

# **Palliative care patients experiences of diminished appetite or food intake, and/or cachexia – a narrative literature review**

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*It is a worry  
The more I eat  
the longer I can go on*

*If you don't eat  
you won't last long*

*I know what the ultimate is  
Think of prisoners of war  
They didn't get food  
Look where they ended up*

# Food

- Physical well-being
  - Grow/maintain
  - Heal
  - Physical strength
- Social meaning
  - Shared meals
  - Identification
- Emotional meaning
  - Comfort
  - Hobby



# Lowered appetite/weight loss

- Common symptoms in patients in palliative care independent of underlying diagnosis
- In newly diagnosed patients with cancer approximately 50%
- In advanced cancer disease >70% (Poole 2002)
- Concern 36-43% (Hopkinson 2006)

# Physical loss

- To see your physical body change –
  - Wellcome at first?
  - Later loss of familiar physical body
  - Associations between starvation and cachexia
- Wanting others to acknowledge – or not?
- To feel your body weaken
  - Hard to get, prepare and eat food
- Smells causes nausea or loss of appetite
- Appetite, desire or disgust – a fickle phenomenon

*“Now I´ve lost all  
this weight I really  
don´t like my  
partner to see it.  
You can see all the  
lumps and bumps  
more because I´ve  
lost the weight. It´s  
not very pleasant to  
look at”*

*Bob, Hinsley 2007*

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# Social loss

- Beeing with others most often includes sharing meals or drinks.
  - How do you take part in social life if you are not able to eat as before?
- Cooking and serving food is a way of showing love.
  - Rejection of the food served can be experienced as rejection of the person cooking and serving.
  - Patient often eat to please others – to avoid conflict with carer, and to decrease the sense of beeing a burden to the carer.



*Sometimes I force food  
down. It's hard to  
force it down. I know  
she gets upset about it.  
I know she goes and  
has a little weep  
sometimes.*

*She's put everything  
into it and I don't eat.*

*Patient 69, Hopkinson 2016*

# Emotional loss

- Food, prior a source of pleasure, is becoming a source of distress.
- Part of our identity – what kind of food we like

*Now I just hate eating.  
I wish I could get by  
without any eating at all.  
At the end of the meal I  
think to myself "I'm glad  
that's all over". It's a sort  
of punishment.*

# Strategies, coping

- To lower anxiety and distress
- Acceptance
- Resistance

*Listen*

*Listen carefully*

*Understand the restraints*

*If someone says*

*I can't face that*

*Accept*

*This is what the case is*

*Be understanding on that*

# What patients want us to do

- Acknowledge the problems –respond to it
- Educate patients and families
- Introduce supportive intervention if possible
- Explore the way patients and family members self-act/cope - encouragement (Reid 2010, Hopkinson 2006)