

# Powerless in Daily Living (PDL care), a multidisciplinary care method for patients with late stage Huntington`s disease; a case report

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## Background

PDL care is a multidisciplinary care method developed in the Netherlands for patients with severe chronic conditions such as dementia. PDL care is based on the patient`s wishes and focusses on stabilization and dealing with disabilities for which no recovery is possible (Figure 1). PDL care can reduce pain and discomfort in patients.

Caregivers noticed that patients with late stage Huntington`s disease (HD) experience pain and discomfort during washing and dressing in bed. They also indicated that there is a physical overload because of the care in bed of these patients. The occupational therapist suggested to start with PDL care. However, it is unknown whether PDL care will cause less pain and discomfort in patients with late stage HD and less physical burden in caregivers.

**“At that moment [regular care], she was still restless and sometimes we did proceed... And now [PDL care], I was really aware I had to wait until she answered or responded with her eyes.”**

Figure 2: Quote caregiver

### PDL care:

- Maximal use of residual capabilities in daily living, not used during care
- Care on a one-to-one basis, more personal contact
- Values of the patient are leading
- More use of tools like a transfer / turning sheet or tailored clothing

Figure 1: A few provisions and aids of PDL care

## Case Report

One female patient (59 years) with late stage HD is observed for two weeks in 2018. In the first week regular personal care was given. In the second week PDL-trained caregivers washed and dressed the patient according to PDL care. Pain and discomfort in the patient was measured with the PACSLAC-D pain observation scale [range 0-24]. Physical burden of the caregivers was measured by the BORG Rating of Perceived Exertion Scale [range 6-20] (Table 1). In addition caregivers were interviewed. According to the PACSLAC-D PDL care caused less pain and discomfort in the patient during washing and dressing. Possibly, PDL care had a positive effect later on the day. PDL care did not lead to an overall increase in time investment during care (Table 1). Caregivers assessed the method as positive and applicable (Figure 2).

Table 1. Pain and discomfort, physical burden during washing and dressing, and time duration of the care moment.

	PACSLAC-D <sup>1</sup> patient Morning (mean)	PACSLAC-D <sup>1</sup> patient Afternoon (mean)	BORG-scale <sup>2</sup> caregiver 1 (mean)	BORG-scale <sup>2</sup> caregiver 2 (mean)	Time duration (minutes)
Regular care	7,6	2,5	12,75	10,5	16,4*
PDL care	4,2	1,6	11,8	N/A	26,2**

<sup>1</sup>PACSLAC-D scale for pain and discomfort [range:0-24], <sup>2</sup>BORG-scale for physical burden[range: 6-20], \* for two caregivers, \*\*for one caregiver

## Conclusions

PDL care in bed may lead to less pain and discomfort in patients with late stage HD. Patients with late stage HD can be washed and dressed in bed by one caregiver instead of two. Further research is needed.

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