

# Experiences of patients with Huntington's disease on home cooked hot meals in a long term care facility

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## Background

Huntington Expertise Centre Atlant offers multidisciplinary care to 51 patients with Huntington's disease (HD) institutionalized in 2 Skilled Nursing Facilities (SNF). In June 2015, patients of one SNF (n=24) were relocated to a new ward. Anticipating more self-management, the 3 communal living rooms of this ward were completed with a contemporary kitchen unit. Once a week a professional cook prepared hot meals in one living room. Patients indicated to appreciate these hot meals. Until 2015, patients consumed facility-provided food. We wondered whether home cooked hot meals will contribute to quality of life, wellbeing and to what extent patients have a say in selecting food and the amount of food intake.



Figure 1. Nurse and patient cooking together

"I have more energy because I eat these hot meals"

Table 1. Experiences of HD patients with home cooked meals

	January n=19	July n=19
Mean weight in kg	74.7	73.0
<b>Results survey; yes/no</b>		
	January n=14	July n=14
Did you have sufficient choices of the meals?	11 / 3	11 / 3
Could you decide for yourself how much you ate?	11 / 3	13 / 1
<b>Rating (scale 1 - 10)</b>		
	January n=14	July n=14
Taste of meals	7	8
Smell of meals	7	8
Choices of meals	7	7
Presentation of meals	7	8
Own disicion in quantity	8	9
Contribution to quality of life	9	9

"Because the food is so good I can eat no more than 1 dessert"

## Conclusions

HD patients appreciated home cooked hot meals very much. It seems to have a positive effect on their quality of life and self-management. Participation of family members was received positively by everyone involved. Due to the positive results, we extended the frequency of the home cooked hot meals from 3 to 5 times a week.

## Case histories

Since January 2016, we cooked hot meals 3 times a week in every living room. Family members volunteered to assist on a regularly basis. Experiences of 19 patients were monitored using a survey. As weight loss is a risk factor to HD patients, body weight was monitored as well on a monthly basis. Results show that all patients enjoyed the hot meals more than before; they have a say in what to eat, can scoop the amount they prefer and enjoy the smell of food (Table 1). In addition, patients became more and more involved in preparing the meals (Figure 1). Six patients gained weight; 5 had no change and 8 patients lost some weight. This weight loss can probably be attributed to the progress of the disease. Every patient found that a good hot meal positively influenced their quality of life, rating this with an average of a 9 out of 10 points.

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