“WHEN THE ANSWER IS NO…” TO GASTROSTOMY

Decision making and support for patients, families and professionals.

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OBJECTIVES

By the end of this presentation, you will be able to:

- Understand the correlation between MND and nutrition.
- Explain when is the right time to discuss a gastrostomy.
- Identify the pros and cons of a gastrostomy.
- Identify the various reasons for declining to have a gastrostomy.
- Ways to support the patient in the community.
- List resources that would be useful for both health professionals and patients.

ISSUE

About 5000 people are living with MND in the UK at any given time.

MALNUTRITION

- Is a negative independent prognostic indicator of survival.
- Is present in approximately 20% of patients with MND at diagnosis, irrespective of the presence of swallowing difficulties.
- Evidence suggests a 5% decrease in body weight is associated with a 30% increase in earlier death.

CAUSES

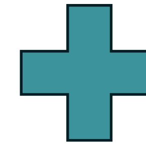
CHALLENGES THAT IMPACT NUTRITIONAL INTAKE

PHYSICAL FACTORS

- Dysphagia: Affects about 70% of people with MND
- Weaking grip strength
- Fatigue
- Salivary issues
- Poor appetite
- Difficulties in buying, preparing and eating food
- Constipation

PSYCHOLOGICAL FACTORS

- Anxiety
- Depression
- Cognitive impairment
- Insomnia
- Family worries
- Spiritual distress



Disease related hyper- metabolism

Malnutrition in 15- 50%

NUTRITION MND TEAM

- MND practitioner
- Nutrition specialist nurse
- Neurosciences dietitian
- Speech and language therapist

DIETITIAN

- Integral part of MDT
- Assess, educate and support
- Soft skills:
  - Calm, supportive, non-judgmental, empathetic
  - Patient-centred communication

WHEN WE RECEIVE A REFERRAL

IDENTIFICATION

- Malnutrition screening tools, sensitive to ALS-specific risk
- Prioritisation

ASSESSMENT

- Weight and BMI
- Percentage weight change
- Midupper arm muscle circumference
- Energy requirement

PLANNING

- Clinical
- Nutritional
- Quality of life

IMPLEMENTING

- Food first
- Oral nutritional supplements

MONITORING

- Rapid and variable progression of the disease

WHEN TO DISCUSS GASTROSTOMY

AS SOON AS YOU NOTICE:

- Swallowing difficulties
- Losing weight unintentionally- BMI of 20 kg/m2, weight loss of 5 % from diagnosis
- Consuming less food and fluids
- Taking longer than expected to eat a meal
- Having problems from dehydration, such as constipation
- Recurrent chest infections
- A gastrostomy is best inserted when lung capacity is strong (FVC greater than 50%)

PROS AND CONS OF HAVING A GASTROSTOMY

PROS

- Maintain nutrition and prevent dehydration
- Increase in energy
- Medication through gastrostomy
- Some can still eat or drink small quantities.
- Prevent weight loss
- Reduces burden of feeling that you have to eat

CONS

- Surgery complications
- Abdominal pain
- Eating and drinking may become more difficult

What is important to patients?

Quality of Life

DECISION MAKING

1. **Structural:** decision-making environment
2. **Interactional factors:** patients' reaction, response to deterioration, and engagement with the multidisciplinary ALS team
3. **Personal factors:** patients' personal philosophies, outlook, perception of control (preservation of independence and control over treatment choices), planning for the future

Patient approaches to decision-making reflect a focus on the present, rather than anticipating future progression of the disease and potential care needs.

REASONS FOR DECLINING A GASTROSTOMY

- Decision-making was a reminder of their inevitable decline
- ‘Giving in' to the disease
- Loss of autonomy
- ‘Physically and permanently altering their natural body’
- Enjoy the taste and social interaction of eating and want to maximize this
- Misconceptions- it will be used indefinitely
- Burden on caregiver

CHALLENGES

- How best to engage each patient in decision-making for symptom management and quality of life
- Patient's personal values and philosophies are supported by collaborative relationships between the patient and the multidisciplinary ALS team

IMPORTANT!

- We are here:
  - ✓ For the patient
  - ✓ Improve their quality of life
  - ✓ Respect their wishes

- We are NOT here to:
  - × Project our beliefs on the patient
  - × Do what *we think* is best for them
  - × Coerce them into a certain path of treatment

YOUR DIETITIAN THINKS ABOUT...

- Dietitians are experts in nutrition.
- They apply science and evidence to your personal circumstances to prevent or treat disease and improve health and wellbeing.
- They will consider a range of factors about you to work towards helping you make the right food choices.

BDA The Association of UK Dietitians

bda.uk.com/WhatDietitiansDo

NHS
Sussex Community
NHS Foundation Trust

FRAMEWORK OF HEALTH-RELATED QUALITY OF LIFE

Self Identity

Physical sensations

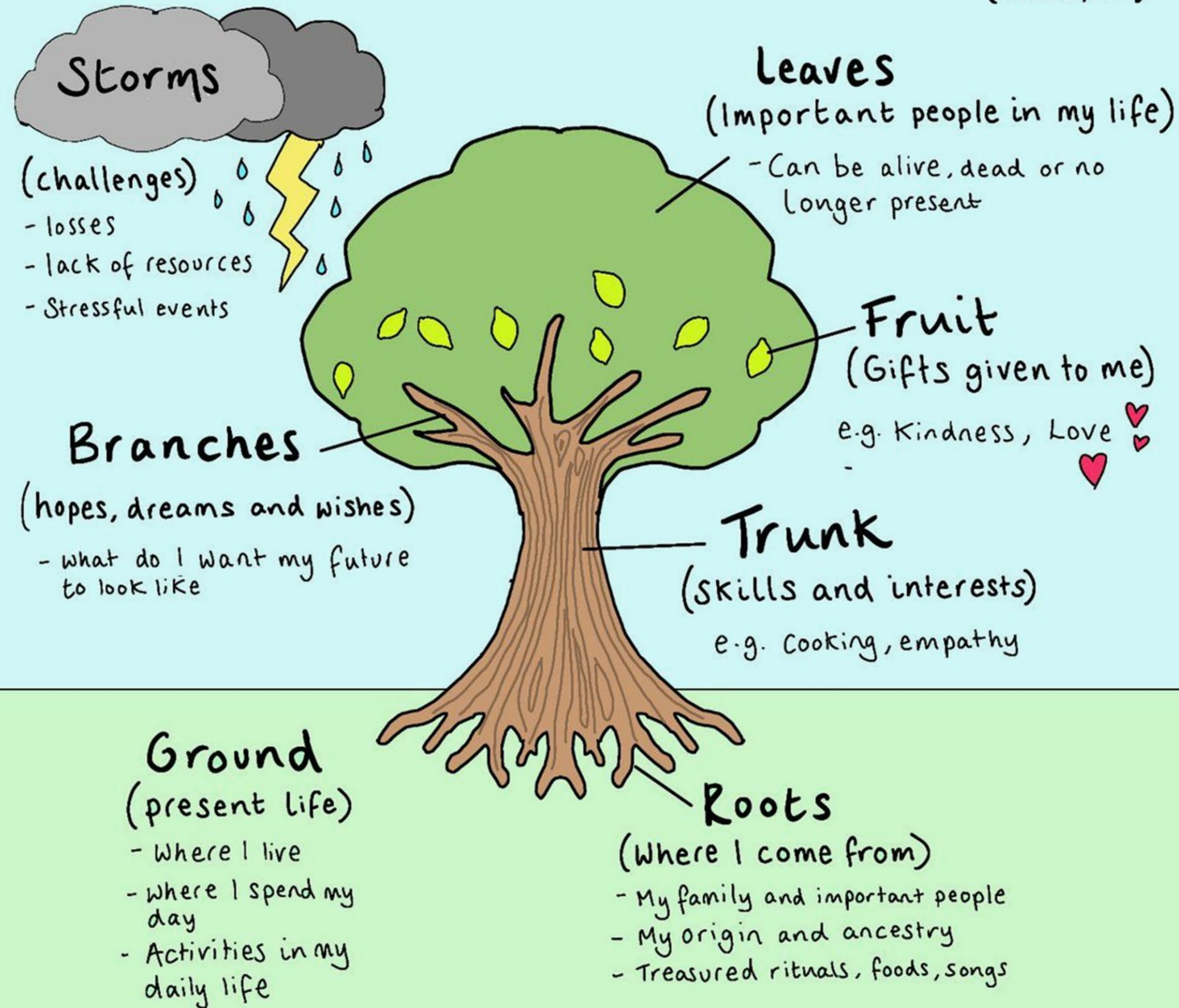
Activity

Autonomy

Cognition

Relationships

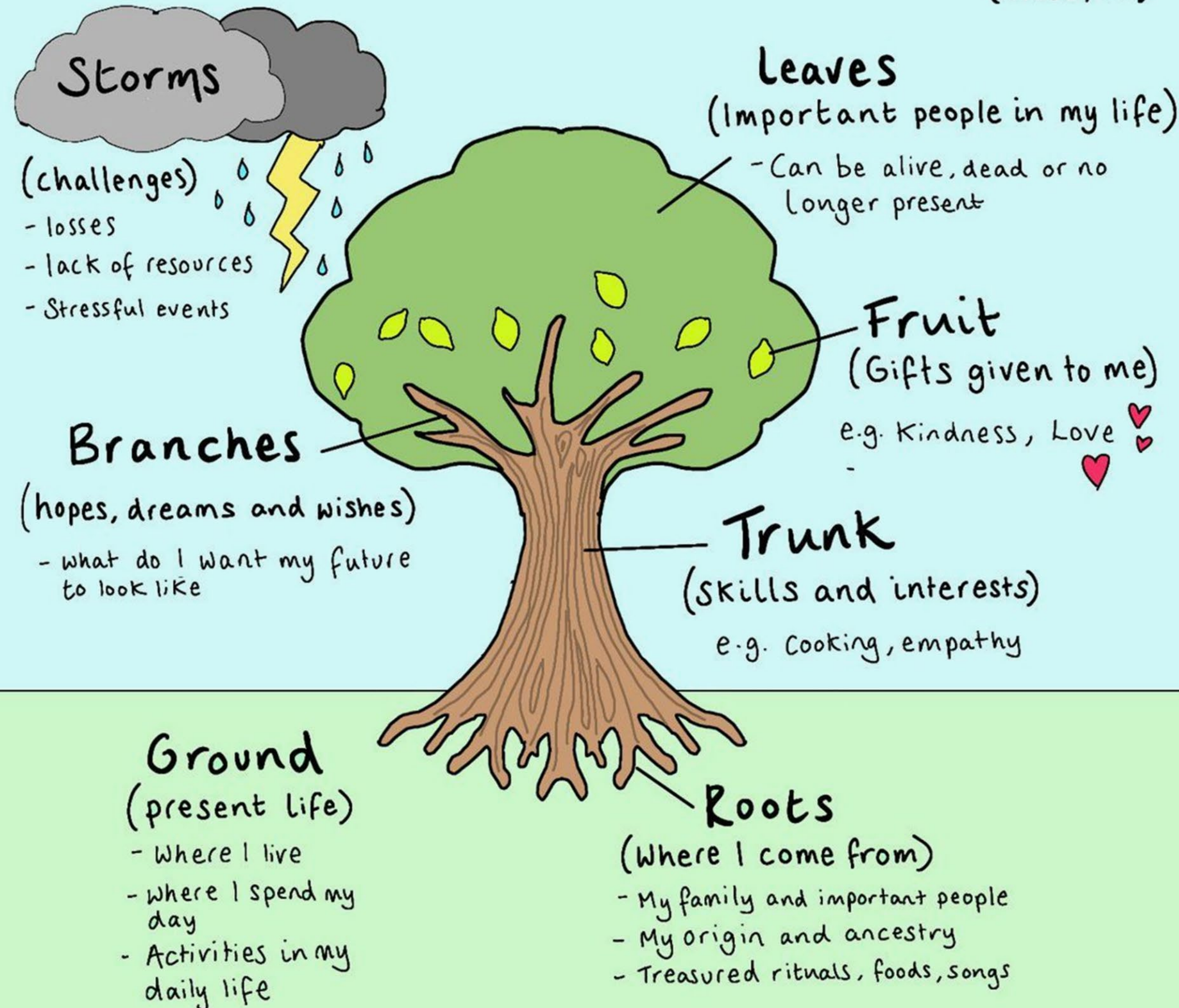
Feelings and emotions


① How to draw a...
Narrative Therapy Tree of Life
(Ncube, 2006)
Storms
(challenges)
- losses
- lack of resources
- Stressful events
Leaves
(Important people in my life)
- Can be alive, dead or no longer present
Fruit
(Gifts given to me)
e.g. Kindness, Love
Branches
(hopes, dreams and wishes)
- what do I want my future to look like
Trunk
(skills and interests)
e.g. Cooking, empathy
Ground
(present life)
- Where I live
- where I spend my day
- Activities in my daily life
Roots
(Where I come from)
- My family and important people
- My origin and ancestry
- Treasured rituals, foods, songs
Illustrated by Juliet Young
@creative.clinical.psychologist

Health/ eating changes/ control?

Using food goals?

Routines and pleasure from food



Food providers/ sharers/ recipients of

Giving/ sharing of food as a sign of care

Skills, caring role, knowledge

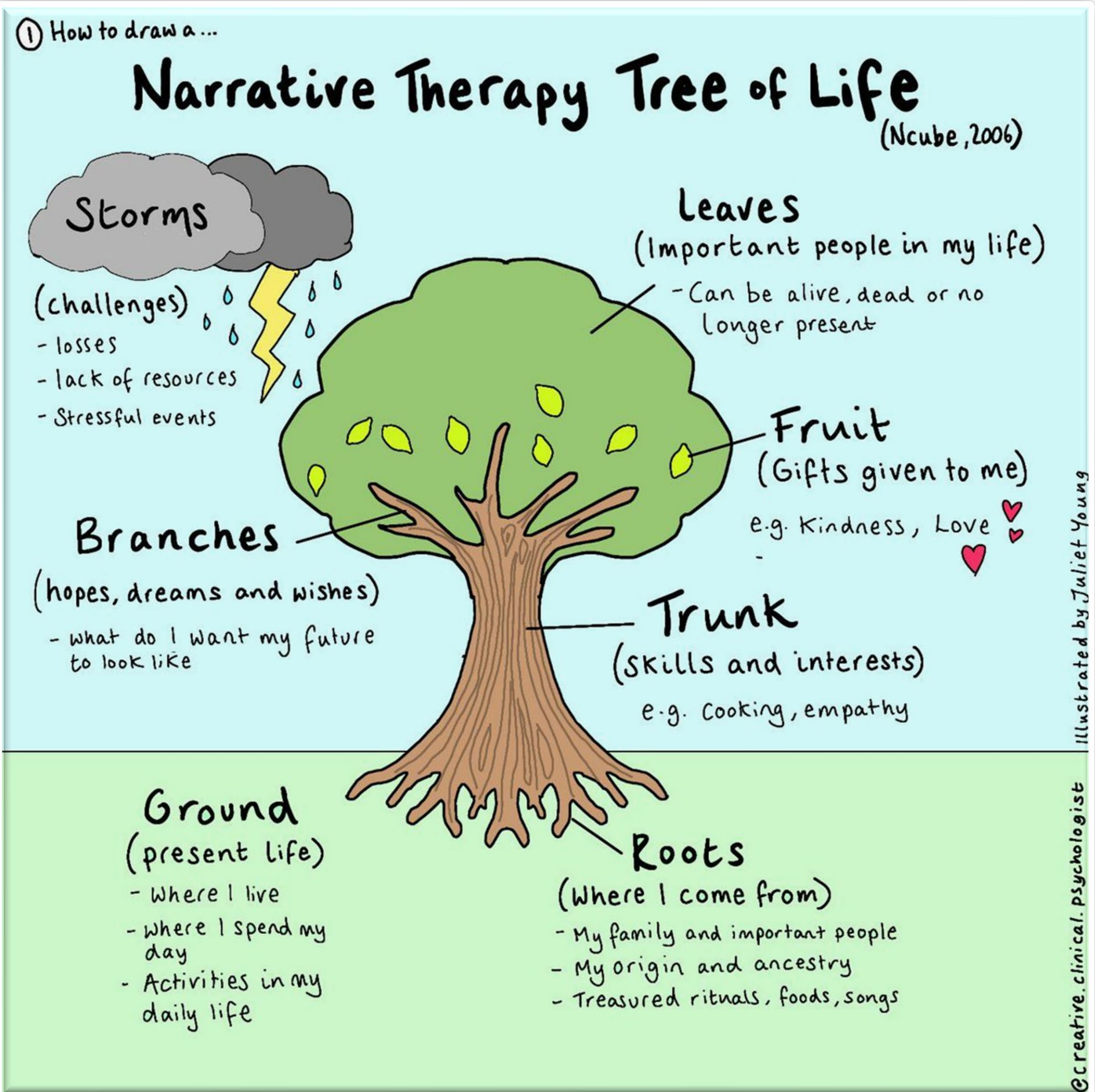
Food customs, memories

Feelings and emotions

Autonomy

Activity

Physical sensations



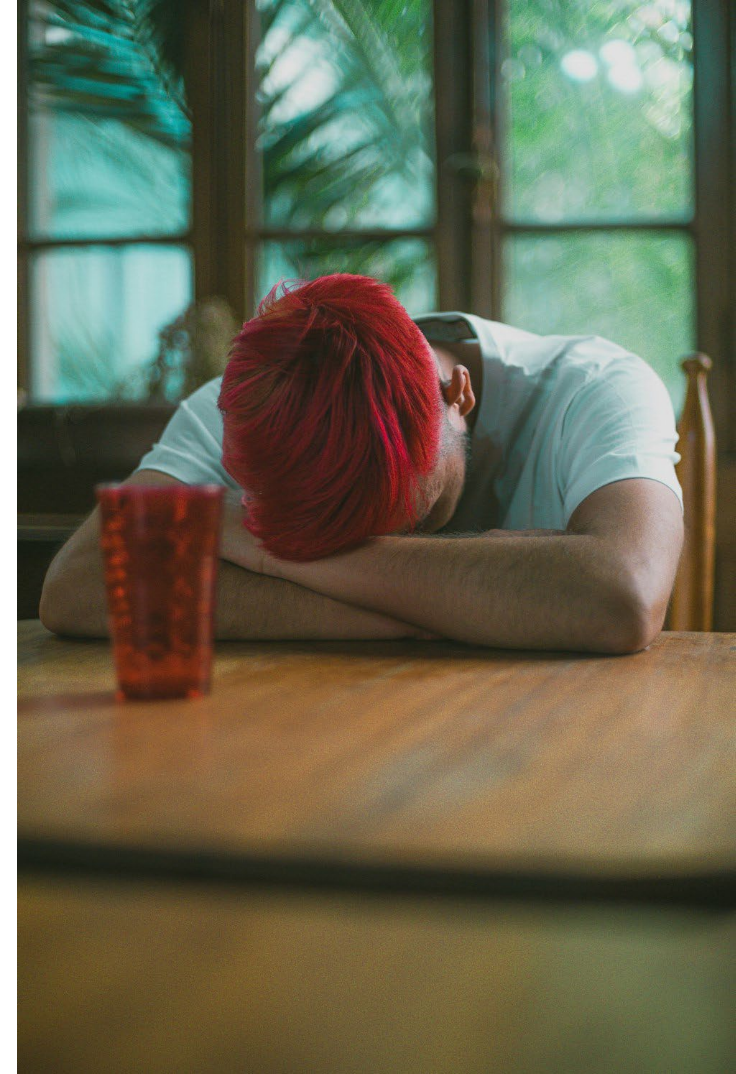
Relationships

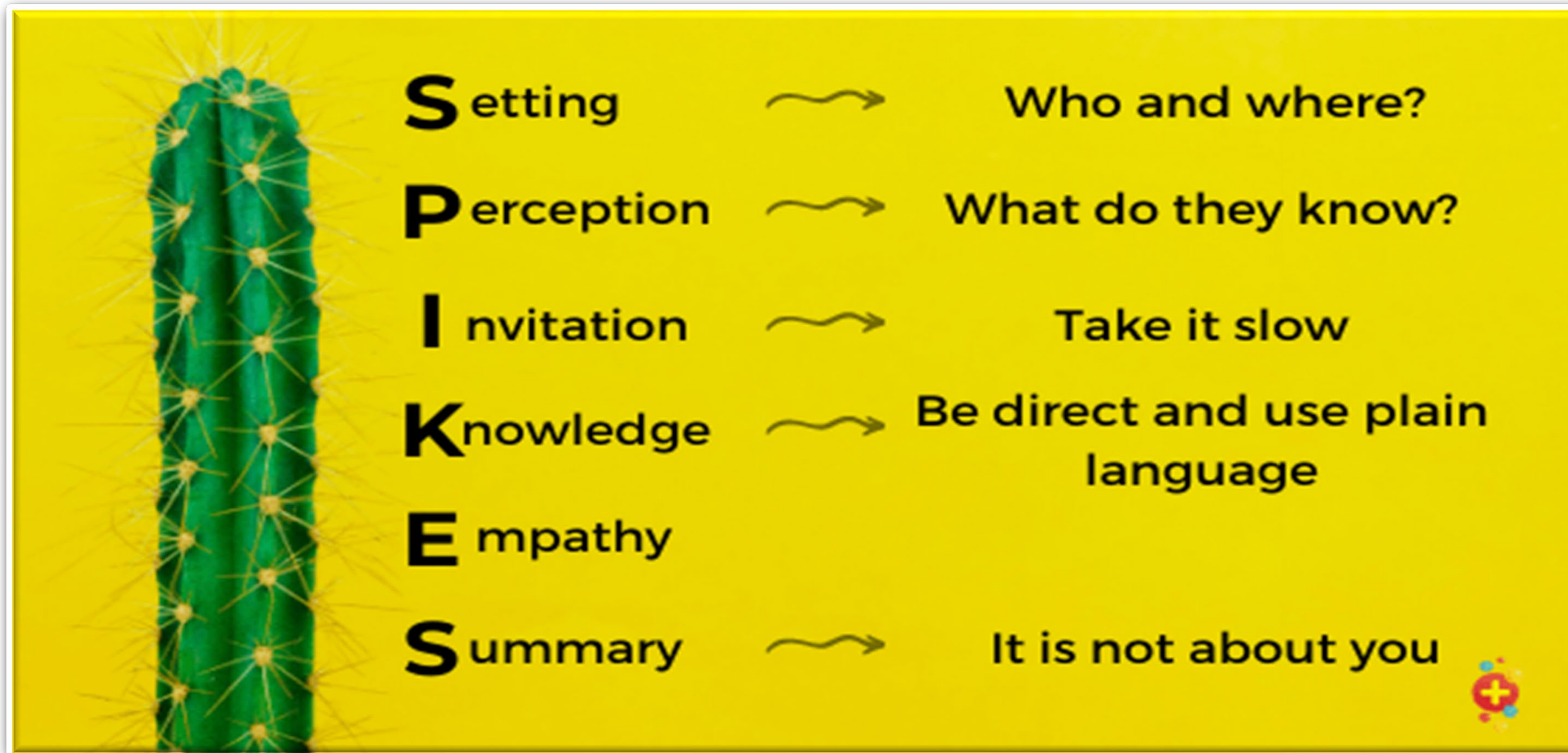
Cognition

Self Identity

MOST COMMON EATING CONCERNS

- Being influenced by HCP / family / friends / caregivers.
- CAUTION! Language and timing are really important. Trust is key.
- Be realistic – adequacy over perfection.
- Quality of Life.
- Takes time – food is THE most important issue for some patients at certain times.





Communication skills: breaking bad news in the clinical setting. R Radziewicz 1, W F Baile PMID: 11475881

THE SAGE & THYME MODEL

SETTING — If you notice concern - think first of the setting, create some privacy - sit down.

ASK — "Can I ask what you are concerned about?"

GATHER — Gather all of the concerns - not just the first few - "Is there something else?"

EMPATHY — Respond sensitively - "You have a lot on your mind."

TALK — "Who do you have to talk to or support you?"`

HELP — "How do they help?"

YOU — "What do YOU think would help?"

ME — "Is there something you would like ME to do?"

END — Summarize and close - "Can we leave it there?"

HOW PROFESSIONALS SHOULD COMMUNICATE

" Message to professionals: You can't make it better, but you can make it easier."

" I believe that people have defences for a reason, and what is important is to make it safe enough for them to let those defences down, even if only for a brief conversation."

" Be honest and say it how it is, but say it as gently as possible."

Study participant, living with MND

MNDA website

RCSLT DECISION-MAKING PROCESS

Eating and drinking with acknowledged risks: Multidisciplinary team guidance for the shared decision-making process (adults)

September 2021

WHAT WE *CAN* DO TO HELP

- Range of support at home
- Strategies for dehydration / constipation / hunger / thirst
- Support with gastrointestinal symptoms or changes
- Reduce risks of secondary problems – overdosing of nutrients, developing pressure areas, UTI etc.
- Access to Dietitians and supportive products / medication / literature
- Experts in nutritional products – it’s not straightforward!

STRATEGIES FOR HUNGER – FOOD FIRST

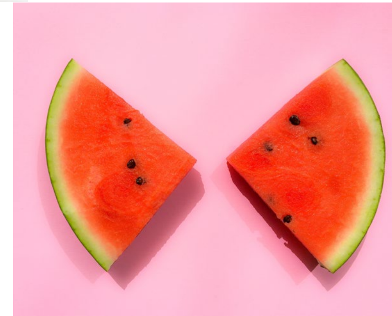
- Provide diet sheets and tips to meet their nutritional needs through food

- Treating poor appetite
  - Consider portion size
  - Very small portion sizes of high energy foods
  - Eat 6-7 times a day

- Maximising nutritional content – Food Fortification
  - Add extra fats / oil / butter / margarine
  - Use full fat milk
  - Add cream / sugar / jam / honey

STRATEGIES FOR HUNGER – FOOD FIRST

- Texture
- Type i.e. sweet v savoury
- Soft
- Cold foods for nausea
- Citrus / mint / ginger
- Avoid cooking smells
- Fresh air
- Sit out or at the table
- Avoid distraction or socialise
- Fluid intake
- Alcohol?
- Oral nutritional supplements?



DIETITIANS – EXPERTS IN NUTRITIONAL SUPPLEMENTS

- To bridge the gap between what the patient can eat versus what their needs are
- Range of supplements are available
- Dietitians can identify what is best suited for each patient

AIDS TO ENJOY MEALS

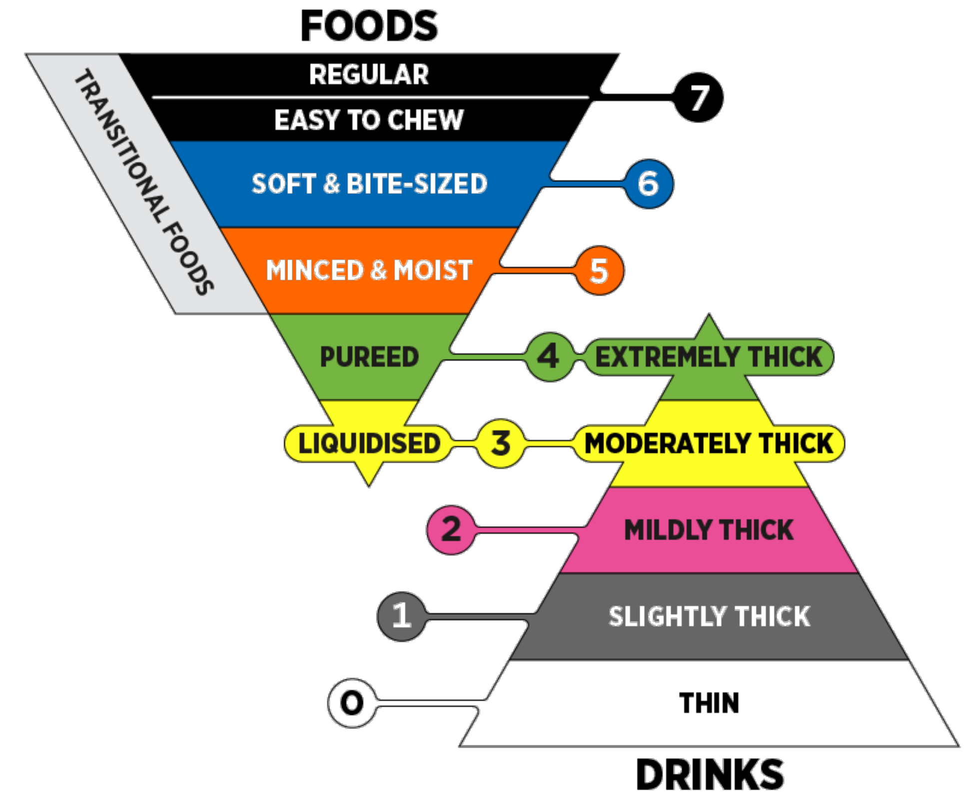
Help patients retain independence and enjoy family meals

- Liaise with Occupational therapists
- Use adapted cutlery / crockery

https://livingmadeeasy.org.uk/category/at-home/eating-and-drinking/cutlery/product/good-grips-weighted-utensils

SUPPORT: SWALLOWING CHANGES

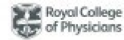
- Work with the Speech and Language therapist for texture modified diet as dysphagia progresses
- Dietitians support carers transition from normal diet to texture modified diets



SUPPORT: COMMON CONCERNS

Concern	Reason	Tips
Constipation	Reduced food /fibre intake Poor fluid intake Reduced mobility Medication Anxiety	Add fibre Fibre-based supplements Laxatives/ Stool softeners/ Suppositories Fluids (as per SLT)
Dehydration	Dysphagia Poor acceptance of thickened fluids Salivary issues	Fluids (as per SLT) Higher moisture content (thick soups / sauces, yogurts, custards, milky puddings) Oral nutritional supplements Subcutaneous or IV fluids Ensure no diuretic medication
Thick saliva/ mucus/ drooling	Weakness of mouth muscles Poor lip seal NIV Dehydration	Correct head position Suction / cough assist machine Fluids are regular intervals Sialorrhoea: Hyoscine, glycopyrronium, botox Thick saliva: Carbocisteine, humidifiers / nebulisers

ACCESS TO DIETITIANS & LITERATURE



Royal College of Physicians

Supporting people who have eating and drinking difficulties

A guide to practical care and clinical assistance, particularly towards the end of life

Report of a working party

First Community Health and Care

NHS

First Dietitians

Finger Foods

Finger foods are foods which are easy to be eaten by hand. They can prolong independence and dignity, or simply help increase calorie intake by easy snacking. They can be particularly helpful for people who have small appetites, find the use of cutlery difficult, or those who are finding it harder to identify foods (such as for people with dementia).

If you or the person that you are supporting have difficulty with specific textures, we recommend that you seek advice from a health care professional such as GP, Dietitian or Speech and Language therapist before introducing new foods.

Breakfast

- Cereal bars
- Toast with preserves
- Teacakes
- English muffins
- Flapjacks
- Sandwiches or bagels
- Crumpets
- Dried or fresh fruit
- Yoghurt in a tube
- Mini sausages
- Toast with mashed fish
- Boiled egg
- Eggy bread squares
- Omelette sandwiches
- Banana dipped in yoghurt
- Apple slices with peanut butter
- Dry finger size cereal (e.g. ...i-Weetabix)
- Shre...
- Pa...

Lunch and Tea

- Chicken drumsticks
- Mini sausages
- Mini burgers
- Meatballs
- Kebabs
- Mini quiches
- Frittatas
- Mini pies
- Mini fishcakes, fish goujons, fish sticks, crab sticks
- Cold smoked fish pieces
- Small pieces of meat
- Boiled egg
- Scotch eggs
- Pizza slices
- Mini spring rolls

PFD_TS076 Finger Foods v1 Review Date April 2024

First Community Health and Care

First Dietitians

100 Calorie Boosters

NHS

The following examples are approximately 100 calories each. These boosters could be added to meals to fortify them, or eaten as a snack.

Try to have an additional five boosters every day, as snacks or added to your meals, to help increase your intake. An extra 500 calories a day may help you to stop losing weight and/or promote weight gain.

Snack and drink ideas*

- 2 digestive biscuits
- 2 Jaffa cakes
- 1 French Fancy
- 1 slice of malt loaf
- 1 crumpet
- 1 cereal bar
- 4 squares of milk chocolate
- 1 bag of crisps
- 1 ½ boiled eggs
- 1 snack-sized sausage roll
- 1 slice of bread and butter
- 25g mixed nuts
- 1 banana
- 30g dried fruit
- 250ml orange juice
- 200ml whole milk

...soups and snacks

- 1 tablespoon of peanut butter
- 2 tablespoons of skimmed milk powder
- 50ml coconut cream
- 1 tablespoon of butter/ margarine
- ½ an avocado

...snacks*

- 2 tablespoons of crème fraiche
- 2 tablespoons of double cream
- 2 tablespoons of condensed milk
- 2 scoops of ice-cream
- 1 tablespoon of mascarpone
- 4 tablespoons of evaporated milk

First Community Health and Care

NHS

Eating and Drinking at the End of Life: Information for Carers and Families

In the final stages of a life-limiting illness, when someone is approaching the end of his or her life, the focus of care for that person may change and tends to be centred on helping them to be as comfortable as possible.

Food and drink

At this time, people often experience a decrease in appetite and a loss of interest in food and drink.

This can be worrying for families and carers, but it is a natural and expected part of the dying process. Most people at the end of life do not experience hunger or thirst. The body is slowing down, and if someone eats or drinks more than they really want to it can cause them discomfort.

Families and carers may worry about the effects of reduced food intake or dehydration on the person they are caring for and it is natural for families to want to continue providing nourishment at this time.

Nutrition or nourishment?

When someone is at the end of their life, meeting their nutritional needs may become less important than providing comfort. Consider whether just offering a small amount of the person's favourite food and drink can provide that comfort, rather than focusing on the need to consume a larger amount to meet nutritional requirements.

When someone is being **tube fed** they should be reviewed regularly to check that the benefit of feeding is not outweighed by any side effects.

In the last days of life **hydration** will be assessed by your community and discussion should be had about the risks and benefits of hydration options. Providing regular mouth care can often help with feelings of thirst should the person no longer be able to swallow food or fluid.

Prescribed nutritional products are not generally recommended as they do not contain anything which cannot be found in food, and most people seem to prefer the flavour of ...

Use your local Dietetic service!

ACCESS TO SUPPORTIVE PRODUCTS

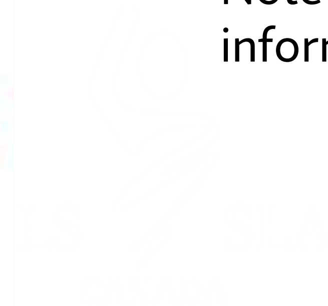
Eating and drinking with motor neurone disease (MND)

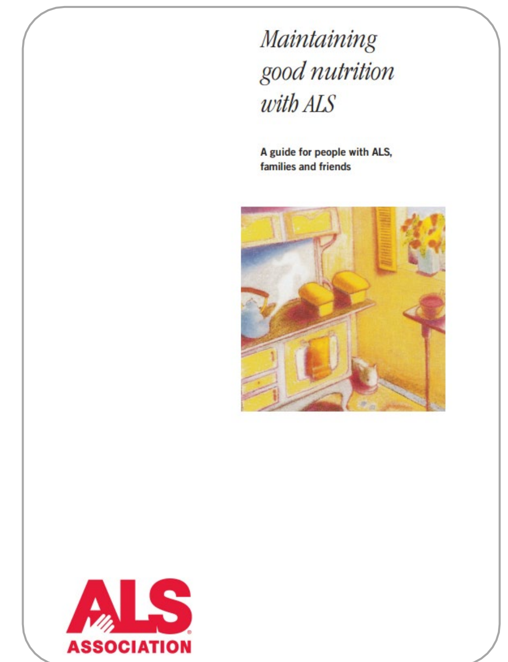
Information, tips and easy-swallow recipes

ACCESS TO DIETITIANS

- First Choice always; your local Dietetic service and BDA.

Note other sources of information (caution):





IMPORTANT!

- If a patient is undecided regarding tube feeding:
  - Continue with support and regular monitoring
  - Revisit decision at regular intervals

- Consider:
  - Completing Advance Decision to refuse treatment
  - ReSPECT form so all health professionals are aware of ceiling of care

- **Always respect wishes!**

USEFUL RESOURCES

- Nutrition in palliative care | Hospice UK
- Find out your compassionate superpower score! | Hospice UK
- Food Facts (bda.uk.com)

MND patients and their carers were asked – 'What does hope mean to you?'

- Article supporting hope at the end of life - Paula Gawthorpe, Nurse Lecturer, School of Health and Social Work, University of Hull
  https://blogs.bmj.com/ebn/2018/05/07/supporting-hope-at-the-end-of-life/

Useful reading

- Motor neurone disease: assessment and management NICE guideline NG42 Methods, evidence and recommendations February 2016
  https://www.nice.org.uk/guidance/ng42/evidence/full-guideline-pdf-2361774637
- NICE – National Institute for Health & Care Excellence
  https://www.nice.org.uk

Food for Life and Palliation (FLiP)': a qualitative study for understanding and empowering dignity and identity for terminally ill patients in Asia
Paul Victor Patinadan,[1] Geraldine Tan-Ho,[1] Ping Ying Choo,[1] Casuarine Xinyi Low,[2] and Andy Hau Yan Ho [1,3,4]

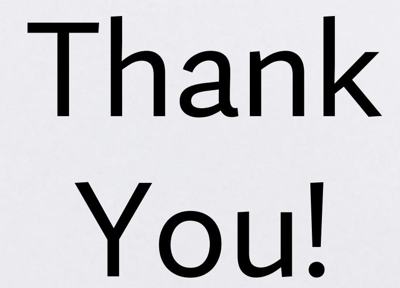
MND Association resources

- Infographic – NICE Quality Standards for MND
  https://www.mndassociation.org/app/uploads/2022/03/NICE-Quality-Standards.pdf
- Infographic – Multidisciplinary teams
  https://www.mndassociation.org/app/uploads/2021/09/77401_MNDA_Infographic_MDT_v4_HR.pdf

Care resources

- Living with motor neurone disease
  https://www.mndassociation.org/app/uploads/2015/07/Living-with-MND-STANDARD-PDF-Oct-20-1.pdf

- DOH 2008, Regulation 14 of the Health and Social Care Act 2008. "providers must make sure that people have enough to eat and drink to meet their nutrition and hydration needs and receive the support they need to do so".
- Shaw C and Eldridge L (2015). Nutritional considerations for the palliative care patient. International journal of Palliative Nursing vol 21, no 1 p 7-15
- https://www1.racgp.org.au/ajgp/2022/may/the-last-12-months-of-motor-neuron-disease
- https://www.tandfonline.com/doi/full/10.2147/PPA.S37851
- https://onlinelibrary.wiley.com/doi/full/10.1111/hex.13786


Thank
You!