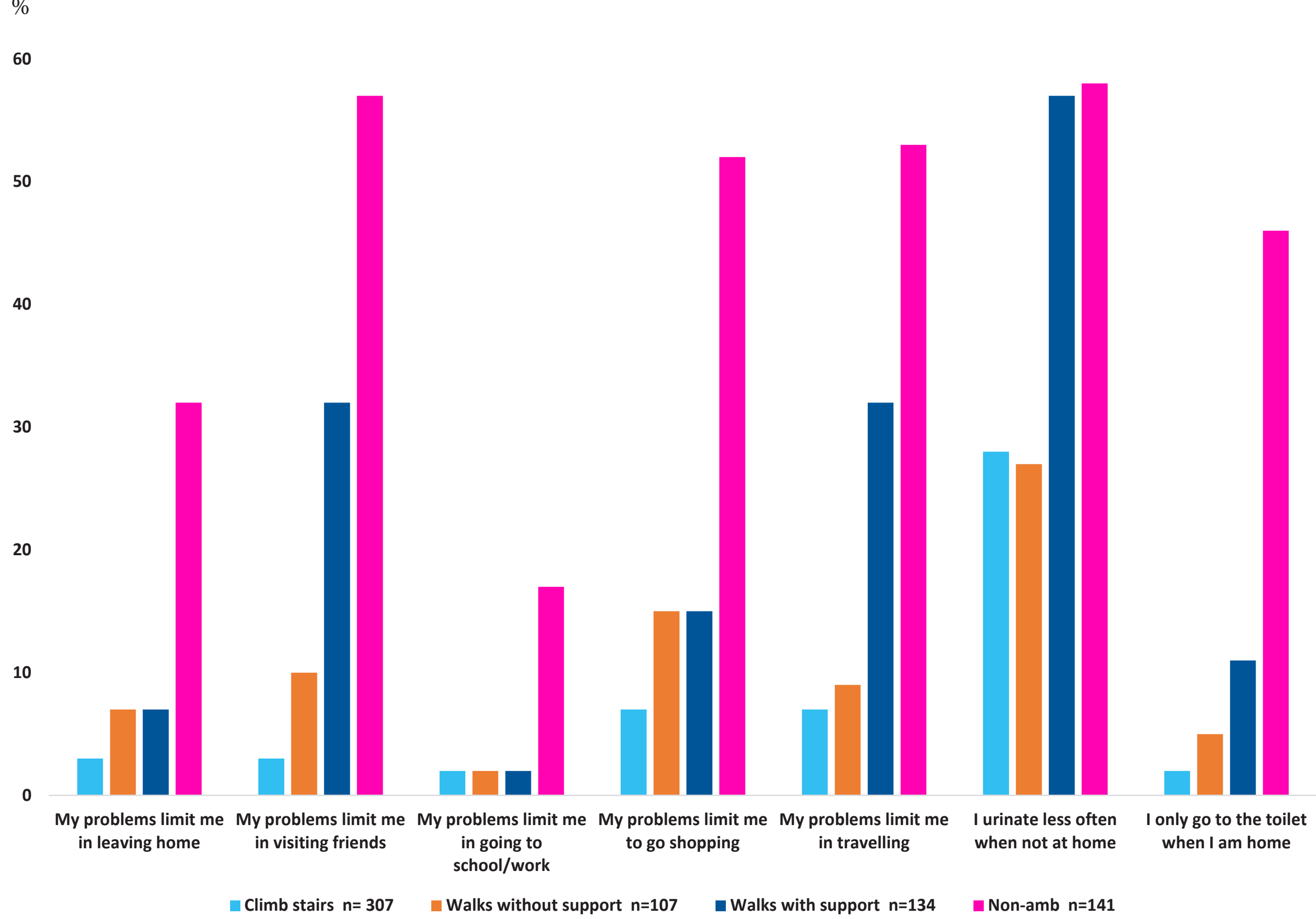
**Only 5% of the women had been referred to neurourological evaluation** and only 15% had discussed voiding problems with their doctor.

Figure 1 Diagnosis and mean age



Dystrophies represent FSHD, LGMD, dystrophinopathies, CMD\*\*Others represent 54 patients who could not find their diagnosis on the questionnaire list, or did not know their diagnosis. Diagnoses with less than five patients (Pompe, MacArdle and DM2) are not displayed in the figure.

Figure 2 Impacts on social acitvy and participation



Impact on social activity and participation according to level of mobility. 689 women responded to whether or not they felt limited in daily activities due to problems in using a toilet when away from home. The bars illustrate the percentage of those who experienced the problem.

### Background

The lack of accessible toilets in the public space makes it difficult for women with physical impairment such as NMD to leave home because transferring to a standard toilet may pose various challenges.

This may impact social activities and participations. Going out without having access to a toilet may further impact body functions with an increased risk of potential bladder health problems.



### Methods

Females ≥ 12 years (n= 1617) registered at the Danish National Rehabilitation Centre for Neuromuscular Diseases were invited to respond to a survey with questions on possibilities and limitations regarding toilet visit when not at home. The questionnaire was developed by the study group consisting of four researchers and three women with NMD. Bladder health were assessed by the ICIQ-FLUTS questionnaire, that assess filling symptoms, voiding symptoms and incontinence symptoms. Influence of age, level of mobility and diagnosis was calculated by Kruskal Walis test.