



Food - The four letter word in end of life care

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Life & Death
Matters

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The blessings of team!



Food can cause conflict and frustration...
for family, staff...

...and for the
dying person



~~Simple~~ Profound truths of nutrition

Dr Michael Downing

- What a patient can eat and drink will become less.
- Eventually both eating and drinking will become zero.
- Stopping eating and drinking is natural to the dying process.

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- What is nutritionally right at one stage may be very wrong at another.
- Aggressive nutritional therapy in advanced disease often contributes to difficulty in symptom control.
- Food can cause more discomfort than pleasure.

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- What one likes is more important than what is 'right' or 'of value'.
- What works is not necessarily what one likes or what is 'right'.
- The atmosphere around eating is more important than what is ingested.

Today's Outline

- The research behind the “TRUTHS”?
- Language and discussion
- Analogies and metaphors
- Culture (less focus)
- Cancer cachexia (more focus)



Peter

Peter is a 72 year old retired Coast Guard officer. He and his wife Eleanor recently celebrated their 49th wedding anniversary. They have one child – a daughter, Marianne.



Peter

Four months ago Peter presented to his family physician with fatigue, weight loss and persistent cough. He was diagnosed with metastatic non-small cell lung cancer, and began palliative chemotherapy. He has tolerated this well and recent imaging shows some tumor shrinkage.



Peter

On your visit with Peter today he is accompanied by both Eleanor and Marianne. He does not seem distressed, but has clearly lost weight. When you ask how he is feeling, he smiles weakly and responds 'Oh, pretty well, I guess, all things considered.'

Marianne, who has obviously been itching to say something, can hold her tongue no longer:



Peter

“Dad will never complain about this, but I’m really worried about his appetite. Every day Mom makes his favourite foods, and after three bites Dad says he’s full. The oncologist says the tumors are shrinking, but Dad is shrinking right along with them. He was never a big man, but now he’s getting skinnier by the day! Isn’t there something we can do about this?”

Anorexia

Anorexia is the loss of appetite, the decreased interest in food and eating.

(Today's discussion is concerning anorexia at end of life only!)

Cachexia

- Involuntary weight loss ($\geq 5\%$ from baseline) with loss of muscle $>$ fat.
- Common in advanced cancer and some other severe, progressive illnesses (e.g. COPD, CHF, AIDS)

Setting the stage

“Appropriate nourishment across the life span”

Let's play: “Eating at the family reunion....”



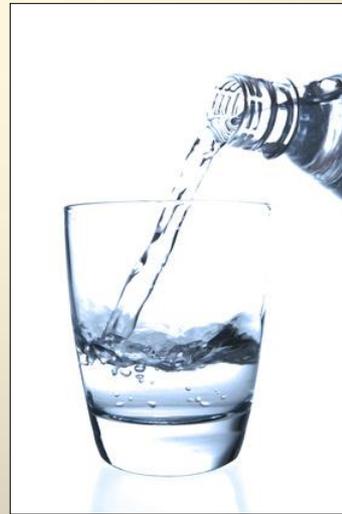


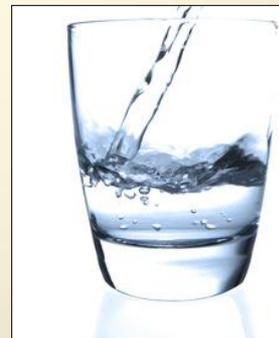












Let's mix the food up.... And give people food that they do not normally eat or like to eat.... What happens?



Can we feed you this fruit
and custard?

Why?

What is the problem?





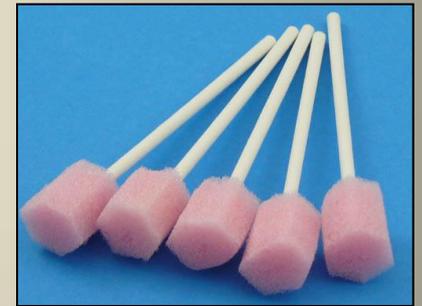
How do you like this food?

How about if we gave it to you at every meal?





How does this food look for you?
What if we gave it to you daily?
Would you eat it if we *really really really* wanted you to?



Hey kids, how about some “Ensure” and mouth care to keep those teeth all shiny?

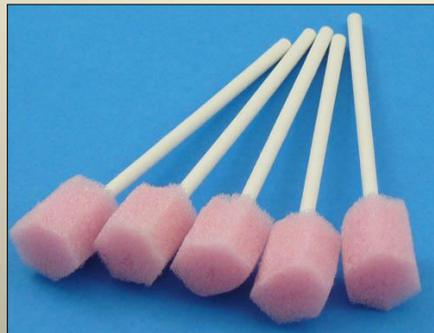


We have some good food for you!
A little fruit, and some cleansing water.
How will you be feeling in a few hours?



“Come on Mom,
just a little more...”





“Come on dad,
just take a sip!”

Conclusion

- Our need for nourishment changes throughout our life
- It also changes when we are sick...

Decreased Nutritional Intake - Multiple Contributing Factors

- Uncontrolled symptoms (pain, dyspnea, nausea)
- Fatigue
- Dry and/or sore mouth
- Difficulty/pain with swallowing
- Aversion to food odors/tastes
- S/E of meds - N/V, Constipation
- Psychological factors: depression, anxiety, stress
- Cognitive impairment
- Cancer Anorexia Cachexia Syndrome (CACS)

Cancer & Appetite

Systemic Inflammation

- IL-1
- IL-6
- TNF- α



- Neural and hormonal signaling between the brain and GI tract
- Controlling appetite and gastrointestinal function



Nutrient Intake

Why won't he eat?

Translation...

- Cancer causes a variety of different problems which tend to reduce people's food intake.
- The body's reaction to the presence of tumor can directly reduce one's appetite,
- But the cancer and cancer treatments also have many other effects that indirectly impact food intake as well

“Is he starving?”

The Physiology of CACS vs. Nutritional Deficiency

	Starvation	Cancer ACS
Metabolic efficiency	↑ “Get more km per liter”	↓ “Get less km per liter”
Muscle breakdown	↑	↑↑↑
Fat breakdown	↑↑↑	↑

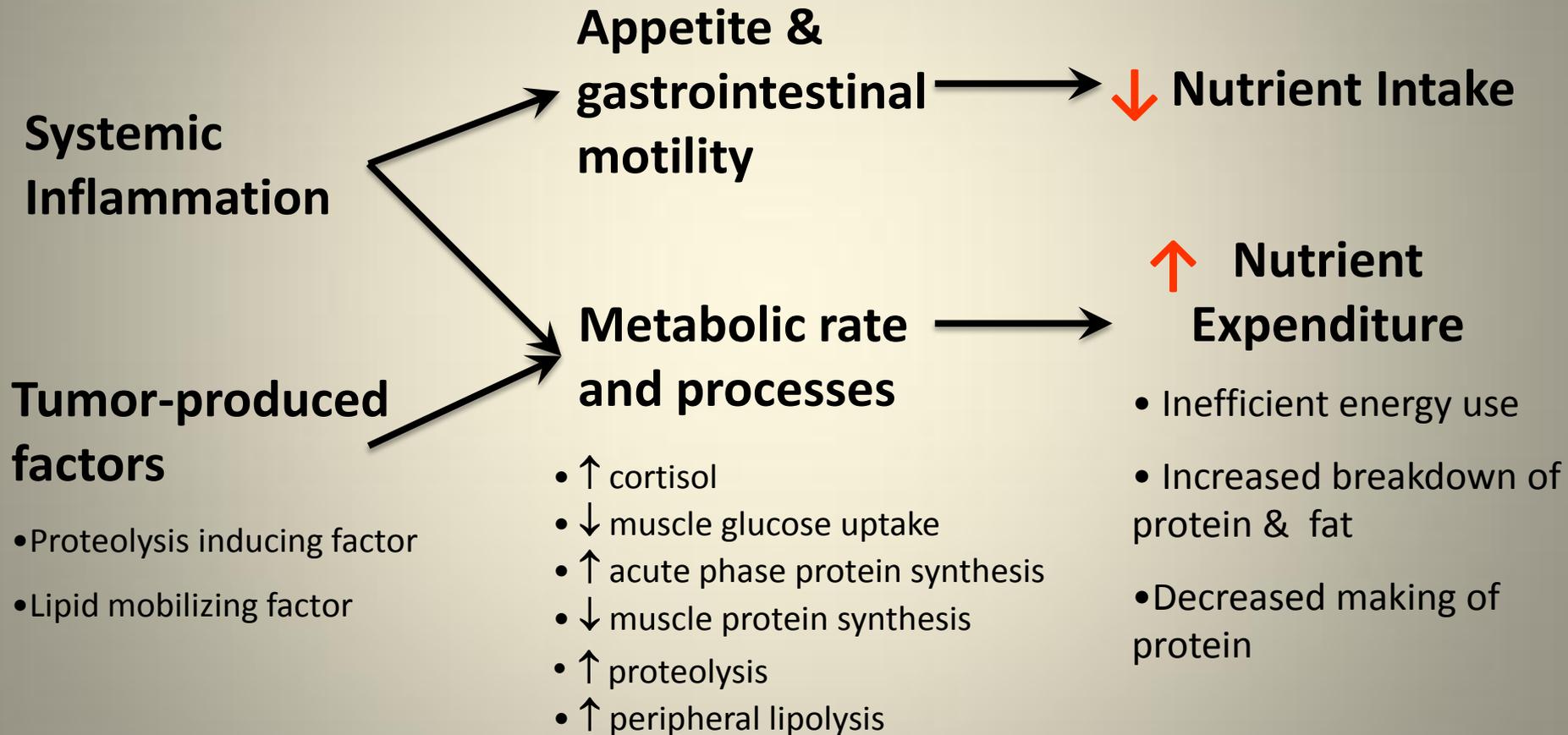
So is he starving?

Translation...

- Cancer Cachexia is different than starvation.
- In starvation, the body seeks to conserve energy and nutrients. In cachexia, the body spends them even faster than usual.

“Why is he losing weight?”

Weight Balance = Intake – Expenditure



Then why is he losing weight?

Translation...

- Inflammation produces changes which accelerate muscle breakdown, and impair muscle rebuilding.
- This becomes a vicious cycle (less muscle → less muscle-building hormone → less muscle)
- On top of that, muscle does not use its energy resources efficiently

“Would “Ensure” or a feeding tube or an IV with food in it help?”

Supplemental Nutrition Doesn't Help

Among patients undergoing non-surgical cancer treatments:

- Parenteral nutrition - net harm
- Voluntary supplements - no effect on mortality

Does supplemental nutrition affect clinical outcome? A Systematic Review
Koretz, Am J Gastroenterology, 2007

“In summary, ... little evidence was found for benefits
...in terminally ill cancer patients...”

Enteral and Parenteral Nutrition in Terminally Ill Cancer Patients: A Review
Dy, Am J Hospice Palliative Med, 2006

“Would “Ensure, ”feeding tube or IV with food help?” *Translation...*

- Unfortunately, not much.
- Supplemental artificial nutrition (e.g. feeding tube) causes at least as much harm as good.

“Would medication help him gain weight?”

Pharmacotherapy for CACS

Agent	Appetite	Lean Body Mass	Notes
Megestrol acetate			<ul style="list-style-type: none">• strongest evidence
Steroids			<ul style="list-style-type: none">• benefit appears to be short-term (weeks)
Cannabinoids			<ul style="list-style-type: none">• not well tolerated by many patients
NSAIDs			<ul style="list-style-type: none">• mixed results in clinical trials

“Would medication help him gain weight?”

Translation...

- Cachexia is caused by a combination of many things *therefore* no single treatment will fix all the causes.
- Combining multiple medications may help, *but* we don't know what would be most safe and effective.
- Megestrol and a steroid may increase his appetite and energy for the short term, *but* won't increase his muscles or strength.

“Does this mean that he will die
sooner?”

“Does this mean that he will die sooner?”

- **People who have anorexia or cachexia or both have poorer survival than those who have neither.**
 - Lasheen, *Supp Care Cancer*, 2010

“Does this mean that he will die sooner?”

Translation...

- Both anorexia and cachexia are bad news.
- Whether he has one or both symptoms makes little difference. The survival appears to be about the same.
- If he had a good appetite and no weight loss, then he might live a few months longer.... it is less about what we do, and more about what is happening in the body.

“Is he dying because he’s not eating?”

CACS is a poor prognostic factor,
and may contribute to the *mechanism* of death,
but is not a *cause* of death.

“Is he dying because he’s not eating?”

Translation...

No, he is not eating

because he is dying.

“That is good information, but Mom just does not understand why he is losing weight?”

Analogy – ideas????

- He is a retired coast guard officer
 - Analogy to explore? A sinking ship

Welcome to the Coast Guard....



Dr Bruera's analogy

“Tell your patient that her stomach is on strike!”

Other ways of “linguaging” this?

“Okay that helps, but Mom fed dad three meals a day for fifty years! What is she supposed to do now?”

Don't fire the caregiver!
Change the job description!

Other ways to nurture, to be with, to witness

Basket of comfort measures









Dialogue and discussion

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(Dr Michael Downing)



Food for Thought

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- What is nutritionally right at one stage may be very wrong at another.
- Aggressive nutritional therapy in advanced disease often contributes to difficulty in symptom control.

Food for Thought continued...

- Food can cause more discomfort than pleasure
- What one likes is more important than what is “right” or “of value”.
- What “works” is not necessarily what one “likes” or what is “right”.
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References

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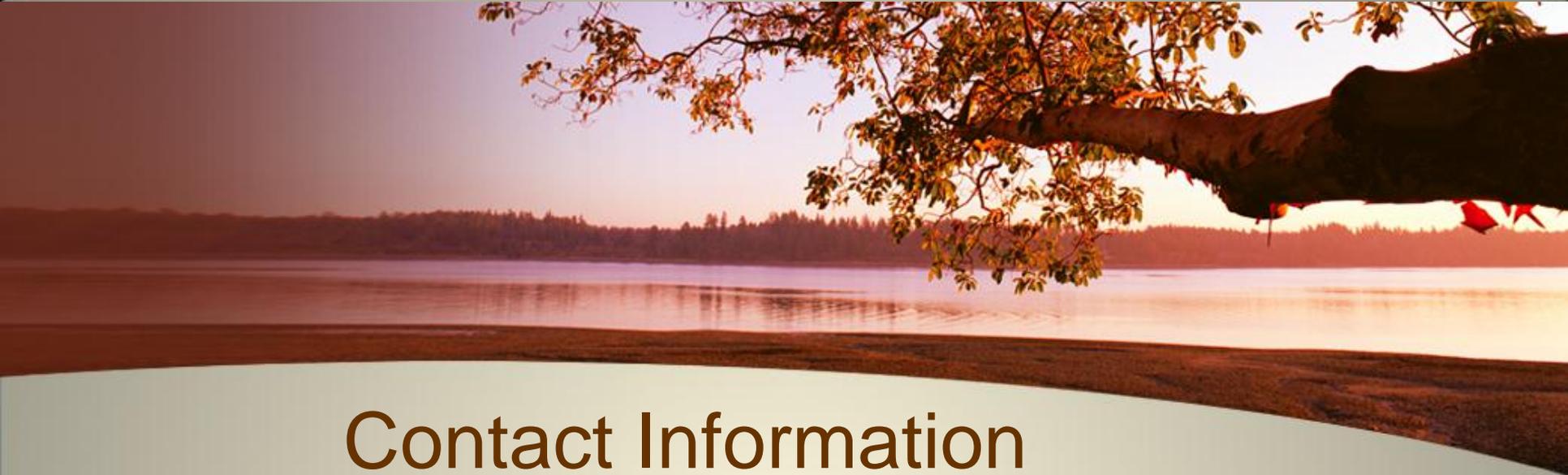
Does Enteral Nutrition Affect Clinical Outcome? A Systematic Review of the Randomized Trials

Ronald L Koretz MD¹, Alison Avenell MD, MRCP, FRCPath, MB, BS, MSc², Timothy O Lipman MD³, Carol L Braunschweig PhD, RD⁴ and Anne C Milne MSc, SRD⁵

Enteral and Parenteral Nutrition in Terminally Ill Cancer Patients: A Review of the Literature

AM J HOSP PALLIAT CARE October 2006 vol. 23 no. 5 369-377

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