

## Press release

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### Basic information

Name: Louise Abildgaard Møller                      Email: [lorasm@rm.dk](mailto:lorasm@rm.dk)                      Phone:                      28607047

Department of: Neurology Aarhus University Hospital

Main supervisor: Pia Dreyer

Title of dissertation: "Ageing life with neuromuscular disease: A phenomenological-hermeneutic study"

Date for defence: 20/8-21                      at (time of day): 13.00                      Place: Auditorium J116-113, entrance J, J110 , Aarhus University Hospital, Palle Juul-Jensens Boulevard 99, 8200 Aarhus N. The defence is also presented online via ZOOM on the following link:  
<https://aarhusuniversity.zoom.us/j/65411167167>

Press release (Danish)

At blive ældre med muskelsvind - et fænomenologisk-hermeneutisk studie af livet som ældre med muskelsvind.

Oplevelse af hverdagslivet når man bliver ældre med muskelsvind samt hvilken støtte og pleje der er behov for undersøges i et nyt ph.d.-projekt fra Aarhus Universitet, Health. Projektet er gennemført af Louise Abildgaard Møller, der forsvare sin afhandling d. 20/8 2021.

Ingen eksisterende medicinske behandlinger kan forlænge levetiden eller forbedre livskvaliteten for mennesker med muskelsvind bedre end den rette rehabiliteringsindsats, pleje og støtte. Inden for nyere tid har forbedret rehabilitering, lindring af symptomer samt teknologisk udvikling forlænget levetiden for mennesker med nogle muskelsvindstyper. Der eksisterer imidlertid kun sparsom viden om, hvordan livet som aldrende med muskelsvind opleves. Tidligere studier peger på, at netop en bedre forståelse af livet som aldrende med muskelsvind kan medvirke til at forbedre rehabiliteringsindsatsen, støtten og plejen til mennesker, der bliver ældre med muskelsvind. Formålet med dette ph.d. studie var, at undersøge og opnå en dybere forståelse af hvordan det opleves 'at blive ældre med muskelsvind samt at skabe forståelse for behovet for støtte og pleje.

Resultaterne viser bl.a., at livet som aldrende med muskelsvind opleves som flere forskellige overgange, der tilsammen rummer en risiko for en oplevelse af manglende sammenhæng i hverdagslivet . Disse overgange omhandler fysiske forandringer, lovgivningsmæssige forhold og ændringer i sociale tilhørsforhold. Ligeledes viser studiet, at deltagelse er en særlig vigtig del af hverdagslivet, fordi det at deltage fører til oplevelsen af at have et formål og en mening i tilværelsen. Endvidere viser studiet, at mangel på professionel viden om aldring med muskelsvind kan have en negativ indvirkning på muligheden for fortsat at deltage i hverdagslivet og at der er behov for en tilgang til mennesker der ældes med muskelsvind, der i højere grad tager udgangspunkt i den enkeltes livssituation, hverdag, ønsker og mål. Således bidrager studiet til en fremtidig udviklingen hvor rehabiliteringsindsatser i højere grad tager afsæt i det enkelte aldrende menneske med muskelsvind.

Forsvaret af ph.d.-projektet er offentligt og finder sted den 20/8 kl. i auditorium J116-113, indgang J, J110 , Aarhus Universitets Hospital, Palle Juul-Jensens Boulevard 99, 8200 Aarhus N. Eller ved online deltagelse via ZOOM på følgende link:

<https://aarhusuniversity.zoom.us/j/65411167167>

Titlen på projektet er "Ageing life with neuromuscular disease: A phenomenological-hermeneutic study". Yderligere oplysninger: Ph.d.-studerende Louise Abildgaard Møller, e-mail: lorasm@rm.dk, tlf. 28607047.

Bedømmelsesudvalg:

Associate professor Ingrid Poulsen, Copenhagen University Hospital, Amager Hvidovre, Kettegaard allé 30, 2650 Hvidovre Denmark

Professor Christine Øye, Department of Health and Caring Sciences, Western Norway, University of Applied Sciences,

Associate professor Hanne Agerskov, Department of Clinical Research, University of Southern Denmark and Department of Nephrology Odense University Hospital

Press release (English)

"Ageing life with neuromuscular disease: A phenomenological-hermeneutic study"

The experiences of everyday life for persons who are ageing with NMD and the care and support needs occurring in this situation are explored in a new Ph.D. project carried out by Louise Abildgaard Møller, who is defending her dissertation on 20<sup>th</sup> August 2021.

None of the current medical treatments can prolong life and improve quality of life for persons who are ageing with NMD better than provision of the right rehabilitation, care and support. Advances in rehabilitation, technology and symptoms management have produced an increased life expectancy for some NMD subtypes and a nearly normal life expectancy for other types. Hence, persons living with NMD now live longer lives in which age-related changes add to their NMD-related disabilities. Nevertheless, knowledge about how ageing life with NMD is experienced remains sparse. Several studies suggest that a better understanding of everyday life with NMD may lead to improved support, care and rehabilitation of persons with NMD. This study aims to explore and understand ageing life with NMD and to arrive at an understanding of the care and support needs in ageing life with NMD. The findings show that ageing life with NMD is paved with multiple transitions all associated with a risk of experiencing incoherence. These transitions occur in areas of everyday life that are related to physical changes, legislative changes, social changes and the question of how to strike a balance between the need for exercise and preserving strength and energy for other areas of everyday life. Furthermore, the findings illuminate that the concept of 'participation' is understood to be an especially important issue in ageing life, as it leads to experience a sense of purpose and meaning in ageing life. A lack of professional knowledge may negatively affect the continued participation of persons who are ageing with NMD. Finally the study show that there is a need for an approach to care and support which takes point of departure in the life situation of each individual who age with NMD. The new knowledge generated through the study contributes to a future development of an intervention to persons ageing with NMD, which centres on the individual's life values, goals and specific life situation.

The defence is public and takes place on 20<sup>th</sup> August 2021. at i auditorium J116-113, entrance J, J110, Aarhus University Hospital, Palle Juul-Jensens Boulevard 99, 8200 Aarhus N. Or Online Via Zoom on the following link:

<https://aarhusuniversity.zoom.us/j/65411167167>

The title of the project is "Ageing life with neuromuscular disease: A phenomenological-hermeneutic study". For more information, please contact PhD student Louise Abildgaard Møller, email: lorasm@rm.dk, Phone +45 28607047.

Assessment committee:

Associate professor Ingrid Poulsen, Copenhagen University Hospital, Amager Hvidovre, Kettegaard allé 30, 2650 Hvidovre Denmark

Professor Christine Øye, Department of Health and Caring Sciences, Western Norway, University of Applied Sciences,

Associate professor Hanne Agerskov, Department of Clinical Research, University of Southern Denmark and Department of Nephrology Odense University Hospital

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