“I don’t enjoy food like I used to”

The views of people with dementia about mealtimes

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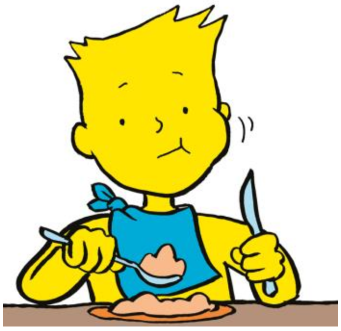
Funded by the Miss EC Hendry Charitable Trust

December 2015



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Background:

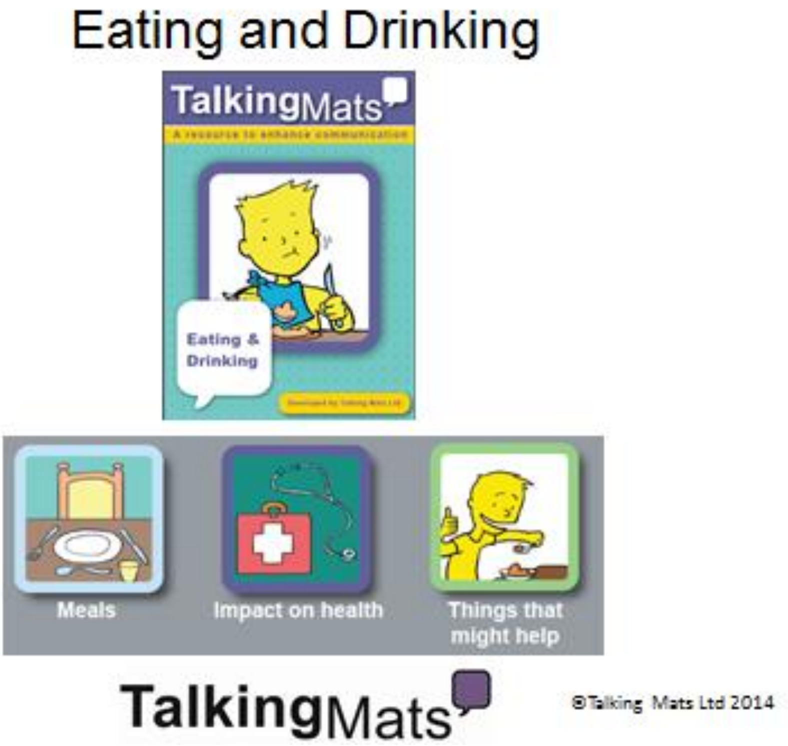
Talking Mats is a well-researched visual communication tool which was developed by a team of Speech and Language Therapists to help people express their views. It has been used very successfully in a previous project funded by the Miss EC Hendry Trust to train family carers to use Talking Mats with their relatives. We are very grateful to the Miss EC Hendry Charitable Trust who funded this current dementia project.

One of the issues which has emerged from the previous Talking Mats and dementia projects, corroborated in other research and clinical studies, is that many people with dementia experience difficulties with eating and drinking and that it can affect people at any stage of dementia. (Markson, 1997)(Martin & Preedy, 2014)(Kellet, 2012) (Eating Well with Dementia A carers' guide, 2014).

Mealtimes involve two of our most fundamental human needs, the basic physiological requirements for food and drink and interpersonal involvement (Shune, 2015). Mealtimes are particularly important for people with dementia as they may develop difficulties both with eating as a source of nourishment and with the social aspects of mealtimes. They may experience a loss of appetite, dehydration from not drinking enough, changes in taste, difficulties with different textures, problems with cutlery, worries about where they eat etc. (Markson, 1997). It can be distressing for all concerned and can have serious implications for a person’s health and well-being (Maher, 2013).

However, it is crucial to find out the views of the person with dementia themselves as carers may often not realise the difficulties or may make decisions for the person. Wherever possible it is important to involve the person with dementia and give them decision-making power to decide what, where and when they would like to eat.

The Talking Mats team have recently developed a new resource specifically around Eating and Drinking (http://www.talkingmats.com/product/talking-mats-and-eating-drinking/



This resource includes 68 symbols divided into three main topics – **Meals**, **Impact on Health** and **Things that might Help**. The resource can be used to help people discuss different aspects of mealtimes and food. It is particularly useful in helping people understand the effect that their eating and drinking difficulties can have on their health.

There are several advantages of using the Talking Mats framework for group discussions involving people with dementia:

- It provides a shared framework for thinking about issues in a visual way that was easy for people to understand and engage with.
- It allows people to consider issues one at a time and communicate their thoughts to others.
- Having the visual and tangible images helps understanding.
- It gives people plenty of time to listen to one other and then express their thoughts without forgetting the specific issue being discussed.

Aim of project:

To gather information from the first-hand experience of people with dementia about changes in their eating and drinking.

Methods:

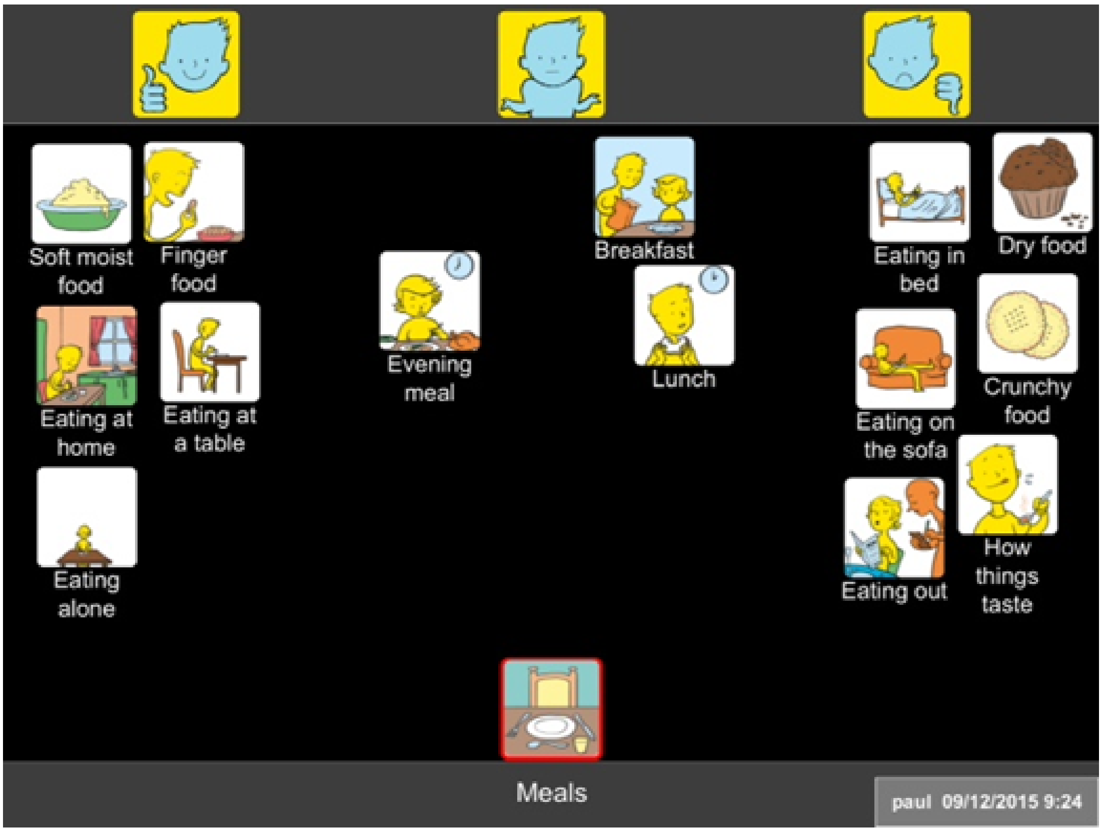
Joan Murphy led the project and was supported by James McKillop, a member of the Scottish Dementia Working Group, which is a national campaigning group, run by people with dementia. James is very familiar with Talking Mats and suggested the idea of investigating the views of other people with dementia about eating and drinking difficulties in a group situation.

We ran three focus groups as this is a method previously used by the Talking Mats team and found to be a successful way to allow people with communication and/or cognitive difficulties to express and share their views.

- The focus groups were run in three Alzheimer Resource Centres – Clydebank, Stirling and Motherwell. In total 13 people with dementia took part. In one venue three spouses also attended. A member of staff from each dementia centre was also present at each group.
- A selection of symbols from the Talking Mats Eating & Drinking resource were used to stimulate and focus discussions (see appendix).
- Participants were shown each symbol one at a time and asked to place it under the appropriate image at the top of the mat to indicate if they were ‘happy’, ‘unsure’ or ‘unhappy’ with each symbol.
- Each participant was given as much time as they needed to consider and then express their own views about each symbol and to share their views and experiences with others.
- All participants gave permission to video record the discussions in order for us to record their views.
- We collated and analysed the results of the discussions thematically.

Findings:

The image below is an example of one participant's mat about meals.



Those participants who had more advanced dementia found it harder to express their views but all appeared to enjoy the discussion and sharing their views with each other, sometimes agreeing, but not always. The following themes emerged from the discussions:

Mealtimes

For several people, their experience of mealtimes had changed since their diagnosis of dementia. Several said that they now skip breakfast and sometimes lunch

- *I just went off it [breakfast]*
- *Sometimes I'll take it [breakfast] sometimes I don't – I try to have it*
- *I can take it or leave it*

Where to eat:

Some found it more difficult to eat out since their diagnosis for various reasons including noise, distractions and unfamiliarity.

- *I can get embarrassed*
- *I don't like eating out now. It's too noisy for me*
- *too much distractions, televisions, too many people talking*
- *If it's family I don't mind but if it's strangers, or even friends, I don't like it*
- *I have difficulty with strange knives , forks and spoons – makes me slower and food gets cold and less tasty*
- *Some cup handles are difficult to hold*

Whereas others really enjoyed going out

- *I do enjoy all these cafes. It's great having company. You feel you're not alone.*

Changes in taste:

Almost all the participants talked about how their taste had changed both for food and drink.

- *I don't enjoy food like I used to*
- *Tastes have changed – I used to eat potatoes and mince for breakfast, dinner and tea [laughs] ….but its not the same*
- *I like a cup of a thing I would never have taken before ….of coffee*
- *I cannae stand anything with fizz now*
- *I can't describe exactly what it is, but it's the tongue. I can't clean it , I can't get rid of it*
- *It's just a bland taste*
- *He doesn't eat vegetables in the way he used to (Spouse)*

Some families had overcome the problem of lack of taste by going for more strongly flavoured food.

- *I now like tasty food*

- *We’ve got the time now that we didn’t have and can concentrate on [cooking] with flavours and different recipes*
- *She adds peppers and spices to my mince now*

Appetite:

This was another aspect that had changed for most participants

- *I rarely feel hungry. Looking at the mat I can tell my eating and drinking isn’t good*
- *Sometimes I don’t eat for 3 days - It doesnae bother me – I just don’t feel hungry*
- *I always used to like my chuck – I’m getting smaller portions now.*
- *I just tend to consume the food rather than enjoy it.*

Remembering to eat or drink:

Another key factor reported by most was the problem of forgetting to eat and drink

- *I don’t drink enough – I keep forgetting*
- *When [my wife] was at work she used to phone me up and ask if I’d eaten – that reminded me*
- *I’m forever getting rows for not eating enough*
- *I would forget but we’ve made a habit of drinking good quantities at specific times during the day*
- *My husband leaves food out for me to make sure I eat it.*

Forgetting to eat was connected to appetite and particularly noted by spouses

- *In 4 years C. has never said he’s hungry. Food to him doesn’t mean much. If he’d been living on his own, he might never eat (Spouse)*
- *He forgets to eat*

Thirst:

When asked specifically about drinking, thirst was noted as a significant change since diagnosis

- *I’m a lot thirstier now*

- *I drink a lot and I go to the toilet a lot*
- *I go to the toilet more than I ever did*
- *I do get a dry mouth*
- *I think we're all the same*

Texture:

The texture of food did not appear to have changed significantly for these participants and was simply a matter of preference.

- *Soft things are fine*
- *Not keen on runny stuff*

When discussing how they felt the changes in their eating and drinking had affected their health, three main issues were noted by all the participants.

Energy:

They all acknowledged that this was poorer than before their diagnosis

- *My energy's not good*
- *Mine's no right*
- *When my grandkids are up I have tremendous energy. I've always said, when they come up I feel like 19, when they leave I feel like 90. But mostly every day, not a lot of energy.*
- *Just not as energetic as I was*
- *Not too good*
- *Very, very bad*

Concentration:

Similarly, they all felt that their ability to concentrate was affected

- *It's poor – I need to have a variety of things to do*
- *Don't think I could watch a whole film*
- *Not easy. Maybe upset or not feeling well. I don't want anyone to come and see me*

- *I can't stand a lot of noise now. It just sends me doolally. I feel as if I've got to escape*
- *I felt bad with concentration because something can come into my head but it's only in and out as quick as that and if I don't get it out, it's gone. I just can't remember it for any length of time. It's just out. I can't help it.*
- *You know sometimes I'm in the middle of telling R. something and my mind just goes blank. And he'll say "can't you remember" and I'll say "no I can't remember" and then I start to cry because I get so frustrated.*
- *I do have moments like that as well.*
- *I never thought of that before until just now. This (symbol) has never left my hands since I picked it up and now I can understand what we're still talking about and what I want to say.*
- *Very difficult - I'm a writer. When I have a complex paragraph or sentence I'm lost.*

Sleep:

Sleep was a topic that the participants added and several wanted to talk about it For them there seemed to be a connection between sleep and eating and drinking.

- *I'm getting terrible dreams*
- *I don't sleep anywhere as much as I should*
- *The dreams that I have, when I do have a dream, are vivid, not horrible, but very vivid.*
- *I sleep too much*

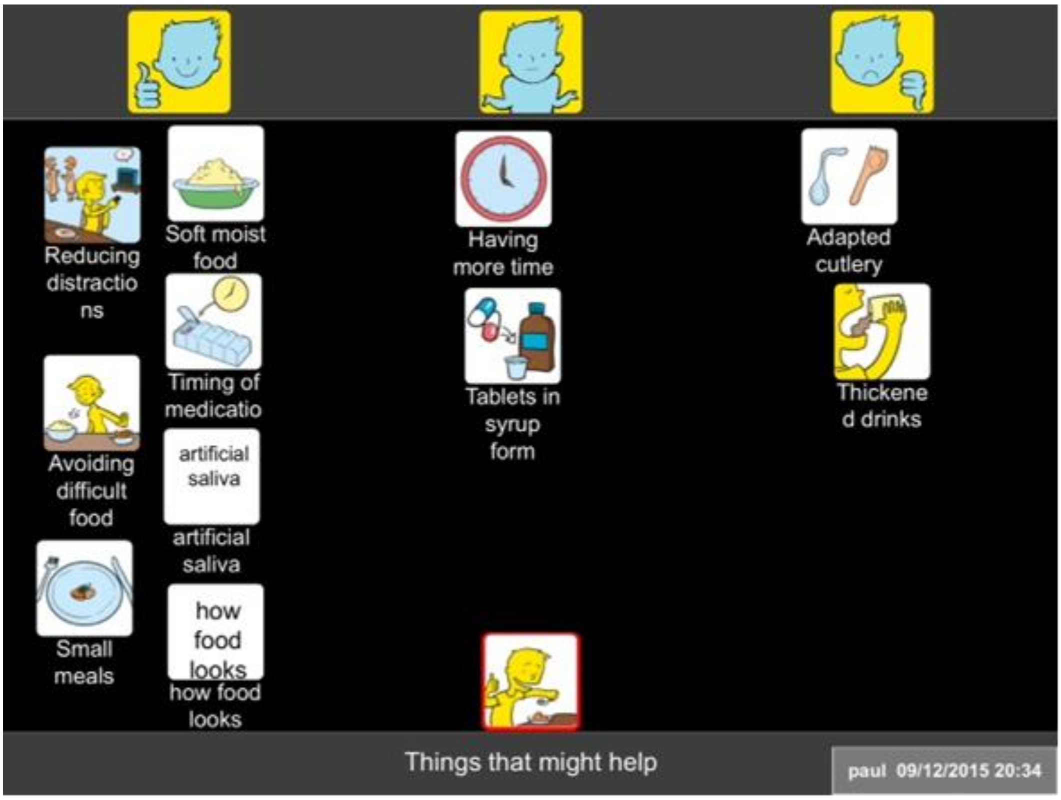
Things that might help

During the course of the focus groups participants discussed ways that they had found to help with eating and drinking problems. Several ideas were shared such as:

- reducing distractions like TV and noise when eating
- avoiding difficult food
- having more time
- getting involved in cooking with a partner

- adding additional flavour to food
- having food which looks attractive
- having smaller meals
- having medication in liquid form rather than as tablets
- being reminded by others to eat and drink
- going to familiar cafes or restaurants when eating out
- having own cutlery when eating out
- using artificial saliva if they have a dry mouth

The image below is an example of one participant's views about which strategies he thought might or might not help him.



A selection of symbols for things that might help is in the Appendix.

Discussion:

The people who took part in this study felt that there were significant changes in their eating and drinking since their diagnosis of dementia. For some, their experience of mealtimes had changed and several said that they now skip breakfast and sometimes lunch. For some this seemed to be related to forgetting to eat and drink, for others it related to changes in taste whereas for others these meals seemed to be simply less important. Forgetting to eat was particularly noted by the participants with dementia and confirmed by their spouses.

The social aspect of eating and drinking also changed for many of the participants and, given the importance of social engagement for quality of life it is important to be aware of the effects of changes in eating and drinking on mealtime dynamics. For some it may be that they are now less interested in the social aspect of eating with others at home. Others found it hard to eat out because of distractions and lack of familiarity while some felt embarrassed about eating out in front of strangers. Others still really enjoyed going out for meals but added that they preferred to go somewhere well-known to them. The shared mealtime may be a particularly crucial opportunity for social engagement as it plays a central role in our daily lives. Social relationships are central for not only enhancing quality of life, but also for preventing ill health and decreasing mortality (Maher, 2013).

Almost all the participants talked about how their taste had changed both for food and drink which in turn affected their appetite. Some families had overcome the problem of lack of taste by going for more strongly flavoured food. When asked specifically about drinking, thirst was noted as a significant change since diagnosis Their feelings about the texture of food did not appear to have changed significantly and was simply a matter of preference.

Three additional health issues which the participants felt were connected with eating and drinking were poorer energy levels than before their diagnosis, reduction in ability to concentrate and changes in sleep patterns.

Outcomes:

We hope that this project has benefited the individual people who took part in the group discussions by helping them to express their views and suggest things that might help. We have also collated their views and produced this report which may be useful to other dementia support groups. In addition we are writing blogs with specific themes of useful information and plan to disseminate the findings via articles for dementia magazines.

In the course of this project we have found other helpful resources including:

- Dementia & Sensory Challenges - Life Changes Trust (2014)
- Eating Well with Dementia A carers' guide (2014)
- Let's talk about dementia: speech and language therapy in dementia (2015)
- Communication and Mealtimes Toolkit (2012)
- Talking Mats Eating and Drinking Resource (2014)

Acknowledgements

We are very grateful to the Miss EC Hendry Charitable Trust who funded the project. We are also indebted to the people with dementia who took part and their families who supported them. Thanks also to the Dementia Centres who organised the groups and provided their premises for the focus group meetings.

References

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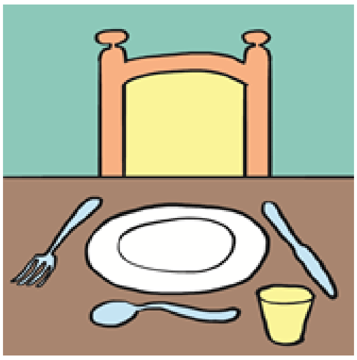
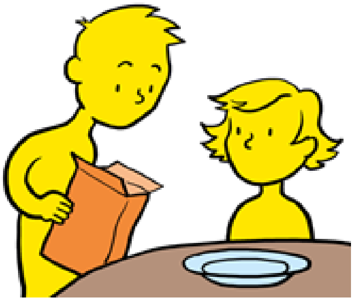
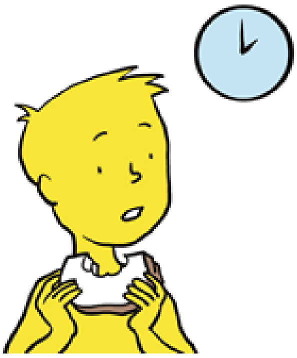
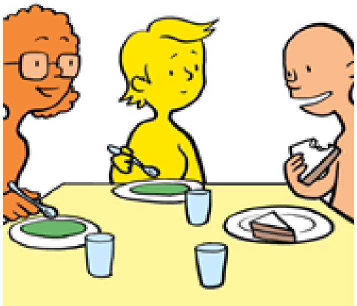
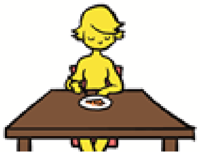
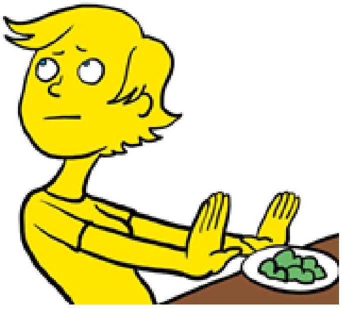
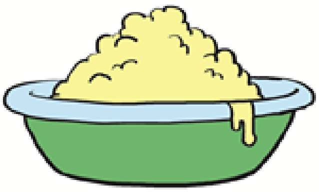
Shune, S. (2015). *Moving beyond the isolated swallow: Dysphagia in the context of the shared mealtime.* Retrieved from Dysphagia cafe: http://www.dysphagiacafe.com/?s=Moving+beyond+the+isolated+swallow%3A+Dysphagia+in+the+context+of+the+shared+mealtime

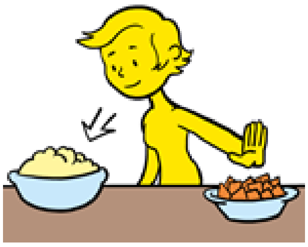
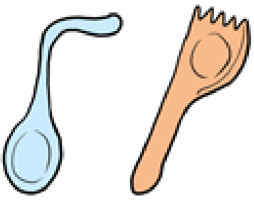
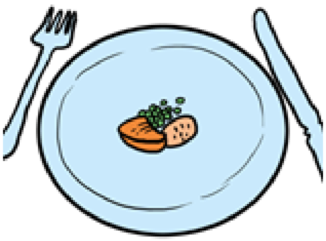
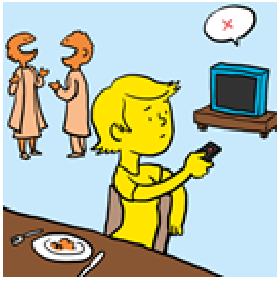
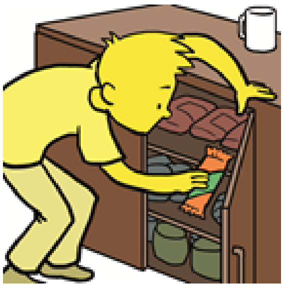
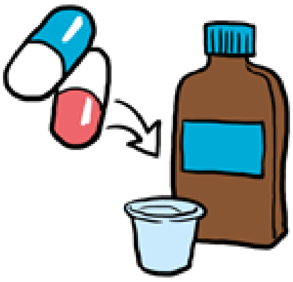
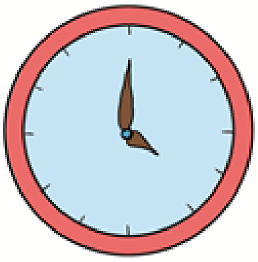
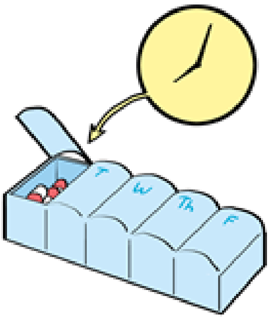
Talking Mats Eating and Drinking Resource (2014). http://www.talkingmats.com/product/talking-mats-and-eating-drinking/

Appendix:

Some symbols used in focus group discussions

Mealtimes 	Breakfast 	Lunch 
Eating with others 	Eating alone 	Drinking 
Taste 	Appetite 	Texture 

Some suggestions that might help

Avoiding difficult food 	Adapted cutlery 	Smaller portions 
Reducing distractions 	Adding flavour 	Tablets in syrup form 
Having more time 	Timing of medication  	Thickened drinks