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Food for Thought

Enhancing dietary preferences for the person with advanced dementia.

Institutions involved:

ERSKINE Proud to care

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Food for Thought: Enhancing dietary preferences for the person with advanced dementia.

1. Summary & Keywords

This pilot project adopted a nurse-led partnership approach, designed to explore innovative ways of eliciting food and drink preferences in a real life setting, in order to underpin the development of a framework or model to enhance dietary preferences for the person with advanced dementia. An adequate nutritional intake is essential for the maintenance of physiological functioning as well as playing a key role in social and psychological wellbeing and quality of life (Green and Jackson, 2006; Healthcare Improvement Scotland, 2012). Having no choice in what you eat and drink threatens dignity and personhood in a culture where choice of food and drink contributes to a sense of self.

The project involved six residents, their family member, and nursing, speech and language, catering, and academic staff. Initially members of staff and family members attended an intensive education programme on eating and drinking in advanced dementia. Following this, for an intervention period of 11 weeks, a sensory framework was used to explore ways of improving the experience of the person with advanced dementia. The results show that engaging all stakeholders and encouraging new ways of working results in positive outcomes. The residents maintained their nutritional status and their eating difficulties decreased. Families and staff reported improved knowledge and understanding of the challenges faced by the residents and developed more relaxed and open communication. Families indicated satisfaction with the changes and staff saw these as ‘just the start’, intending to move forward with further changes. The outcome of the study is likely to be a toolkit to extend the lessons learned to other areas both within Erskine Home and for the wider nursing community.

Keywords
Dementia, Nutrition, Care Home, Dignity

2. Background

When a person can make their preferences known, even by refusing to eat or drink, he or she has control over a vital part of life. When a person reaches the stage of advanced dementia they are no longer able to easily communicate their dietary preferences; this reduction of choice impacts on the person's dignity as a human being. Given the lack of other opportunities for self-realisation at this stage of the condition, enjoyment of food and opportunity to express food preferences is a key nursing consideration. Staff working in Haig House, which cares for people with dementia within Erskine Home, have tried various methods of eliciting dietary preferences from their residents, including picture menus and presenting options from the daily menu. In addition family members are routinely asked about food preferences when the person comes to stay at the Unit and these are recorded in the plan of care. These approaches have had some level of success. However there are a number of residents in the unit who have advanced dementia and the staff are not satisfied that the current way of working is sufficiently robust to ensure they are meeting their needs and preferences. The role of family members is core to the care provided in Erskine and staff are continually exploring ways of increasing the involvement of family and friends in the daily life of their loved one. This project will focus on the person with advanced dementia where there can be a greater challenge to that involvement on a day to day basis.

Erskine Home is a leading charitable organisation in Scotland with a mission to enable members of the ex-Service community to receive the best care and support to achieve maximum quality of life. Work is already underway at Erskine Home to embed the Dementia Standards and the Charter of Rights for the person with dementia (Cross-Party Group on Alzheimer's, 2009). The approach taken to this project upheld the principles of the charter of rights for people with dementia and their carers in providing the opportunity for the person and their supporter to be fully involved in the assessment of their care needs and support for daily living. This project also built on a key quality ambition of the Scottish Government (2010:7); that is to work towards "Mutually beneficial partnerships between patients, their families and those delivering healthcare services which respect individual needs and values and which demonstrate compassion, continuity, clear communication and shared decision-making". The partnership approach was the key to all aspects of this project from partnership with individuals who have advanced dementia, their families and supporters, to partnerships between the community nurses, other professionals and higher education staff.

The person who cannot exert choice may be seen as simply receiving care rather than being partners in care and the involvement of families is key to that partnership (The Local Government Association, the NHS Confederation and Age UK, 2012). This becomes even more significant as the person with dementia becomes unable to maintain that full partnership role. The person with advanced dementia is unlikely to be able to perform any activity of living independently and will have limited or no verbal communication; it is estimated that this stage of the condition may last for an average of four to six years before the end of life (Reisberg et al, 2006). Eating difficulties are common in advanced dementia and food refusal is often seen as an unavoidable consequence of the progression of their condition (Mitchell et al. 2009). Weight loss, while common in advanced dementia, is not seen as inevitable and can be ameliorated or reversed with appropriate interventions (Pivi et al, 2011, Barrett, 2004). Most papers about eating and advanced dementia do not focus on preference or choice of diet; rather they explore and examine the impact of the physiological changes leading to dysphagia (Cleary, 2009) or the need for alternative to eating such as a Percutaneous Endoscopic Gastrostomy (PEG) (Gillick and Marshall, 2002). There is a dearth of research on food choice and preference in advanced dementia indicating that there is little interest in this aspect of care, with most of the emphasis on the nutritional value of the diet and the consistency of the food offered (Gillick and Marshall, 2002). While reports suggest a loss of pleasure in eating (Pivi et al, 2011), studies rarely make any link between this perceived loss of pleasure with the choice of food presented as this is often simply a sentence in the paper.

An adequate nutritional intake is essential for the maintenance of physiological functioning as well as playing a key role in social and psychological wellbeing and quality of life (Green and Jackson, 2006; Healthcare Improvement Scotland, 2012). Having no choice in what you eat and drink threatens dignity and personhood in a culture where choice of food and drink contributes to a sense of self. When a person can make their preferences known, even by refusing to eat or drink, he or she has control over a vital part of life. When a person reaches the stage of advanced dementia they are no longer able to easily communicate their dietary preferences; this reduction of choice impacts on the person's dignity as a human being. Given the lack of other opportunities for self-realisation at this stage of the condition, enjoyment of food and opportunity to express food preferences is a key nursing consideration.

There are a number of ways that have been found to communicate with the person who has dementia, including Talking Points and Talking Mats; however these depend on the person having some residual verbal communication skills. Talking Mats are useful for some people with late stage dementia but not all people at this severe stage can benefit (Joseph Rowntree Foundation, 2007).

3. Aim & Objectives

Aim

To enhance the dignity of people with advanced dementia through the use of innovative methods to facilitate their food and drink choice.

Objectives

- To enhance dignity and the quality of mealtimes for the person with advanced dementia.
- To improve dietary intake by the person with advanced dementia.
- To develop a nurse-led group with the person and their family member who will develop innovative ways of identifying food and drink preferences.
- To develop a sustainable framework or model from this pilot to guide staff in enhancing choice for the person with advanced dementia

4. Design and Methods

This study used a case study approach, defined as a way to investigate a contemporary phenomenon happening in a real life context (Yin, 2014). This was an exploratory, mixed methods approach to explore and develop an understanding of the experience of eating and drinking for the person with advanced dementia living in a care home environment. The participants included six case studies and involve residents with advanced dementia, their family members and nursing and care staff. The individuals with advanced dementia at the centre of the project were unable to provide informed consent therefore the person who was their proxy was fully involved at all stages of the process. Family members were involved from the planning stage and were a vital part of the group of people involved in eliciting choice. They were also invited to be part of the evaluation process.

4.1 Inclusion Criteria

- Diagnosis of a form of dementia.
- Living in Erskine Home for more than two months.
- Assessed as exhibiting features at a FAST stage 6d−7e, defined as the stage when "the cognitive deficits are of sufficient magnitude as to compromise an otherwise healthy person's capacity to independently perform basic activities of daily life such as dressing, bathing and toileting" (Reisberg, Wegiel, Franssen et al, 2006; p83)
- Visited regularly by a family member who has knowledge of the person's life before they developed dementia and who continues to have frequent contact

4.2 Exclusion Criteria

- Acute physical health problems and/or delirium.
- Acute and distressing pain.
- Evidence of paranoid reaction to being observed, this information would be gained from their General Practitioner and care staff.
- Not regularly visited by a family member who has knowledge of the person's life before they developed dementia or family who do not have frequent contact

4.3 Project Management

The project was managed by the manager of Haig house and the project team. The staff of Haig house were fully involved in the project and attended education sessions on eating and drinking for the person with advanced dementia, regular meetings and feedback. The nursing staff who led the engagement with the family members also attended learning sessions on research and interview techniques. The catering manager was the link between the catering team and the care team and advised on portion sizes and food and drink selection and availability. The quality improvement staff supported the care team in Haig House and together with the speech and language therapist provided the programme on dignified dining in advanced dementia. It is suggested that an important element of making change is supporting staff and ensuring they have the appropriate skills and knowledge (Scottish Government, 2011). UWS staff provided support on all aspects of the project and learning sessions about the research process and methods.

4.4 The Sensory Approach

The process and content of this study was decided by a process of unit based engagement and a series of learning and discussion sessions about the experience of dementia, eating and drinking and the research process and methods. The final framework for the study was underpinned by the developing understanding about the importance of the five senses at this stage of dementia. This was supported by literature and the current PhD study of one of the project team. This framework was used to scaffold the interventions used for this study.

A short programme of learning about eating and drinking had already been in place and delivered to all staff at Erskine Home. For this project an intensive sensory learning package was developed by the nursing, speech and language therapist and University staff and was based on experiential learning used at the University of the West of Scotland pre-registration programme. This programme was delivered to Haig House staff and family members by the project team members and included the use of sensory impairment aids to encourage a deeper understanding of the experience of severe dementia when the person is being assisted to eat and drink. When this was complete the intervention period began.

After a baseline week where initial data were gathered, each two week period that followed focussed on one of the senses and how this related to eating and drinking. Staff were reminded about the focus of the two week period by a prominent poster with the inclusive dates displayed and a pocket reminder of the approach to be adopted. This

approach followed intensive learning sessions and was found to be a useful way of reinforcing each of the senses in turn, in order to provide more focus and embed knowledge of each aspect of eating and drinking in relation to these.

In addition interventions for each sense period were introduced. These were new to the staff and most of these suggested by the Erskine team. The prompt card content together with the new interventions and the reported outcomes are provided in tabular form in appendix 1. The outcomes are derived from the food diaries and some of these are also reflected in the focus groups results.

4.5 Research Process

Those residents who fulfilled the inclusion criteria were identified by the unit manager and the speech and language therapist using the FAST rating scale (appendix 2), in addition to the knowledge and experience of the registered nursing staff. The FAST scale is observational and used to identify seven stages in dementia as the condition progresses and is one of the few scales that can measure the later stages (Reisberg et al, 2006). The unit manager then approached the Guardian, Welfare Attorney or closest family member of residents who fulfilled the inclusion criteria to seek informed consent for the involvement of both the person with advanced dementia and the family member in the project.

Following informed consent from the family member, a registered nurse from the team was identified to interview the relative about the person's likes and dislikes about eating and drinking using a pictorial prompt (appendix 3). The nurse and family member explored the biography of the person in detail to examine previous diet preferences and information was sought from the caregiver about their knowledge and experience about the person's previous and current reactions to different types of food and drink. This information was incorporated into the care plans.

The nursing staff and speech and language therapist completed the EdFed[1] and MUST[2] rating scales prior to a period of eleven weeks where staff recorded each person's eating and drinking on a food diary developed for the study (appendix 4).

The Edinburgh Feeding Evaluation in Dementia (EdFed) scale is an 11-item instrument used to assess eating difficulties in people at the later stages of dementia. This observational

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[1] http://consultgerirn.org/uploads/File/trythis/try_this_d11_1.pdf

[2] http://www.bapen.org.uk/pdfs/must/must_full.pdf

scale can be completed in five minutes. This scale can suggest interventions to support or compensate the person who is having difficulty eating (Watson, McDonald and McReady, 2001). The Malnutrition Universal Screening Tool (MUST) is a five step screening tool to identify malnutrition, risk of malnutrition and obesity. This screening tool is used as a standard measure in Erskine Home (Todorovic, Russell and Elia, 2011)

For the 11 weeks period of the study the staff completed a comprehensive food diary, reporting each time the person was provided food and drink (appendix 6). The diary included responses from the resident and comments by the staff assisting, including the level if assistance required.

Finally staff and family members took part in a number of focus group interviews to explore their perceptions of the process and outcomes of the project.

4.6 Analysis

Because of the small number of participants, analysis of the data derived from standardised scales focused on change over time. The food diaries were analysed and a four-point scale was devised to record the level of assistance required at each main meal. This scale was applied to the data and is presented as a table in the results section. Focus groups were audio recorded and transcribed prior to undertaking a thematic analysis.

5. Ethical Considerations

As the research participants had advanced dementia they lacked capacity to consent to the research. This was addressed by ensuring that the data gathered directly from them was non−invasive and involved observation and the collection of information through food diaries kept by Haig House care staff, field notes and observational tools. Every effort was made to identify the views about research involvement held by the person with advanced dementia before they no longer had the capacity to inform others about their wishes. All information used in the study was also clearly identified and discussed with the person with severe dementia's Guardian, Welfare Attorney or nearest relative who was asked to give proxy consent as well as the manager of Haig House, Erskine. Furthermore, it was ensured that such participatory consent gained from guardians, welfare attorneys or nearest relatives on the person's behalf adhered to the guidance in the Adults with Incapacity (Scotland) Act (2000).

As the Adults with Incapacity (Scotland) Act (2000) applied to the research participants, it was essential to ensure that the research was subject to necessary approval therefore ethical approval was sought from the appropriate NHS Research Ethics Committee (NHS REC). NHS Research Ethics Committees safeguard the rights, safety, dignity and well-being of people participating in research. They review applications for research and give an opinion about the proposed participant involvement and whether the research is ethical. Some types of research require NHS REC review by law, whether or not they take place within the NHS or involve NHS patients or other service users. As this research involved adults lacking capacity to consent under the Adults with Incapacity (Scotland) Act (2000), the research proposal was submitted to the Scotland A REC which deals with applications involving Adults with Incapacity in Scotland.

All documents were completed via the Integrated Research Application System and as advised by Scotland A REC, Non NHS Site Specific approval was required and the relevant information form was also completed. All documents were completed as required by 10th October 2014, for review at the Scotland A REC committee meeting on 24th October 2014. As advised by A REC, the Site Specific permission was sought from the West of Scotland REC as the committee geographically local to the research location. However, the West of Scotland REC advised that they did not consider any applications where the research site was non NHS and thus the completed SSI information was not required.

On the 24th October the Scotland A REC meeting was attended by three members of the Food for Thought Team (two from the University of the West of Scotland and the Home Manager for Haig House, Erskine Care Home). Unfortunately, despite receiving positive feedback from the panel on the day, the proposed research was granted an unfavourable opinion on the 29th October 2014. The team then sought further clarification on the unfavourable opinion in a bid to gain permission to move the project forward. After a few weeks, the team received correspondence on the 3rd December 2014 confirming that ethical approval had not been refused; indeed, the project did not require ethical approval under the terms of the governance arrangements for NHS Research Ethics Committees. The project was seen as a service evaluation/practice improvement intervention and as the potential participants were neither NHS patients, nor relatives or carers of NHS patients, recruited because of their past or present use of NHS services, REC approval was not required (see Appendix 5).

Thereafter, the only further permission that had to be sought was from the University of the West of Scotland's University Ethics Committee. After submitting an application to the University Ethics Committee on 5th January 2015, on the 23rd February (Appendix 6), ethical approval was gained, with no conditions to be met and the process of inviting families to consider participation in the research could be commenced.

5.1 Recruitment

The residents with severe dementia were identified by nursing staff in the home using the FAST scale (Reisberg,Wegiel, Franssen et al, 2006), in addition to the knowledge and experience of the registered nursing staff. Following this, the guardian, welfare attorney or nearest relative of the person with dementia who fulfilled the inclusion/ exclusion criteria was approached by the unit manager. They were provided with information on the study and a letter inviting them to consider giving consent for the person with severe dementia to take part in the study (appendices 7 & 8).

Relatives who wished to consider the person with severe dementia becoming involved in this study provided written consent. The researchers were not informed of the identity of the potential participants until the consent form was received. Furthermore, those consenting were advised that they could withdraw their relative from the study at any time, without it having any impact on the care that they received.

In terms of confidentiality, the adult with incapacity's personal medical records were not accessed by the researchers. Data was anonymised using pseudonyms for all the participants involved in the study and any identifying characteristics were removed from all data.

The ethical approach taken to this project upholds the principles of the charter of rights for people with dementia and their carers in providing the opportunity for the person and their supporter to be fully involved in the assessment of their care needs and support for daily living. This project also built upon a key quality ambition of the Scottish Government (2010:7); that is to work towards “Mutually beneficial partnerships between patients, their families and those delivering healthcare services which respect individual needs and values and which demonstrate compassion, continuity, clear communication and shared decision-making”. The partnership approach was the key to all aspects of this project from partnership with individuals who have advanced dementia, their families and supporters, to partnerships between the care assistants, nurses, other professionals and higher education staff.

6. Results and Interpretation of Findings

6.1 Participants

The following section introduces the six residents, people with dementia, who were central to this project including some information about their background and details that emerged from the discussions between the families and the nurses. The residents in Erskine have a service background and this is an important aspect of daily life in the home.

Resident one: Margaret had an ATS background and was a gardener and homemaker. Both of her daughters were frequent visitors. A dainty lady she liked small meals and loved her tea from a china cup. (Margaret sadly died just before the project was completed)

Resident two: Jane was in the WRENS and always had her greatest pleasure when walking or listening to music. Her husband Phil visited her often. Her favourite foods were savoury and hot. A lady who watched her figure, she avoided pudding.

Resident three: Peter had an army background and led an active life, enjoying a range of activities including golf, sailing and a range of ball games. Despite this he dislikes noise and shouting. Hi wife Rose visits frequently and was a great support to him. His favourites were bananas and hot chocolate.

Resident four: Ben had three daughters and one son who visited often, even daily. He loved to dance and enjoyed eating out in company especially with his family. Another man who like the garden especially to sit out in the fresh air. (Ben sadly died just after the intervention period for the project.)

Resident five: Robert had a service background in the Royal Signals and was a walker and fisherman. He also loved art. His wife was a regular visitor. Robert enjoyed a whisky with dinner and his food needed to be hot not cold.

Resident six: Maria was in the ATS. She lost her fiancée in World War Two and never met anyone else. Despite this her life was good and she loved walking and going on cruises to see the world. She was visited by her nephew John and his wife. Maria enjoyed eating in company with others and particularly loved her tea.

6.2 Rating Scales

The following table presents demographic data and the scores for each resident at baseline and following the interventions.

Table 1: Pre and post study period EdFed and MUST scales

Resident	Age	Gender	FAST Score	Pre Study MUST	Post Study MUST	Pre Study EdFed	Post Study EdFed
1. Margaret	97	F	7d	2	Unavailable	9	Unavailable
2. Jane	87	F	7b	2	2	5	3
3. Ben	82	M	7d	2	2	7	14
4. Peter	77	M	7d	0	0	7	2
5. Robert	85	M	7c	0	0	6	5
6. Maria	95	F	6d	1	1	4	1

Inspection of Table 1 indicates that there was little change in the MUST scale for the surviving participants during this period - this stability is unusual for such a frail group of people. The EdFed scale for each surviving resident showed an improved picture and the deteriorating health and increased difficulty in helping Ben (resident 3) eat before his death is clear from the results.

6.3 Food Diaries

The food diaries contained a considerable quantity of data and some of this will be reported here using a chart which links each of the baseline and sensory periods to the degree of dependency shown by the residents. Each food diary was examined and recorded on a scale of 1-4 for each mealtime:

1 - Refused to eat

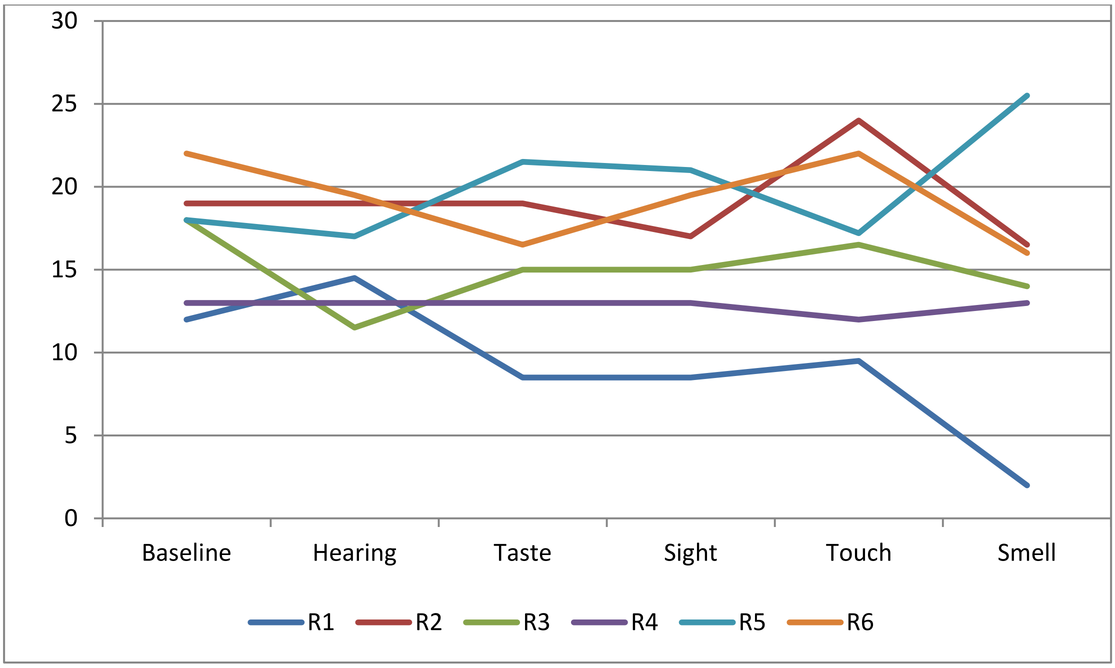
2 - Required full assistance

3 - Required some assistance

4 - Ate independently

The mean score for each day was calculated across all meals; the total mean score for each resident during baseline and for each 'sense period' is shown below.

Figure 1: Dependency during mealtimes by sensory input (two week periods)



Resident one, Margaret, showed an increase in dependency throughout the study and this reflected her deteriorating physical health, culminating in her death just before the end of the study period.

Resident two, Jane, showed an increase in independence during the touch period

Resident three, Peter, showed a small increase in dependence during the hearing period

Resident four, Ben, showed no change in his level of dependency at any point in the intervention period and this may also be a reflection of his deteriorating health as he died shortly after the study was completed.

Resident five, Robert, showed increased independence during the taste, sight and particularly smell periods with a small reduction during the touch period.

Resident six, Maria, showed a reduced independence at the taste period and an increase at the touch period.

None of these findings are statistically significant and are used only to illustrate the variety in the eating and drinking behaviour amongst this group of people who can often be viewed as homogenous and static at this stage of the condition. It may also indicate that the person with dementia may have a particular sense that is either well preserved or dominant at this stage of their life and this may prove to be useful information when devising plans of care and interventions that are person centred in the absence of their ability to provide such information in other ways.

6.4 Focus Groups

Staff and family members were invited to take part in focus group interviews to explore their perceptions of the process and outcomes of the project. These focus groups explored the project experience and were facilitated by staff from UWS. The following table (Table 2) represents the demographics of the focus groups, as can be seen five focus groups/interviews were held, on two occasions only two people attended and on another occasions only one person; thus only two interviews operated as focus groups. Despite this the information gained was informative.

Table 2: Focus group participants

	Attendants	Relationship to resident
Focus group 1	Erskine staff	Carers x5
Focus group 2	Family members x2	Daughter, Husband (Different families)
Focus group 3	Erskine staff	Carers x4
Focus group 4	Family	Friends of resident x2
Focus group 5	Family member	Wife

Thematic analysis revealed three dominant themes from the families and staff involved in the study, 1) eating as a sensory experience, 2) improving quality of life, and 3) being involved. Quotations are included for illustrative purposes and are not indicative of all views.

6.5 Eating as a Sensory Experience

This approach was recognised as useful by most of the families and staff as the key to a successful dining experience. Staff quickly appreciated the importance of reducing noise in the dining area to help the residents increase the amount of food they consumed:

> *I find that when the environment is quieter, rather than the television being on, music being played, that the clients are more settled and they sit better when they are eating their dinner. (Staff)*

Clear differences were identified with the other units. It seemed more noticeable to staff when they compared their own approach:

> *Everyone was sitting having their dinner, nobody was shouting, nobody was annoyed, it was just a very, very nice settled meal and my colleague went into the other unit and she came back 20 minutes later, she was totally harassed, she couldn't believe it, because the television was on, the music was playing as well, it wasn't just continuous music it was a radio station which was giving out pop music. The woman in the kitchen was banging the dishes and the other staff member was talking really loud, the clients were banging, another client was shouting and upset and my colleague said to me "Oh my God the difference in the two units is unbelievable" so you're seeing a difference that way. (Staff)*

Improving communication was a theme and, while thinking they had always been very good at communicating with residents, staff still appreciated that the training had helped reinforce the importance of telling the person what they were about to eat:

> *I think telling people when you're assisting sitting in front of them and telling them what you're going to give them is very helpful, like it's a piece of veg that's coming and she was opening her mouth but for example if you were telling her that the potatoes were coming, she didn't want them. Sometimes that was very helpful, telling people what is coming to their mouth if they can't smell or taste. (Staff)*

This had a greater impact at times than expected:

> *Like George. A mean George disnae talk anyway, but I would say to George when I was working on that side when he was having his soup "are you enjoying that George" and he was say "yes" and George didnae really talk. (Staff)*

The programme and the project also helped to focus their general approach to the eating experience:

> *When I started doing the Food for Thought, thinking that you're doing Food for Thought today, you were starting to explain what they were eating. That kinda, sitting in front of them well, you know just explaining more. (Staff)*

Sight and touch in particular related to the cutlery and crockery that had been introduced during the project was considered to be a real success by most staff. Brightly coloured crockery and small soft tip spoons had been introduced and table covers and mats provided high contrast to these:

> *I think the contrast between the plates and tablecloth is making a difference, especially with their vision. They're tryin tae find things so with a dark table cloth and the light coloured plates it's a lot better. (Staff)*

The clear contrast empowered some of the residents and increased their ability to be independent in some aspects of their dining experience:

> *But when it's bright he's okay, you can guide him and he's going to see round the plate, and he can really eat finger food himself if you guide him. (Staff)*

The education programmes had focussed a good deal on this aspect of the environment and staff increasingly connected with thinking about what the resident was seeing and touching rather than their own perspective on the presentation of food:

> *I think the colour of the plates help because sometimes the plates are white and if it's potatoes or macaroni and cheese they don't see their dinner. So I think the colour that makes a big difference. (Staff)*

The smaller soft tip ridged spoons were successful in a number of residents. Some preferred the small bowl size:

> *Cos the normal cutlery you know was too big a quantity for them, you know*. *(Staff)*

The ribbed texture of the new spoons also seemed to stimulate some of the residents to take the food and swallow more effectively:

> *Aye well I think it helps, that wee man … he tends to suck rather than opening and biting, he sucks his food in, in that respect they wee spoons are good that way right enough. (Staff)*
>
> *The spoons were the big thing for me even the other day when I went into my Dad and I went to the café and they gave us one of these spoons from the café and I knew right away that he would not take that, because you needed the one with the ridge because he needed to know, like the baby thing, the stimulation of the spoon*. (Family)

One of the care staff found that the metal spoons had been causing discomfort or may have been conducting too much heat from the food making some resident draw back from these:

> *Because sometimes I find with him when you're using the metal spoon and you maybe, I don't know whether because it's metal and it's hitting his mouth or maybe it's too much, but I find with the smaller spoon it's better, because you're not putting too much in his mouth and the texture of the spoon helps. (Staff)*

The small bowl also helped one of the ladies when she tried to take food independently as she spilled less. As a fastidious person this had stopped her eating process with the larger spoons in the past. Others also appeared to have increased independence with the smaller soft tip spoons:

> *She eats better with the plastic spoons than she does with a metal spoon, if you give her a metal spoon you know, I don't really think she knows what to do with it cos I changed it today I gave her bigger spoon with her rice crispies and then changed it for a wee spoon and she ate really well with that. (Staff)*

The team had purchased an ODE machine which emits food odours throughout the day and these change to smells associated with different mealtimes. While staff clearly understood the value of smell in the enjoyment of food this was a mixed result. The ODE machine was not useful in the large dining area and the smell was largely lost.

> *I've smelled them once only and that was when the dinner was finished it started to smell then, once in two weeks' time and I think that's the only time. (Staff)*

Negative comments related to the fact that this is more difficult to control in a care environment:

> *We do all different smells whether it's personal needs, or whether it's the trollies coming up, the housekeepers using different cleaning things, you know, so there's all different smells. (Staff)*
>
> *In general the idea was accepted but they felt the need for stronger and more natural smells from food being prepared would be more useful. (Staff)*
>
> *But a think if it was like a bigger machine that blew more smells. (Staff)*

Taste was a challenge as residents often had been eating similar food most of their lives. The interviews with family members were invaluable to increase staff insight into the person's dining preferences but families also found much to learn by working more closely with the staff and completing the education programme.

> *Sometimes the girl would say to me, "we gave your dad beans the day" and a couple of months ago I would have said "don't ever give my dad beans because he doesn't like beans", who am I to say that he doesn't like beans? (Family)*
>
> *I have learned that his taste buds have changed and he likes sweet things and he will always eat ice cream and he loves these wee sundaes and things like that and he will eat it. (Family)*

This project has for some staff made a real change in the way they approached the dining experience for the residents.

> *Before we were just feeding them, giving them their dinner… (Staff)*

The sensory framework used in the project and reflected above is drawn together by one of the family members, who explains the changes she has seen in the unit.

> *Peaceful music (if any) at mealtimes rather than football or quiz shows! Properly laid tables with soft tipped cutlery. Attractively presented food and if rejected something else substituted until the resident would try a little. Taking time to feed and importantly explaining what was on the spoon or fork that was being proffered. Bright colours to assist the partially sighted to identify objects such as cups and plates. (Family)*

6.6 Improving quality of life

The enjoyment of food was recognized as a significant part of life and noted as extremely important for all residents:

> *The whole of society revolves round food and tables and meals and things like that. (Family)*

There was also recognition that the enjoyment of food is about the whole eating experience and not just the physical act of eating;

> *The presentation of food is really important. (Staff)*

> *When you go to a restaurant you get individuality…….if you went to a restaurant and someone came and fed you with stuff you would be horrified…….just because you've got dementia it doesn't mean you shouldn't be treated like you are the most special person……what you get in a first class restaurant, people should get in a nursing home. (Family)*

Whilst asserting choice is challenging as dementia progresses, some family members acknowledged that although dementia had brought about some changes in eating and drinking, their relative still managed to make decisions regarding food choice:

> *If he wants to have milk in his coffee let him, we've gone with the changes that he's asked. (Family)*

> *I'm learning about what my Dad likes now that he didn't like before. (Family)*

Ultimately, despite some family members having differing opinions on the best way to achieve a good quality of life for someone with advanced dementia, the unifying outlook was the goal that their family member was content and peaceful:

> *If the carer, the next of kin or relatives or whatever, if he or she sees that the resident is contented, he or she is contented…….it may take different forms of reaching that contentment, but the same object. (Family)*

> *The sole object is to reach a maximum degree of contentment on the parts of the residents. (Family)*

> *She's happy and I'm especially happy when she's happy. (Family)*

6.7 Being involved

A recurring message was the involvement of all stakeholders in the experience. The partnership and exchanges among all those involved was clear:

> I *think I've benefited from it because I read all your stuff into it in a big way, but I liked it as well because I very much that things like "My Dad doesn't like a big spoon" and I used to say that, you know "don't try and even feed him with a big spoon, he doesn't like the big spoon" but then as we were going through it he doesn't even really like metal spoons, so the cutlery and the spoons and things like that have been a big thing for me but you kind of, I knew that of my Dad before he came in "don't ever feed him a pudding with a big spoon" and things like that, so for me the cutlery is a big thing as well and I think the other thing that they did which I thought was really good was where to sit them at a table and don't sit them at a round table because they can't. (Family)*

Staff were very positive about their involvement in the whole process and the importance of their role was valued and they recognised this:

> *It has been quite good actually, it's been a good idea from whoever thought it up, you know really, cos involving likes of us gives us a wee chance to get something to say because we just go in there, feeding them an making sure they get their food, with no input you know. So at least they got a bit of input off the staff you know from the other side rather than just, sorry for being so cheeky, some faceless wonder sitting somewhere you know, which you tend to get, you know. (Staff)*

7. **Discussion**

The project was intended to be a comprehensive approach embracing not only staff and family education, using experiential methods of learning, but also the evaluation of a series of sensory-based interventions used over a ten-week period using quantitative and qualitative data. This was an extensive, aspirational study and although the process has proved positive in most aspects there were some real challenges for all involved.

This was a complex and ambitious project and involved a range of stakeholders. The successes of the programme included the impact it has had on the dining experience of the residents of Haig House. While only six residents were part of the study, the staff gained knowledge and skills that also impacted positively on the care they provided to all of those in their care setting. The impact on the surviving residents was generally good and they maintained stable results in their wellbeing. This can be seen in their MUST and EdFed scores which show an achievement in this fragile group of people.

The aims and objectives of this project were to enhance the dignity, quality and choice for the person with advanced dementia in their experience of eating and drinking using a range of innovative methods, involving collaboration and engagement with family and staff to develop a sustainable approach to practice. Some of the key outcomes from the project related to these are discussed below.

7.1 Changing Practice

One of the key aspects of the study that is not strongly reflected in the data presented here, but reported by nursing staff in project meetings, was the changes in the relationships with some of the families involved. Family involvement is a vital part of the Haig House care approach and relationships are generally very good. During the project those families who had been seen as less engaged with staff began to interact more frequently about a wider range of aspects of care than before. The developing relationships have continued to improve and this is seen by nursing staff as a welcome and unlooked for development.

The involvement of staff from all departments and at all grades added to the benefits of the project. The care staff in particular, were positive about the impact this involvement has had on their morale. UWS research staff and the Alzheimer Scotland Dementia Nurse Consultant have been regular visitors to the Unit and staff have welcomed them not only in their research and teaching role but as a support for them as the study progressed:

> *Yes it was a change, because usually you would have the television on and music on, you would maybe have a conversation with your colleague if you have two people that you have to assist with their feeding. (Staff)*

Nursing staff have taken a lead role in this development of practice and have developed research skills and knowledge related to ethics and methods of gathering data. One of the outcomes of this work has been the communication between the nurses and the family members and some of this is the result of the picture board used to discuss the food preferences at the start of the study. This approach allowed a more conversational approach than conventional assessments and this had an impact on the relationships as a result.

7.2 Learning about Eating and Drinking

The care staff appreciated the education and support they received as part of the study, however there was no significant change in the residents' outcomes in terms of weight or nutritional status. This is a finding reflected in similar educational intervention studies with care staff, where despite intensive educational input there was no change in nutritional status (Chang and Lin, 2005) or indeed feeding difficulties worsened (Suominen, Kivisto and Pitkala, 2007). This is most likely to reflect the very frail group of residents in care homes. At the severe stage of dementia it is more likely that there will be an irreversible loss of weight throughout this period until the end of life. However, in this study the nutritional status of all participants was maintained over the three month period of the interventions. In addition there were changes in the level of assistance needed and staff were beginning to encourage a more self-directed approach to eating:

> *A tried to get my wee lady to feed herself today, but she just wasn't for doing it you know I was trying to give her the plate and saying "You take your spoon, you feed yourself" but she just wasn't for doing it, so had had to feed her three course. (Staff)*

The new approaches staff were taught and the innovations they introduced have increased their confidence in the care they provide. They have incorporated those interventions that they recognise have an impact on the residents but within their own experience of the person's needs. Much of the food diaries and the focus groups reflected this person centred approach as they recognise that each intervention is not always likely to be successful for all residents and even where this is useful the individual resident's immediate condition may not allow this to be helpful. They give examples of interventions that will not be useful when the resident is too tired or not feeling well and they will use different strategies until they find what will work on that day and at that time.

Their learning through the project has given them a toolbox of interventions that they are beginning to learn how to use and this is seen very positively by all concerned, particularly the family members.

7.3. Learning about Research

One of the aims of the funding stream was to involve community nurses in the research process. Staff from Erskine fulfilling a variety of roles became actively involved in the process. For some members of staff the project was completed too soon, just when they felt that they were beginning to fully understand and appreciate the aims:

> *But I would be willing to do it again, cos second time round you know, you know better from the first time. A don't think everybody's like that "Oh my God, it's that Food for Thought thing, oh no here we go, this is a pain in the backside", but really at the end of it, it does all kind of make sense, but just do it more. (Staff)*
>
> *It's was good experiment and I cannae wait to read all the final outcome and everything and see all the weights and everything and see if it did make a difference. (Staff)*

One member of staff suggested that the changes should be implemented across the whole home rather than just Haig House.

> *A would like to see it across the board. I feel as if the way it's been done just for certain clients, I think if they had it for the whole unit. (Staff)*

7.4. Innovation and Future Plans

The changes that were implemented over the time of the project prompted staff to look at the environment afresh and in some cases drew attention to further changes that could be implemented:

> *That you could make the dining rooms look better because it looks like a wee café in the East-end of Glasgow going in for a cuppa tea and a bit of toast. I think the environment that they are in could be nicer I don't think the environment that they're in is nice. (Staff)*

7.5. Challenges

One of the most difficult aspects of the project was the challenge to the Erskine staff of being part of a complex research study and maintaining their normal work-load. Care home staff are not usually familiar with research methods and each while each stage of the process was supported by the University staff the extra work was a real challenge at times. The nurses who were the lead practitioners in the project attended extra learning sessions on the research process, the project and in methods such as interview techniques. This did reduce their anxiety about the project to a degree but they still found the extra time required of them a concern.

7.6. Frailty of the Residents

Members of staff drew attention to how difficult it could be caring for residents with advanced dementia. Some found the process of helping the person to eat and drink enough to maintain their wellbeing when the person was unable to communicate or apparently understand much of the process emotionally difficult to manage.

> *A just think it's very difficult, it's okay with frail and elderly, but, with the dementia it's hard, it's very hard, and sometimes we get frustrated if we see somebody losing weight because they're not eating, so it is hard isn't it, you know, because you're trying your hardest to get this person to eat, you can't force them to eat, but you're trying your hardest and then you feel as if you're letting them down because they just don't want to eat. It is hard. (Staff)*

7.7. Maintaining Interest

Maintaining interest amongst staff was particularly challenging when the project was delayed due to securing ethical approval. The initial application to the NHS committee and subsequent application the University ethics committee took several weeks during which it was not possible to progress. This did affect the morale and interest of all who were involved as the team appeared to be treading water for some time and staff learning sessions were delayed creating challenges when these had to done promptly when the project was in danger of overrunning.

7.8. Staff Moves and Resources

A recurrent theme was staff shortage and movement of staff between care areas. This was recognised as a challenge by both staff and families:

> *They are very short staffed so it's difficult to put into practice everything that you want. It's very difficult. (Family)*
>
> *There have been a lot of staff changes. (Family)*
>
> *Residents are having to wait until we've got time to feed them. It's no right. (Staff)*

Staff were brought in to the Unit who had not been in the project at the start and the initial excitement of the team was dissipated to some degree.

7.9. Paperwork

Whilst staff recognised the importance of completing the food diaries:

> *It's good for the residents when you can see their intake. (Staff)*

Not everybody was following the rules:

> *I don't even begin to know how they keep a good record because I've came in once or twice and they said "We're trying to clean up", "We're trying to wash up" and I would say "What did Jean have today?" and they would say "Oh eh…" and it's just the practical difficulties. (Family)*

The paperwork was challenging in an already over stretched care environment:

> *You find that you'll be done your work and then you remember last thing "Aw … I've not done the Food for Thought thing" you know you're doing it last thing at night and your wanting to get out the door sort a thing, as I say that's just one of the hazards of this job. (Staff)*

The recording of the food diaries was not particularly successful despite support from nursing and speech and language staff. The non-registered staff found these onerous and tended to revert to the way they had always completed these. Much of the information on the person's preferences was passed verbally and staff believed they knew the person's likes and dislikes. When talking in the focus groups they were more forth coming and innovative in the changes they would like to see in the future.

7.10. Sustainability

The sense-based approach used in the study and this is well understood by all staff and some of the families involved. The nursing staff are particularly keen that this is further developed to produce a package of learning and guidance for promoting good practice in assisting the person with severe dementia eat and drink. This approach is embedded in Haig House and will be rolled out across Erskine Homes. This approach has required some additional staff learning and time and further development of the sense-based approach and the learning materials will be required. The project has the potential to be used in a variety of care and learning settings and this particular area of care has a dearth of specialist material available. Despite a variety of materials available for the person with dementia in the earlier stages of the journey, this stage is referred to in small sections and this does not reflect the specialist approach that needs to be disseminated.

8. Conclusion

The project was intended to be iterative and inclusive and this has been successful. It has also meant that the process was developed as the project moved forward and this was a challenge for the project team, firstly to keep the project on track and secondly to maintain the momentum with the staff and families. In order to do this, regular information was relayed to all involved and the monthly meetings about the project allowed the project to stay on track.

The project aim was to enhance the dignity of people with advanced dementia through the use of innovative methods to facilitate their food and drink choice. Finding such innovative ways to elicit choice was ambitious and this process has really just begun as staff are developing more knowledge and understanding. Innovations in the project were small, such as the soft tip spoons, but they did make a difference and this has opened up new possibilities.

Other aspects were less successful, such as the ODE machine although this did give staff further ideas. The main changes were not necessarily new ideas but they were presented *differently* to the staff by the education programme and the sensory framework. As there is a dearth of research in relation to providing education and training in care home setting in eating and drinking at this stage of dementia (Prince et al, 2014), it is hoped that this study may encourage more work in this area of care. The sensory approach to eating and drinking seems to be an obvious match and could be developed further.

9. Recommendations

This study has shown the importance of the multifaceted role of the nurse within a care home environment. Nurses make a distinct contribution to the care of the older adult to help achieve the best possible quality of life (RCN, 2004) and this distinct role was apparent during Food for Thought. However, to achieve success through excellent care delivery, it is essential that nurses work in partnership with their patients and families but also as part of an effective and forward thinking multidisciplinary team. Food for Thought brought together a multidisciplinary team with a common goal of care improvement and through high levels of team participation and innovation sought to make a coordinated and complementary effort to improve the dining experience for residents.

It is essential that community nursing policy recognises the impact of effective team working and takes cognisance of recommendations such as the National Patient Safety Agency (2009) to ensure good nutritional care and a dignified dining experience for all. Following the experience of Food for Thought, the project makes the following recommendations for nursing practice;

- The Implementation of a nutritional steering group with representation from all disciplines and service user/carer involvement
- A nutritional policy for all Erskine Care Homes to ensure quality improvement in all aspects of nutritional care
- The implementation of ‘dining champions’ whereby registered nurses can make a distinct contribution to nutritional care, taking the lead on all aspects of knowledge exchange, care improvement and innovation relating to nutrition
- Implementation of a specialist nutritional ‘toolkit’ for the patient with advanced dementia

The potential for such recommendations is already apparent when considering the impact of the Food for Thought project.

10. Impacts of the Project

This project has already had an impact on the residents, staff and families of Haig House and the wider Erskine community. The partnership approach taken in this project upheld the principles of the charter of rights for people with dementia and their carers in providing the opportunity for the person and their family to be fully involved in care decisions. This project also built on a key quality ambition of the Scottish Government (2010:7); working towards “Mutually beneficial partnerships between patients, their families and those delivering healthcare services which respect individual needs and values and which demonstrate compassion, continuity, clear communication and shared decision-making”.

Such partnerships and communication between staff and families as part of Food for Thought has helped built stronger connections and mutually valuable experiences:

> *I have learned a lot and what I’ve learned I’ve put into practice with my dad. (Family)*

> *I’ve enjoyed building useful relationships with the families involved in Food for Thought. We all have a common goal of wanting the best for their family member because when they arrive at Haig House, they become our family member too (Staff)*

This project has also helped to retain the person with dementia’s rights, choice and quality of life as advocated in the Dementia Strategy and Standards of Care for Dementia in Scotland (Scottish Government, 2010, Scottish Government, 2011) whilst ensuring a dementia journey that is as unique and individual as the person, as supported by the Promoting Excellence Framework (Scottish Government, 2011).

The training helped staff empathise with the dementia journey of their clients:

> *You wonder how they must feel…….it must be frightening for them. (Staff)*

Whilst family members realised that no two dementia journeys are the same:

> *It’s about an individuality thing. (Family)*

There was also an impact on the development of individuals and the team, in particular around leadership and research capability. The involvement and engagement of all members of the unit has created a research ready environment in the Unit. The Unit manager was newly appointed at the beginning of this study and this has created an environment for other innovative ways of working to improve the quality of life of residents:

> *They’re depending on us, they can’t just go and make their dinner or take there self out, they’re depending on us to make it a good experience for them so at the end of the day it does come down tae us, so the ball is in our court to make it better for them. (Staff)*

11. **Dissemination Plan**

- The project has been reported in the Erskine Home website and newsletter.
- UWS have published this on the University website.
- A poster developed by student nurses in Haig House will be presented at the UWS student conference on the 10th September, 2014.
- The project is a finalist in Scotland's Dementia Awards for 2014, announced on the 25th September, 2014.
- The project has been accepted as a poster presentation at the Alzheimer Europe Conference on the 21st and 22nd October, 2014.
- The findings will be written up for publication

12. Future Developments/ Next Steps

The results will be used to inform the Dining with Dignity project within all units and homes in the Erskine Care Home group. The next step is to work with the team to develop a learning toolkit. The team will use what has been learned during this project to develop a toolkit for learning called "Making Sense of Eating and Drinking in the Advanced Stage of Dementia". This toolkit will be used in training within Erskine Homes; for the pre and post registration nursing programmes at UWS and as part of the Alzheimer Scotland care at home training programme currently under development. The proposed toolkit will be evaluated at UWS as part of the undergraduate programme of learning

The staff at UWS and the Alzheimer Scotland Dementia Nurse Consultant have already incorporated the learning from the project into their own teaching sessions and programmes of learning. Staff in Haig house have a range of interesting suggestions about improving the dining experience for their residents and the team in Haig House will continue to meet and introduce these ideas.

Further research could include methods of recording the dining experience of the person with advanced dementia based on a sensory framework; exploring the impact of this type of programme on the relationships of staff and family members and the impact of co-production on the self-efficacy of family and care home staff.

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14. Financial Report

Our Project Ref:	**P398CHA**
QNIS Reference	**ENFFT01**
Project Title	**Food For Thought**
Project Manager	**Dr Pauline Banks**

	Days on Project	Costs		UWS TOTAL Costs		ERSKINE Total Cost	TOTAL
Pauline Banks	2.7	£961.83		£961.83			
Margaret Brown	12	£3,333.33		£3,333.33			
McWhinnie Hazel	8	£2,027.39		£2,027.39			
TOTAL	22.7	£6,322.55		£6,322.55			
TOTAL for Investigators				£6,322.55		To be confirmed	£6,322.55
Other costs				£0.00		22.13	£22.13
ODE						838.9	£838.90
Travel and Subsistence				40.95			£40.95
TOTAL costs per Project				£6,363.50		£861.03	£7,224.53

Interventions and Outcomes

Sense period	Learning prompts These prompts were derived from the learning sessions experienced by staff and were provided as pocket cards for each sense period.	Interventions and Outcomes These were the specific interventions introduced during the sense periods and commented on by staff
Auditory (hearing)	• Provide a quiet ambient environment • Use quiet music or music of their choice in the immediate area. • Speak using as few words as possible. • Use verbal prompts such as 'swallow'. • Do not talk to others in the environment when assisting to eat.	A variety of music was played during meal times and no real response, however staff noted that it was the level of sound that appeared to make a difference and a quiet ambient sound of music or voice seemed to help the resident focus on the food. Staff speaking quietly while they ate also was reported positively. Loud noises such as doors banging was reported negatively and these were repaired as a result of the study.
Gustatory (tasting)	• Provide one food taste at a time. • Provide a dry spoon after each few mouthfuls to encourage swallowing • Provide water between each different taste offered.	The chef used a variety of different spices and herbs, bringing these on to the unit during this period to try with some of the residents. These included ginger and Tabasco. Apart from a dislike shown to the very strong spices by some residents i.e. Tabasco the response to the others varied considerably. The key appeared to be sweet flavours for all residents. Lemon and orange sorbet and pineapple juice was readily accepted by all of the residents. Staff discovered that offering a small amount of sweet food first encouraged the person to eat more

		of the savoury food that followed. Wastage of food was minimal during the project but even so this period showed a small reduction.
Visual (seeing)	• Place the person's seat where the activity of preparing to eat is within their visual field. • Ensure the plate is placed in the person's visual field. • Table set before them at a level within their visual field. • The caregiver who is assisting the person to eat should be seated within their visual field and face the person. • The caregiver should mimic chewing and swallowing actions. • Provide the plate of food before the texture is altered.	A variety of photographs of foods were converted to high-resolution and high contrast visuals and these were presented as non-glare pictures and on computer screens to residents. These elicited little response. Plates of food were offered where the food stood out in sharp contrast to the background. These were held in the person's visual field and caused most residents to reach for the plate. There was very little discrimination about the content of the dish. One of the most successful interventions appeared to be the high contrast crockery as staff noted that residents were looking at the food and tryong to reach for this. Most successful was the staff member sitting close to the resident where the face and the plate of food could be seen.
Tactile (touching)	• Provide the person with tactile clues to eating, such as placing a spoon in the hand and a napkin placed over clothes. • Encourage the person to explore plates and cutlery before beginning to eat. • Use hand over hand, or hand resting on hand, approach to assist with eating. • Use soft tip spoons to prevent reflexive biting responses.	This period included the introduction of two main approaches. The first was the use of the soft tipped spoons. These were successful in the main where residents were more advanced in their conditions and challenged in their ability to accept the spoon, swallow the food and release the spoon. One resident was given the spoon in her hand and managed some of her meal with minimal assistance. The small bowl and shape allowed her to lift the spoon and keep it in the correct position. The second approach used a hand over hand approach taught to staff during the training programme. This allows the residents hand to move with the staff to the mouth and

		provides them with some extra control over what they accept in their mouth. They are also empowered to push the spoon away if they wish. This approach worked for some of the residents. The success was related to the resident's reaction at that meal. If the resident was tired they made less effort and accepted the spoon from the staff.
Olfactory (smelling)	• Check there are no intrusive non food smells near the person • Place the person near the areas where food is prepared for serving • Encourage the person to smell the food provided before eating. • Use the ODE machine to generate appropriate smell for each meal.	This was the least successful of the periods of intervention. ODE machines, which are electrical devices, which give off food smells, had won a design award for dementia care. Three of these were purchased and placed in the dining areas of the unit. The odours are timed to release thirty minutes before each main meal. Staff did not appear to notice these and the area may well be too large to allow these to have effect. They may be more effective in the home environment. The kitchen is next to the eating areas and this provides a stronger source of food odours. Unfortunately the odours of other areas in the care environment reach the dining room and this is a source of concern for staff. There is a plan underway to enclose the eating area to increase the impact of the food odours for the residents. Staff used the odour of the plated food but there was little impact noted apart from one resident who responded by eating more independently.

FAST SCALE ADMINISTRATION

The FAST scale is a functional scale designed to evaluate patients at the more moderate-severe stages of dementia when the MMSE no longer can reflect changes in a meaningful clinical way. In the early stages the patient may be able to participate in the FAST administration but usually the information should be collected from a caregiver or, in the case of nursing home care, the nursing home staff.

The FAST scale has seven stages:
1 which is normal adult
2 which is normal older adult
3 which is early dementia
4 which is mild dementia
5 which is moderate dementia
6 which is moderately severe dementia
7 which is severe dementia

FAST Functional Milestones.

FAST stage 1 is the normal adult with no cognitive decline. FAST stage 2 is the normal older adult with very mild memory loss. Stage 3 is early dementia. Here memory loss becomes apparent to co-workers and family. The patient may be unable to remember names of persons just introduced to them. Stage 4 is mild dementia. Persons in this stage may have difficulty with finances, counting money, and travel to new locations. Memory loss increases. The person's knowledge of current and recent events decreases. Stage 5 is moderate dementia. In this stage, the person needs more help to survive. They do not need assistance with toileting or eating, but do need help choosing clothing. The person displays increased difficulty with serial subtraction. The patient may not know the date and year or where they live. However, they do know who they are and the names of their family and friends. Stage 6 is moderately severe dementia. The person may begin to forget the names of family members or friends. The person requires more assistance with activities of daily living, such as bathing, toileting, and eating. Patients in this stage may develop delusions, hallucinations, or obsessions. Patients show increased anxiety and may become violent. The person in this stage begins to sleep during the day and stay awake at night. Stage 6 is severe dementia. In this stage, all speech is lost. Patients lose urinary and bowel control. They lose the ability to walk. Most become bedridden and die of sepsis or pneumonia.

Instructions To the Administration of the Mini Page 1 of 1
http://geriatrics.uthscsa.edu/educational/med_students/fastscale_admin.htm 2/13/2008

Functional Assessment Staging of Alzheimer's Disease. (FAST)©

1. No difficulties, either subjectively or objectively.
2. Complains of forgetting location of objects. Subjective word finding difficulties.
3. Decreased job function evident to co-workers;
   difficulty in traveling to new locations. Decreased organizational capacity.*
4. Decreased ability to perform complex tasks (e.g., planning dinner for guests), handling personal finances (forgetting to pay bills), difficulty marketing, etc.
5. Requires assistance in choosing proper clothing to wear for day, season, occasion

6a. Difficulty putting clothing on properly without assistance.
b. Unable to bathe properly; e.g., difficulty adjusting bath water temperature) occasionally or more frequently over the past weeks.*

c. Inability to handle mechanics of toileting (e.g., forgets to flush the toilet, does not wipe properly or properly dispose of toilet tissue) occasionally or more frequently over the past weeks.*
d. Urinary incontinence, occasional or more frequent.
e. Fecal Incontinence, (occasional or more frequently over the past week).

7a. Ability to speak limited to approximately a half dozen different words or fewer, in the course of an average day or in the course of an intensive interview.
b. Speech ability limited to the use of a single intelligible word in an average day or in the course of an interview (the person may repeat the word over and over
c. Ambulatory ability lost (cannot walk without personal assistance).
d. Ability to sit up without assistance lost (e.g., the individual will fall over if there are no lateral rests [arms] on the chair).
e. Loss of the ability to smile.

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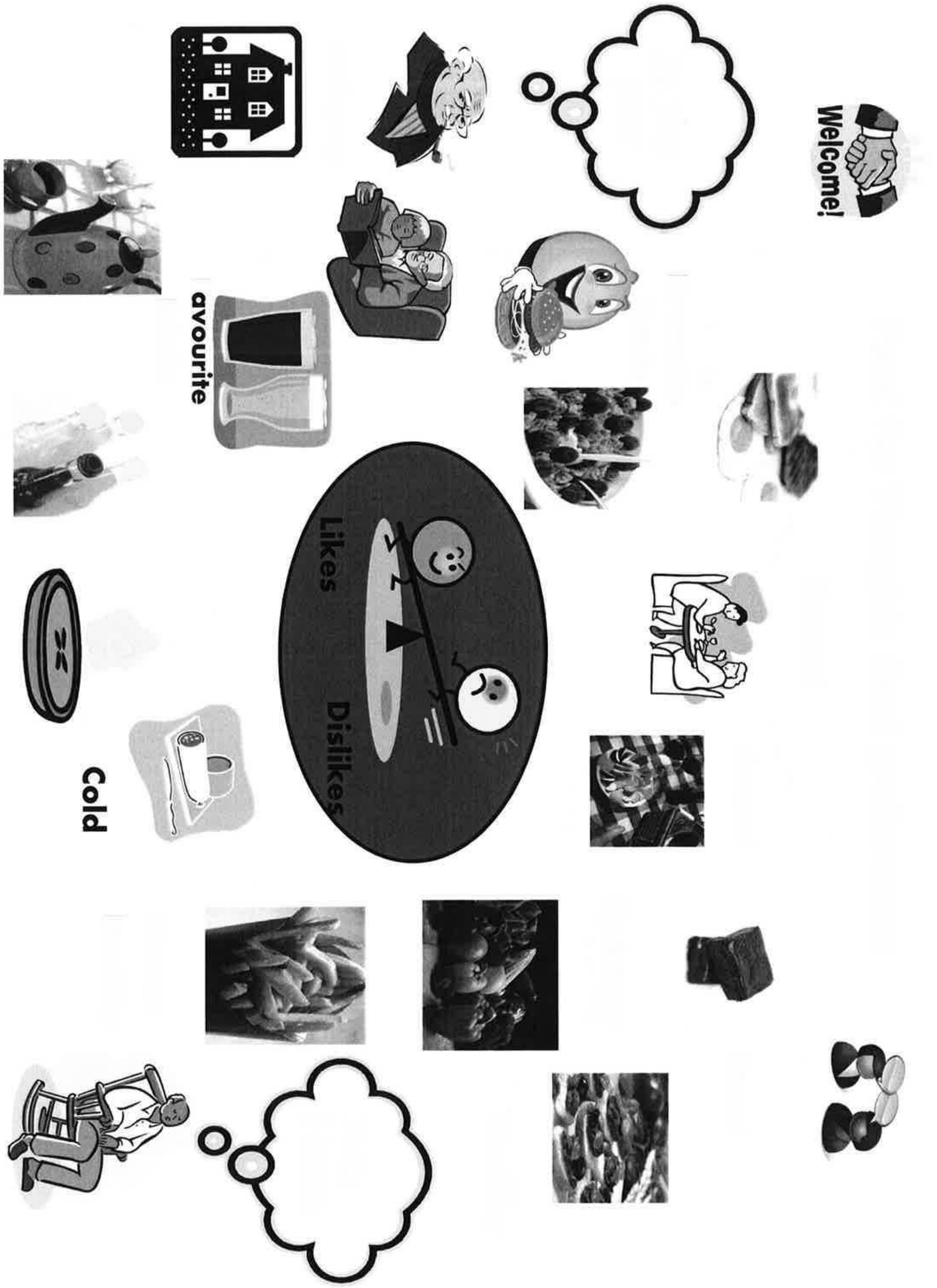
Welcome!
avourite
Likes
Dislikes
Cold

Appendix 4

Name:		**Week Beginning:**		**Weight (kg)**	

	Monday				Tuesday				Wednesday			
	Food/Fluid Offered	Amount Eaten	Comments / Reaction	Initials (Carer / Relative)	Food/Fluid Offered	Amount Eaten	Comments / Reaction	Initials (Carer / Relative)	Food/Fluid Offered	Amount Eaten	Comments / Reaction	Initials (Carer / Relative)
Breakfast												
Mid am												
Lunch												
Mid pm												
Evening Meal												
Early Evening												
Supper												

Please also record any nutritional supplements offered and amount taken e.g. Fortisip, Fortijuice, Calogen

Appendix 4

	Thursday				Friday				Saturday				Sunday			
	Food/Fluid Offered	Amount Eaten	Comments / Reaction	Initials (Carer / Relative)	Food/Fluid Offered	Amount Eaten	Comments / Reaction	Initials (Carer / Relative)	Food/Fluid Offered	Amount Eaten	Comments / Reaction	Initials (Carer / Relative)	Food/Fluid Offered	Amount Eaten	Comments / Reaction	Initials (Carer / Relative)
Breakfast																
Mid am																
Lunch																
Mid pm																
Evening Meal																
Early Evening																
Supper																

Any other relevant information:

NHS
Lothian

South East Scotland Research Ethics Service
1 Headquarters
Waverley Gate, 2-4 Waterloo Place, Edinburgh EH1 3EG
Chair: Mr Brian Houston
Chief Executive: Tim Davison
Lothian NHS Board is the common name of Lothian Health Board

Date: 03/12/2013
Your Ref:
Our Ref: NR/1312AB1
Enquiries to: Alex Bailey
Direct Line: 0131 465 5679

Name: Pauline Banks
Address: School of Health, Nursing
and Midwifery
Caird Building (Room 1.22)
Hamilton Campus
Hamilton
ML3 0BA
Email: alex.bailey@nhslothian.scot.nhs.uk

Dear Pauline,

Project Title: Food for Thought: enhancing dietary preferences for the person with advanced dementia

You have sought advice from the South East Scotland Research Ethics Service on the above project. This has been considered by Scotland A REC and you are advised that, based on the submitted documentation (email correspondence, Research Protocol v2.pdf, 13_SS_0192 Food for thought_UWS.pdf), it does not need NHS ethical review under the terms of the Governance Arrangements for Research Ethics Committees (A Harmonised Edition).

The advice is based on the following:

The potential participants of this service evaluation are neither patients (identified from, or because of, their past or present use of NHS services) nor relatives or carers of patients (recruited for this reason)

If the project is considered to be research you may require ethical approval as outlined in The Research Governance Framework for Health and Community Care. You may wish to contact your employer or professional body to arrange this. You may also require NHS management permission from host care organisations (R&D approval). You should contact the relevant NHS R&D departments to organise this.

For projects that are not research and will be conducted within the NHS you should contact the relevant local clinical governance team who will inform you of the relevant governance procedures required before the project commences.

This letter should not be interpreted as giving a form of ethical approval or any endorsement of the project, but it may be provided to a journal or other body as evidence that NHS ethical approval is not required. However, if you, your sponsor/funder feels that the project requires ethical review by an NHS REC, please write setting out your reasons and we will be pleased to consider further. You should retain a copy of this letter with your project file as evidence that you have sought advice from the South East Scotland Research Ethics Service.
Yours sincerely,

Alex Bailey

Scientific Officer
Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG

South East Scotland Research Ethics Service
2 Headquarters
Waverley Gate, 2-4 Waterloo Place, Edinburgh EH1 3EG
Chair: Mr Brian Houston
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South East Scotland Research Ethics Service

Appendix 6

Title of Project: Food for Thought: Enhancing Dietary Preferences for the Person with Advanced Dementia

Information sheet: Guardian, Welfare Attorney or nearest relative of the person with dementia

We would like you and your relative to take part in a research project. Your relative is not able to decide whether to participate in this research study. To help decide if he/she should join the study, we would like to ask your opinion whether or not they would wish to be involved. Please consider what you know of their wishes and feelings about research and to consider how they might feel about this study. Please let us know of any advance decisions they may have made about participating in research.

If you decide that your relative would have no objection to taking part we would ask you to sign the consultee declaration form. You will be given a copy of this to keep. If your relative does take part, you would be kept fully informed during the study and you would be able to let staff in Haig House or a member of the research team know of any concerns about your relative’s experience of the research. You can withdraw them from the study at any time, without it having any impact on the care that your relative receives. If you decide that your relative would not wish to take part it will not affect any of the care they currently receive.

The following information is the same as we would have provided for your relative if they were able to give consent to be involved.

This information sheet is intended to help you decide if you wish to allow your relative to be involved in this study. We will be available to go through this with you in order to discuss any issues or concerns and explain any aspect that is not clear.

Who are we?

Val Logan House Manager at Haig House, Erskine will be managing the project. The project team are Matthew McDowall; Care Assistant, Pauline McIntyre; Clinical Governance Coordinator, Maxine Bayliss; Quality Improvement Manager, John Booth; Catering Manager and Karen Herron; Speech and Language Therapist. In addition, staff from the University of the West of Scotland will be supporting the research process. These staff are: Margaret Brown; Senior Lecturer, Pauline Banks; Professor Older Persons Health and Hazel McWhinnie; Lecturer.

What is the purpose of the research?

The research is intended to determine the feasibility of developing new ways to identify food preferences for the person with advanced dementia.

Why have you been invited to become involved?

The senior nurses here in the care home have identified you as the Guardian/ Welfare Attorney/ nearest relative of (insert name of relative) and that you are the person who is able to agree that they may be included in this study.

What information will be gathered about my relative/friend if they take part?

The research involves gathering a variety of different information about your relative. This information will be recorded by a staff member who knows them well and regularly works with them.

Baseline measurements will be taken using assessment tools that consider stage of dementia, resident weight and eating difficulties.

A food diary will also be kept by the staff, monitoring food intake for each resident for three weeks before the intervention and during the intervention period of nine weeks. The staff will also note each resident’s reaction to food, for example speed of eating, body language, expressions etc. Staff and relatives who are involved will be invited to take part in a focus group interview to provide qualitative information. The focus group interviews will be tape recorded and then what has been said will be written down. This will allow us to study the information that has been given and develop a more careful and detailed understanding of what has been discussed.

Are there any risks involved?

In the unlikely event that your relative may be unwilling to be observed, their involvement in the study will not continue. This will not affect the standard of care provided to your relative in any way. Regular discussion with staff and family members will explore how the resident is responding to the observations.

Are there any benefits?

It is intended that this project will impact on nursing practice during the process of the intervention by enhancing staff knowledge, skill and understanding of the needs and preferences of the person with advanced dementia. You may also benefit from contributing to a study that may benefit your family member and others in future who find themselves in the same situation.

What if you are unhappy about any aspect of the research?

If you have any complaint about the way you have been dealt with in the course of the research, this will be addressed by Val Logan (House Manager, Haig House). There is also support for both family and caregivers within the home from qualified Registered Nurses and managers.

In addition, Alzheimer's Scotland provides support for families at all stages of the caring journey and staff from UWS have agreed to provide contact and support for family members if they require this and have agreed to this course of action.

What will happen to the information about your relative/ friend?

The information will be used to enhance staff knowledge, skill and understanding of the needs and preferences of the person with advanced dementia. All personal information will be kept confidential. The people who take part in this study will not be identified by name on any of the material. The material may be seen by the care giving staff from Haig House and the research team from The University of the West of Scotland. All the research information will be kept in a secure, locked environment in Haig House. All recorded information from focus groups and written material, such as the food diaries will be kept for five years and then disposed of. No information regarding your relative/ friend from the care home will be removed from the home or copied.

What will happen to the results of the research?

The project will be presented initially to the family carers and staff at Haig House and then more widely to family carers and staff at all Erskine Homes. This charitable organization has a robust quality improvement approach that will direct the dissemination of the outcomes of the project to other units within the organisation. Further dissemination will include poster presentations and journal articles to disseminate the project results more widely.

Who has given permission for this research?

The research is funded by The Queens Nursing Institute Scotland. The Research Ethics Committee for Adults without Capacity has examined this proposal and given permission. The managers of the care home have also given permission.

What if you need more information?

If you need any further information please contact Val Logan, Haig House, Erskine (phone number) or Valerie.logan@erskine.org.uk

Thank you for taking the time to read this information sheet.

ERSKINE Proud to care   Qnis   UWS UNIVERSITY OF THE WEST of SCOTLAND

Consent form

Title of Project: Food for Thought: enhancing dietary preferences for the person with advanced dementia

Name of Lead Researcher: Val Logan

Please initial the box

1) I confirm that I have read and understand the information sheet dated: 28/08/2013, version one, about the above study. ☐
   I have been given the opportunity to consider the information, ask questions and have had these questions answered to my satisfaction.

2) I understand that I have agreed to the voluntary participation of my relative in the research and that I am free to withdraw their involvement from the study at any time. ☐
   I do not need to give a reason for this and the care of my relative will not be affected if I do so.

3) I understand that appropriate parts of the material collected for the research may be looked at by responsible individuals from ☐
   The University of the West of Scotland and Haig House and I give permission for these individuals to look at this material. The

published study will not identify individuals who take part

4) I agree that my relatives GP and any other health professional directly involved in their care will be informed of their involvement in the study. ☐

5) I agree to my relative taking part in the study. ☐

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Name of participant Date Signature

------------------------------------ ---------------- --------------------------

Name of researcher taking consent Date Signature

One copy of this form will be retained by the consultee and one by the researcher.

End of Project Financial Report

Staff	**Costs included in protocol**	**Days**	**Actual spend**	**Requested from QNIS**
UWS	£3,991	22.7	£6,323	£3,991
Erskine	£3,393	243.25	£4,443	£3,393
Sundries			£16	£16
ODE machine			£839	£839
Spices			£6	£6
Crockery			£178	£178
Travel: UWS staff Hamilton to Erskine	£389	20 x Hamilton to Erskine @.45p per mile	£450	£389
Transcription of focus group interviews			£162	£41
Family carers home to Erskine 6 x 8 visits approx. 50 miles	£1,080	Families did not wish to claim expenses and have requested this amount is used for Haig House, inclusive of a celebratory event.		
Printing	£110		£110	£110
Posters	£48		£48	£48
Dissemination (event 150 x £5-75)	862-50	Dissemination event to take place		£862
	£9,873-80		£12,575	£9,873