

# Nutritional management of people living with MND

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**Clinical Nutrition**

journal homepage: <http://www.elsevier.com/locate/clnu>

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**ESPEN guideline clinical nutrition in neurology**

Rosa Burgos<sup>a,\*</sup>, Irene Bretón<sup>b</sup>, Emanuele Cereda<sup>c,d</sup>, Jean Claude Desport<sup>e</sup>,  
 Rainer Dziewas<sup>f</sup>, Laurence Genton<sup>g</sup>, Filomena Gomes<sup>h</sup>, Pierre Jésus<sup>e</sup>,  
 Andreas Leischker<sup>i</sup>, Maurizio Muscaritoli<sup>j</sup>, Kalliopi-Anna Poulia<sup>k</sup>, Jean Charles Preiser<sup>l</sup>,  
 Marjolein Van der Marck<sup>m</sup>, Rainer Wirth<sup>n</sup>, Pierre Singer<sup>o</sup>, Stephan C. Bischoff<sup>p</sup>

**NICE** National Institute for  
Health and Care Excellence

**Motor neurone disease:  
assessment and  
management**

*European Journal of Neurology* 2012, **19**: 360-375  
doi:10.1111/j.1468-1331.2011.03501.x

**EFNS GUIDELINES**

**EFNS guidelines on the Clinical Management of Amyotrophic Lateral Sclerosis (MALS) – revised report of an EFNS task force**

The EFNS Task Force on Diagnosis and Management of Amyotrophic Lateral Sclerosis: Peter M. Andersen<sup>a</sup>, Sharon Abrahams<sup>b</sup>, Gian D. Borasio<sup>c</sup>, Mamede de Carvalho<sup>d</sup>, Adriano Chio<sup>e</sup>, Philip Van Damme<sup>f</sup>, Orla Hardiman<sup>g</sup>, Katja Kollweh<sup>h</sup>, Karen E. Morrison<sup>i</sup>, Susanne Petri<sup>h</sup>, Pierre-Francois Pradat<sup>l</sup>, Vincenzo Silani<sup>k</sup>, Barbara Tomik<sup>l</sup>, Maria Wasner<sup>m</sup> and Markus Weber<sup>n</sup>

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**Clinical Nutrition ESPEN**

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Original article

**Understanding the current nutritional management for people with amyotrophic lateral sclerosis - A mapping review**

Munira Essat<sup>a</sup>, Elizabeth Coates<sup>a</sup>, Mark Clowes<sup>a</sup>, Daniel Beever<sup>a</sup>, Gemma Hackney<sup>a</sup>,  
 Sean White<sup>b</sup>, Theocharis Stavroulakis<sup>c</sup>, Vanessa Halliday<sup>a,\*</sup>,  
 Christopher McDermott<sup>c</sup>, on behalf of the HighCALS group

- High level overviews
- General recommendations
- Focus on dysphagia and gastrostomy
- Little detail about oral nutrition support



# Malnutrition in MND

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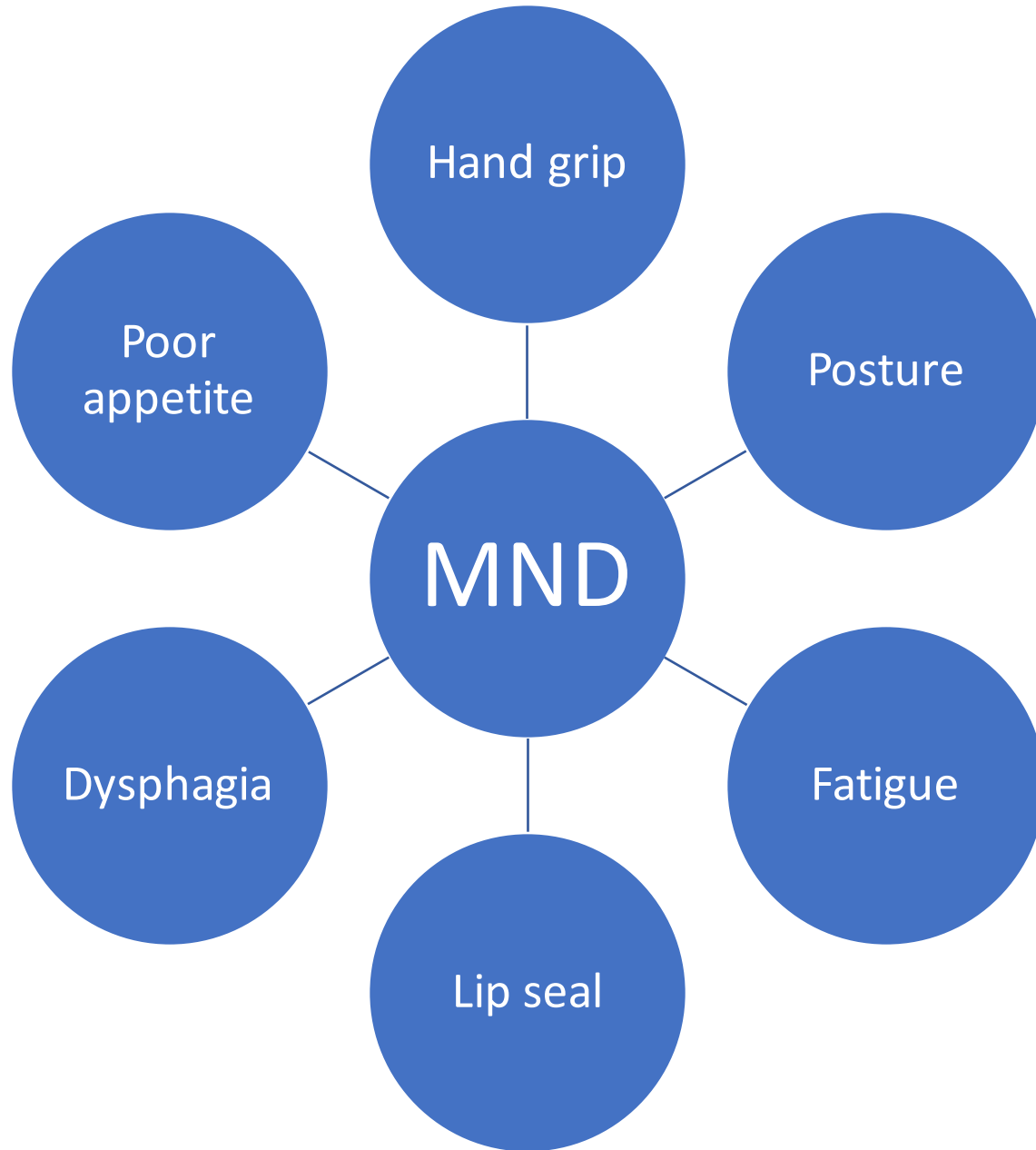
Why does it happen?

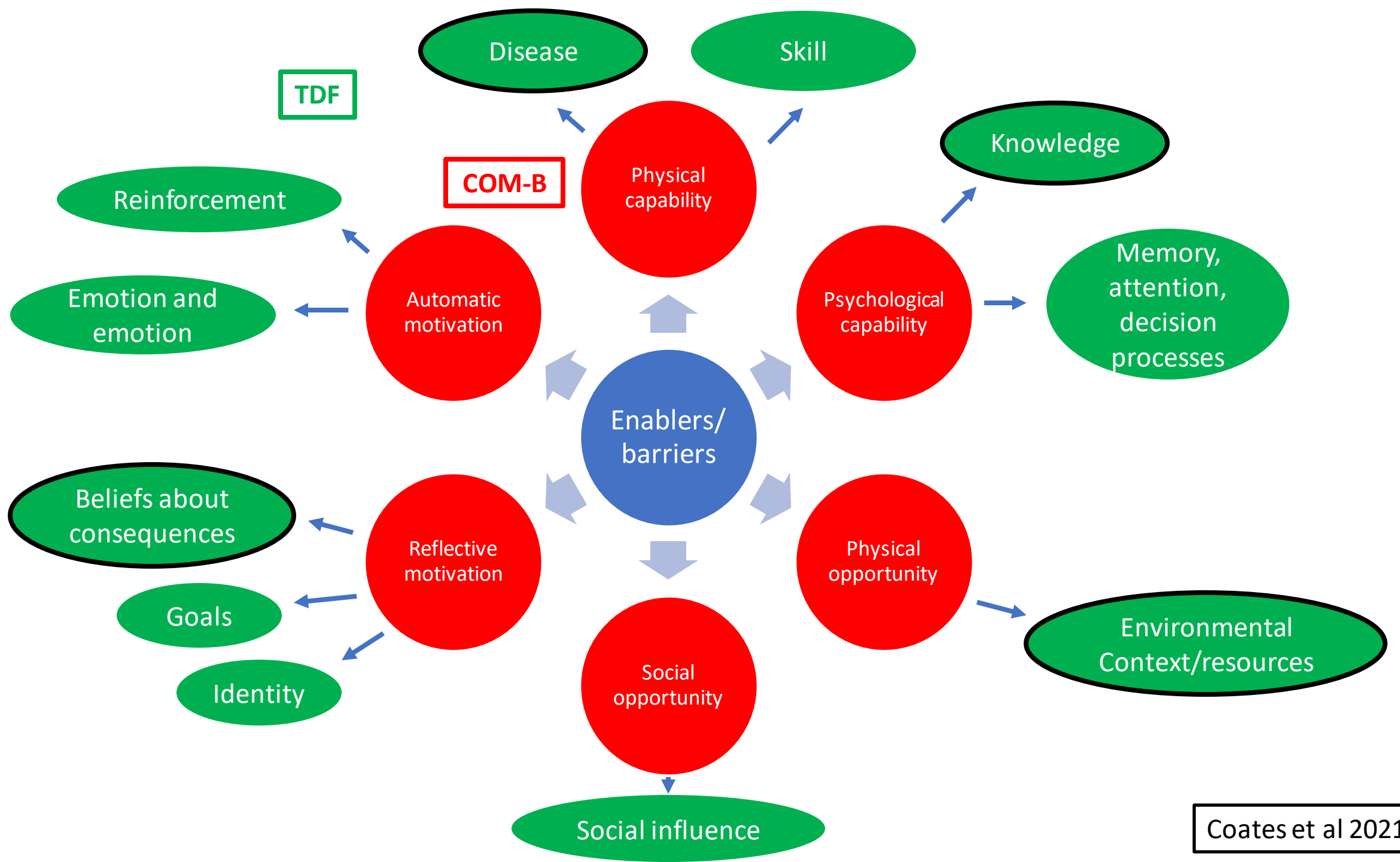
Why does it matter?

What can we do about it?

Nutritional intake







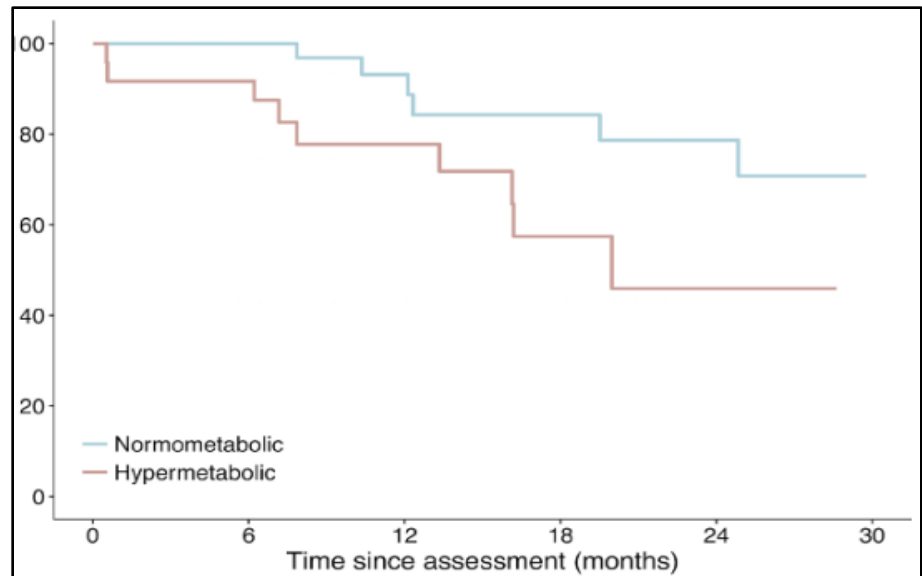


**Psychological  
Factors  
(Zarotti et al 2019)**



# Hypermetabolism



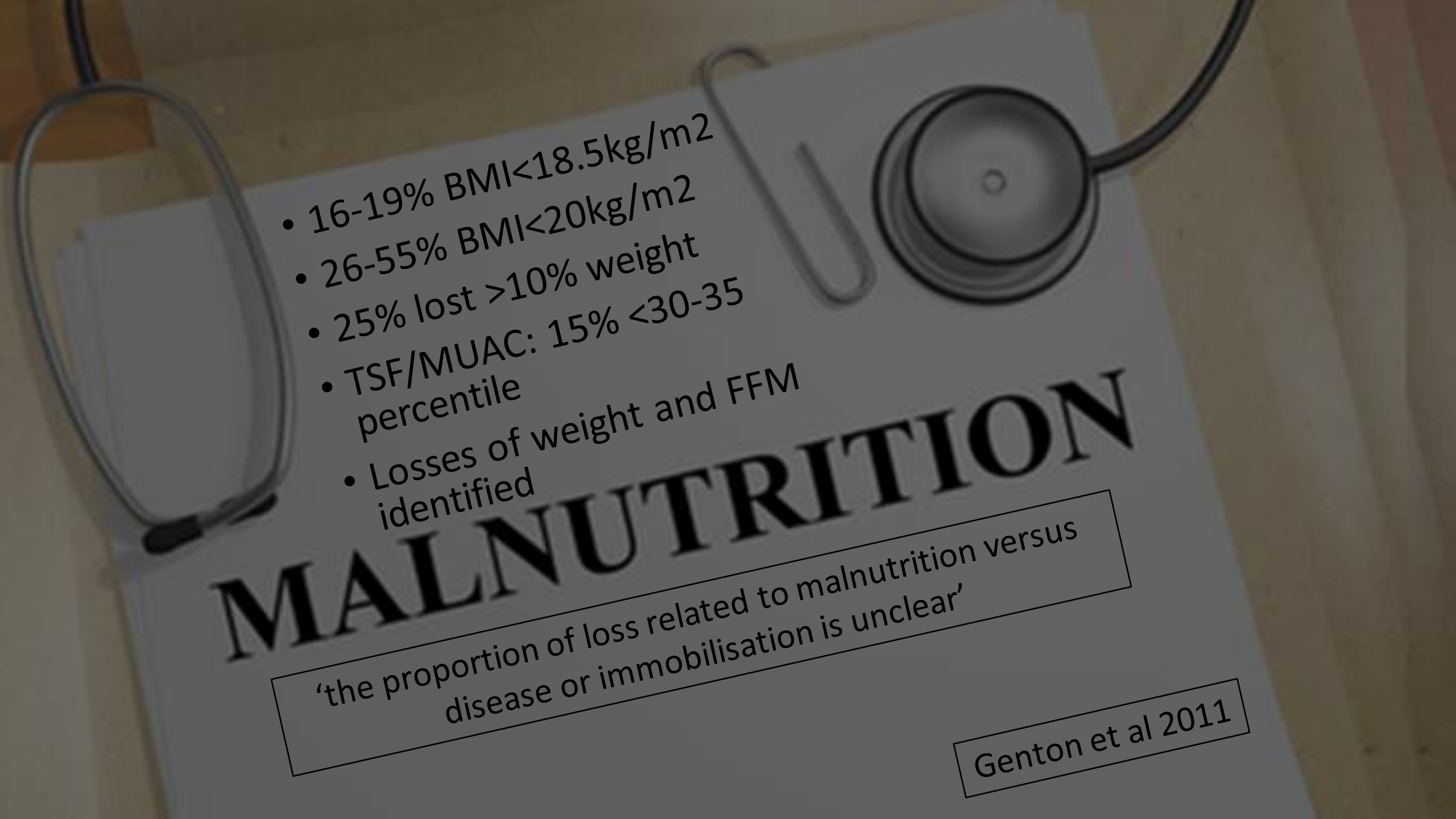


Steyn et al 2020



Desport et al 2001  
Vaisman et al 2009  
Kasarskis et al 2014

Nutritional status

- 
- 16-19% BMI < 18.5 kg/m<sup>2</sup>
  - 26-55% BMI < 20 kg/m<sup>2</sup>
  - 25% lost > 10% weight
  - TSF/MUAC: 15% < 30-35 percentile
  - Losses of weight and FFM identified

# MALNUTRITION

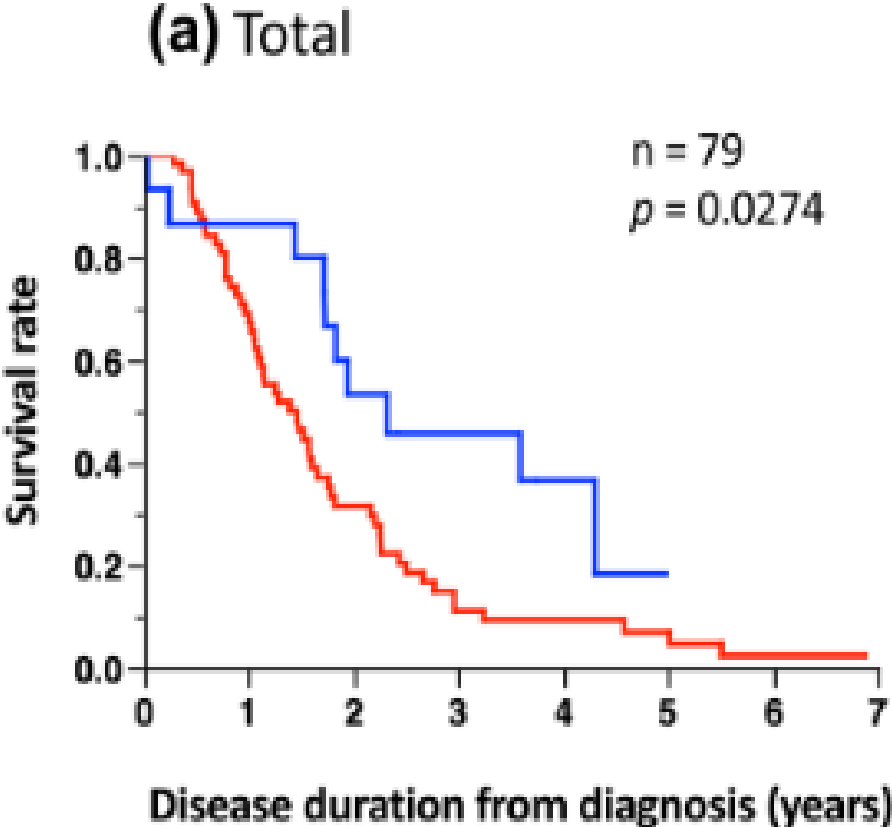
‘the proportion of loss related to malnutrition versus disease or immobilisation is unclear’

Genton et al 2011

# Weight matters in MND:



After diagnosis



Are we  
aiming high  
enough?

Malnutrition screening uncommon

Late referral to dietitian

Using predictive equations validated for pwMND?

Weighed too infrequently

**Recommendation 5:**

**In ALS patients, weight loss is detrimental for survival, but whether oral or EN should aim at weight stabilization or weight gain has not been clarified and may depend on baseline nutritional state. Weight gain should be recommended in patients with a baseline body mass index (BMI <25.0 kg/m<sup>2</sup>), weight stabilization in those with a BMI between 25 and 35 kg/m<sup>2</sup>, and**



# Nutritional interventions



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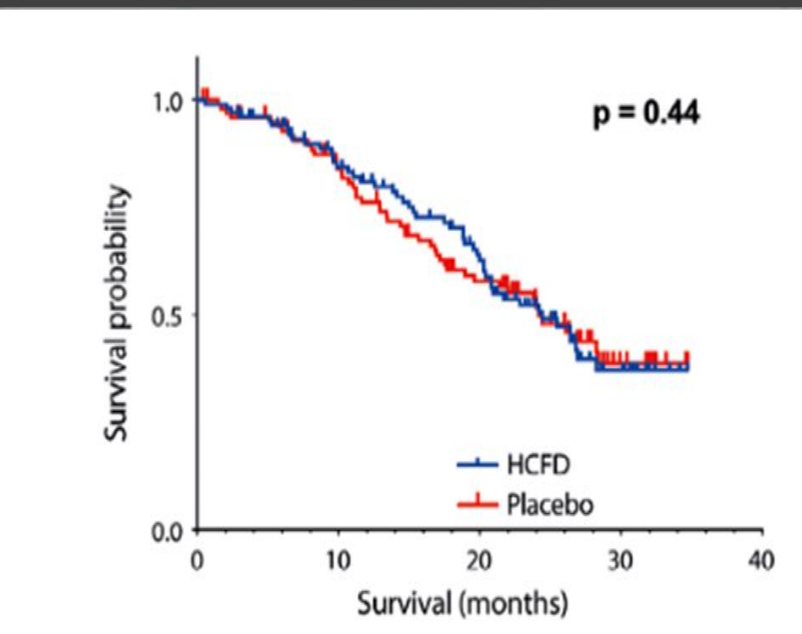
## Clinical Nutrition

journal homepage: <http://www.elsevier.com/locate/clnu>

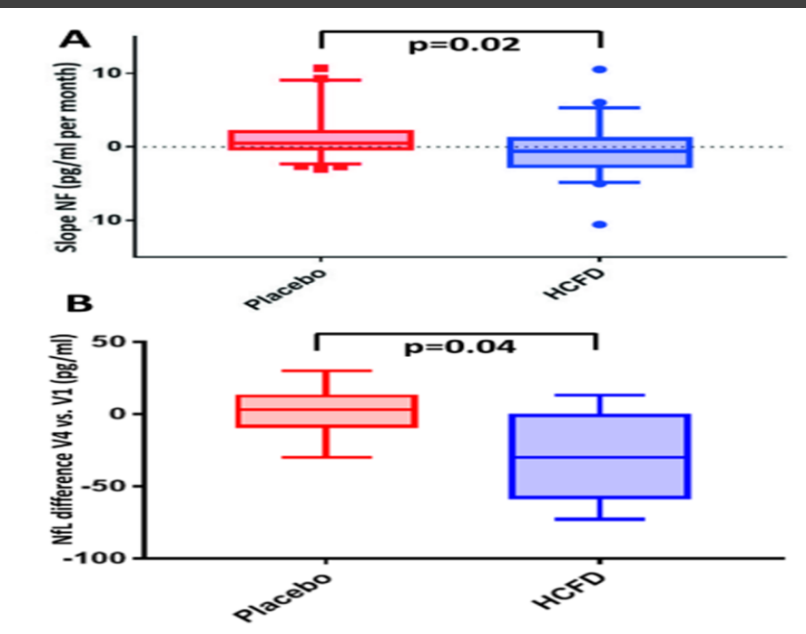
Original article

**Interventions to promote oral nutritional behaviours in people living with neurodegenerative disorders of the motor system: A systematic review**

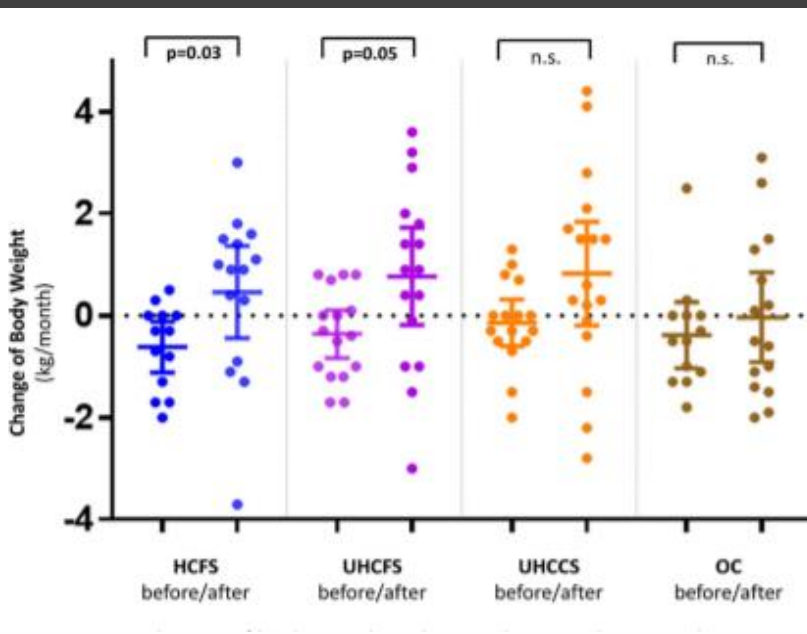
Munira Essat <sup>a</sup>, Rachel Archer <sup>a</sup>, Isobel Williams <sup>b</sup>, Nicolò Zarotti <sup>c</sup>, Elizabeth Coates <sup>a</sup>, Mark Clowes <sup>a</sup>, Daniel Beever <sup>a</sup>, Gemma Hackney <sup>a</sup>, Sean White <sup>d</sup>, Theocharis Stavroulakis <sup>c</sup>, David White <sup>a</sup>, Paul Norman <sup>b, \*</sup>, Christopher McDermott <sup>c</sup>, on behalf of the HighCALs group



Ludolph et al 2020



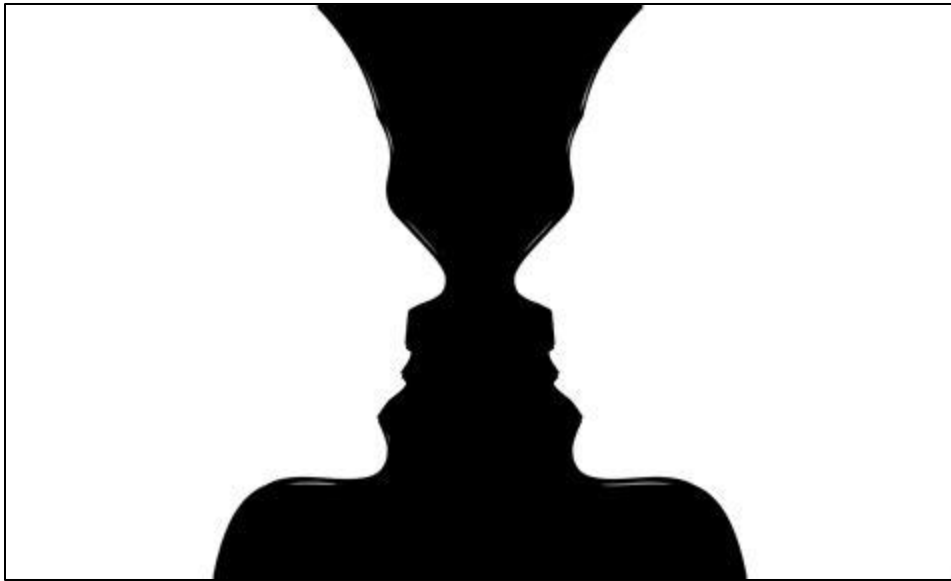
Dorst et al 2020



Dorst et al 2022

**BEWARE**

- Follow up?
- Total kcal/nutritional intake?
- Description of intervention and standard care?
- Attrition?
- Sample size?





My Food Diary

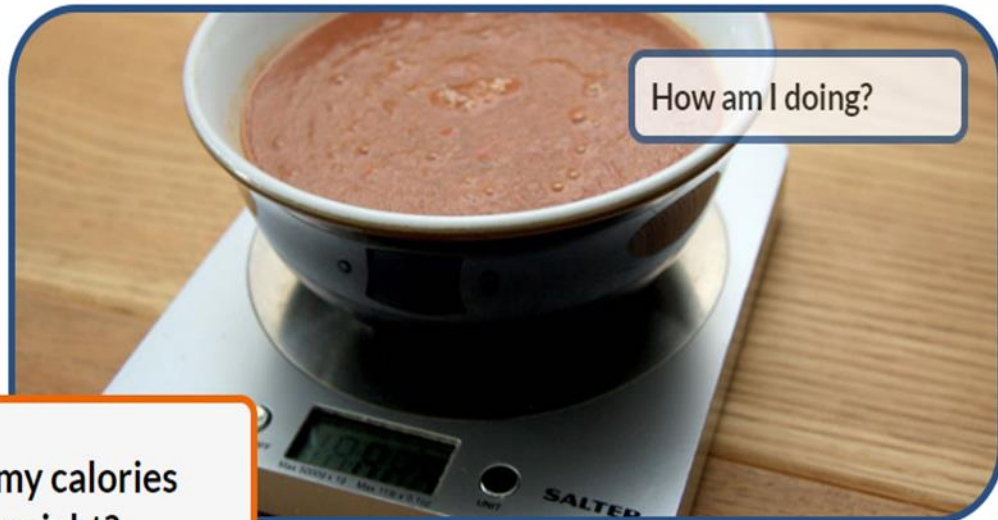
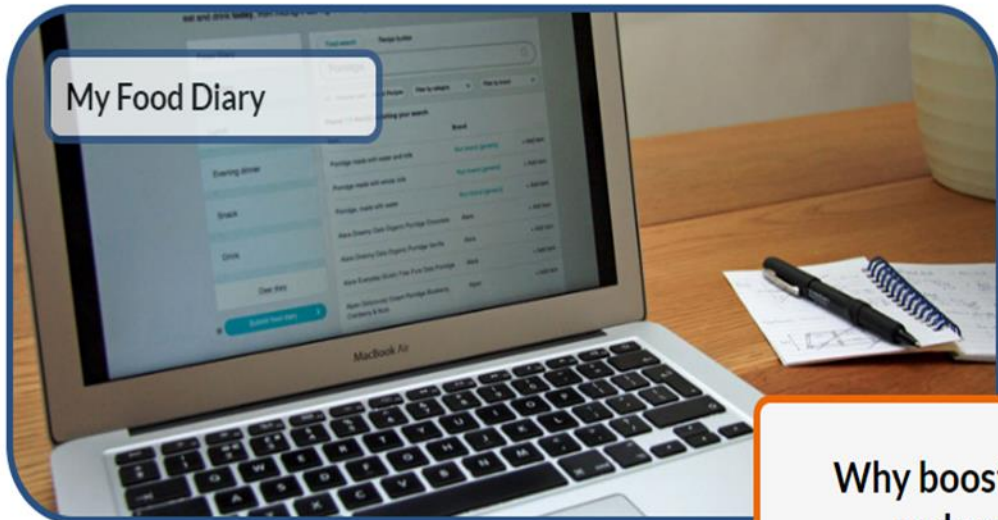
How am I doing?

All Resources

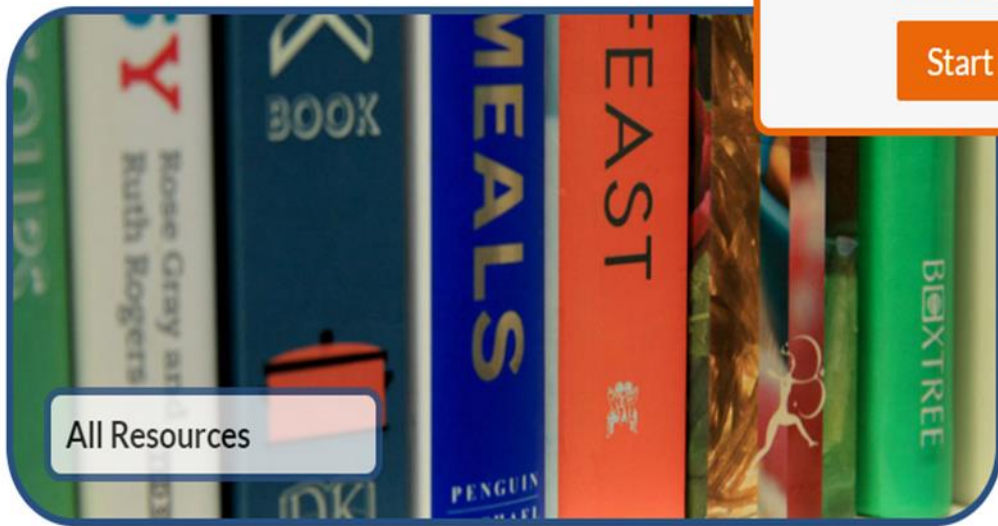
My Resources

Why boost my calories and my weight?

# Welcome to OptiCALS, HCP mock ppt AFO



Why boost my calories and my weight?  
[Start Here >>](#)





## Summary

Nutritional status  
associated with  
outcomes

Well designed  
and reported  
studies

Develop and  
evaluate targeted  
interventions

# References

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