

# GUIDELINE NUTRITIONAL CARE IN ALS

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## INTRODUCTION

A guideline is developed by reviewing the literature, combined with practice based experience of ALS dietitians. This guideline provides dietitians with information, to optimise nutritional care for the individual ALS patient.

There is need for more evidence based information on nutritional care in ALS.

## TARGET DIETITIAN

The target of nutritional intervention in ALS is to preserve the quality of life of the ALS patient by:

- optimising nutritional status
- prevention of undesired weight loss and catabolism
- adaptation of food consistency
- sufficient fluid intake
- reducing sialorrhoea
- defecation without distress

## WEIGHT

### Early phase:

prevention of weight gain at BMI > 30

### Mid phase:

maintaining nutritional status

### Late phase:

preventing undesired weight loss and muscle catabolism as much as possible

## ENERGY

Strong weight gain: 20 kcal/kg/day, based upon a BMI of 27

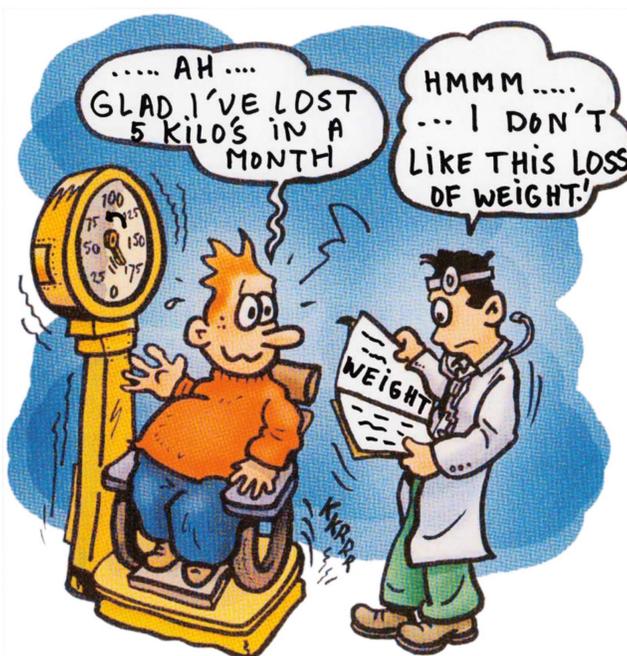
Despite decreasing mobility and increasing paresis energy requirements are similar to healthy persons to maintain energy balance: 25 kcal/kg ideal body weight/day

Undesired weight loss and malnutrition: increased energy requirements are (if possible) 30-35 kcal/kg ideal body weight (BMI 22.5)/day (is inclusive 10% hypermetabolism)

## PROTEIN

No increased metabolic requirements

Protein need is according to RDA: 0,8 g/kg ideal body weight. Comorbidity may increase the need for protein (e.g. malnutrition, decubitus ulcer)



## PEG/PRG/NASOGASTRIC TUBE

Ethical decision, made by patient.

Reasons for introduction: dysphagia, dehydration, severe fatigue and decrease of VC. PEG should be placed before VC is lower than 50% of the predicted VC value.

Enteral nutrition is a medical treatment.

The dietitians role in counselling.

Tube feeding gradually from bolus, to smaller bolus more frequently, to continuous drip supply.

## FIBRES

### Early phase:

according to RDA: 14 g/1000 kcal/day.

Intake decreases based upon the quantity and consistency of food, additional medical fibre supply may be necessary.

Increasing respiration insufficiency requires daily defecation; In case of diaphragm weakness, severe respiratory insufficiency, poor condition and fast progression of ALS, low fibre feeding is indicated in combination with a laxative management.

## PALLIATIVE NUTRITION

In ALS when PEG/PRG/tube is not possible or refused: Provide nutrition and fluids as a means of reducing complaints and providing energy as long as the patient lives .

In ALS, when PEG is utilized, palliative nutrition is given, based upon to the wellbeing of the patient.

## CONCLUSIONS

The guideline is the initial step in providing a coherent nutritional policy.

Initiate a discussion, in order to establish a consensus on the clinical nutritional requirements of ALS patients.

Research is needed in order to get more evidence based information on nutrition in ALS.

## REFERENCES

- van den Berg JP, de Groot IJM, Joha BC, et al. Development and implementation of the Dutch Protocol for Rehabilitative Management in Amyotrophic Lateral Sclerosis. Amyotroph Lateral Scler Other Motor Neuron Disorder 2004; 5: 226-229.
- van den Berg JP, Kalmijn S, Lindeman E, et al. Multidisciplinary ALS care improves quality of life in patients with ALS. Neurology 2005; 65: 1264-1267.
- Wijnen C. Nutritional Guideline ALS: in (Dutch) Handboek Dieetbehandelingsrichtlijnen. Elseviers Gezondheidszorg Maarssen 2007.