

What do the Dutch dietitians know about Huntington's Disease?

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Background

Approximately 1,700 persons in The Netherlands are suffering from Huntington's Disease (HD). It's estimated that in addition 6,000-9,000 people are at risk. One of the characteristics of HD is a very high energy requirement and swallow difficulties. To prevent malnutrition proper guidance by a dietitian is essential. To prevent malnutrition proper guidance by a dietitian is essential. However, outside the specialized HD centres only a few dietitians in The Netherlands know about this disease and it's diet. **Time for action!**

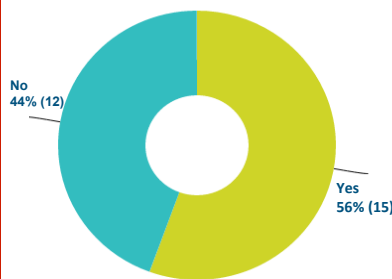
Aim

The aim of the study is to determine the level of knowledge of the treatment of HD-patients among dietitians in the Netherlands.

Method

During the General Meeting of the Members of the Dutch Dietitians Association in November 2015 the members of the Network Dietitians Huntington Disease of The Netherlands (DHDNL) handed out questionnaires. The attendants were asked to complete these to indicate what they knew about Huntington's Disease and whether they ever-had treated a patient. We also wanted to know if there was a need for more information about nutrition and HD

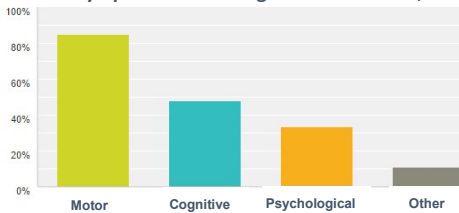
Are you familiar as a dietitian with Huntington's Disease?



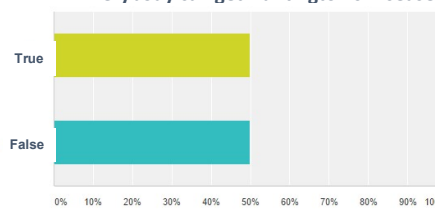
Results

The questionnaire was completed by 27 dietitians (62% independent, hospital, 15% Nursing Homes, and 4% Mental Health Care, 4% other, like students). The general level of their knowledge of HD treatment turned out to be quite low. The majority had never treated a HD patient (81%), although nearly half (46%) practiced as a dietitian for 10 years or more.

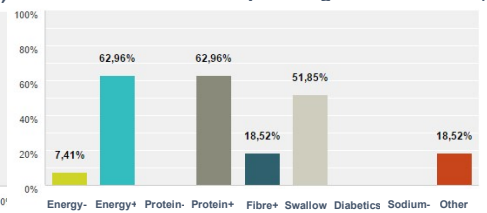
Symptoms of Huntington's Disease are;



Everybody can get Huntington's Disease;



Most common diets by Huntington's Disease are;



Conclusion

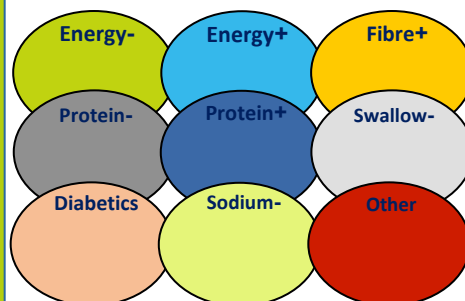
Many of the Dietitians, which are working outside the specialized HD centers, are not or hardly familiar with HD and the appropriate diets. However, they, too, can treat these patients in their own practices. For the next few years the DHDNL will the dietitians to find more information on their website and by training.

Do YOU know what a dietitian can do for HD patients?

How much calories does an average HD patient need?

- 2000-2500 kcal:
- 2500-3000 kcal:
- 3000-3500 kcal:
- 3500-4000 kcal:
- >4000 kcal:

Most common diets with HD are?



Do you see or consult a dietitian in your work with HD patients?

- Yes;
- No;
- Comment;

