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# Enhanced Sensory Day Care

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Developing a new  
model of day care for  
people in the advanced  
stage of dementia: a  
pilot study

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Alzheimer Scotland Centre for Policy and Practice

Institute of Healthcare, Policy and Practice

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## EXECUTIVE SUMMARY

### BACKGROUND

As dementia advances and the complexity of care needs rises, there is a gap in the provision of appropriate services for people who are living at home. The increasing numbers of people in the later stages of dementia and the increased demands for caring at home, create the imperative to develop dementia capable services to address this need. Standard day care services struggle to provide the high levels of support required for people with advanced dementia, and family caring is compromised by the absence of alternative provision. Set against this backdrop, a programme of sensory interventions and a new day care model were developed and piloted within South West Scotland.

### AIM

To collaboratively pilot and refine a new Alzheimer Scotland Enhanced Sensory Day Care model for individuals with advanced dementia.

### EVALUATION DESIGN AND METHODS

This mixed method study involved a 3 months exploration of the impact of the new service on the recipient of care, and also captured perspectives of the family, staff and volunteers. In addition, we interviewed relatives of individuals who were receiving standard day care from other Alzheimer Scotland Centres to determine and compare their experiences and preferences for Day Care.

- The study used a mixed method approach and initially included six people with advanced dementia who had previously attended a standard day care service delivered by the same organisation, and eight family carers. Due to attrition from the study, complete data sets were obtained for four service-users and five family



carers.

- A quality of life questionnaire was completed by family carers prior to their family member starting the new service, and again after three months of attendance.
- In-depth semi-structured interviews using emotional touchpoints were also conducted after three months. The same interviews were conducted with a further eight family carers from a different standard day service provision, whose relatives did not attend an enhanced sensory model of day care for comparison with family carers who received the new service.
- The perspective of staff and volunteers was sought before and after delivery of the new Enhanced Sensory Day Care model using emotional touchpoint group interviews prior to the model commencing as a baseline, and again at 12 weeks.
- A self-efficacy questionnaire was completed by staff and volunteers, also to give a baseline at week 1 and repeated after 12 weeks of the new service.
- Further data collected included: an observational log completed by staff/volunteers and documentary photography to capture individual responses in the moment of care.
- After 12 weeks feedback interviews were conducted with staff/volunteers and family carers to gain further information on what was working well and identify possible refinements of the new model.

**Key Findings**

1. Quality of life was perceived to be higher for 3 of the 4 people with dementia after 12 weeks. For one participant, their quality of life was perceived to be lower after 12 weeks.
2. Staff and volunteers perceived that the Enhanced Sensory Day Care Service improved service-users' quality of life due to the increase in communication from the service-user.
3. Staff and volunteers attributed improved communicative abilities on the part of service-users with the one-to-one attention they were able to give as a result of the higher staff-user ratio.
4. Shared sensory activities, such as brushing service-users' hair or giving a hand massage, facilitated 'magic moments' in the caring relationship.
5. Overall, participants whose relatives attended standard day care services and the enhanced sensory service felt supported in their day care arrangements.
6. Family carers of relatives attending Enhanced Sensory Day Care worried that if the enhanced service did not exist, then their relative would not have the option of day care at all.
7. Family carers of relatives attending Enhanced Sensory Day Care would have preferred to attend more training sessions on sensory care, although some already engaged in sensory activities with their relatives.
8. Both Enhanced Sensory Day Care and standard day care family carers expressed concerns about the prospect of having to move their relative into a

care home, fearing that 'no one will look after them as well as I will'.

9. Staff/volunteer confidence in their ability to engage with a person who has little or no verbal communication increased over the pilot study period, with improvement being most marked across the sensory activities.

This was a preliminary study of a new pilot service; the findings, conclusion and recommendations must be considered within this context recognising the importance of a service that meets the needs of both the person with dementia and their family.

## CONCLUSIONS

The pilot study has demonstrated the viability and potential benefit of Enhanced Sensory Day Care as a model for the supportive care of people in the advanced stage of dementia. Whilst outcome determinants with people in the advanced stage of dementia are understandably challenging, creative approaches to the methodology and to interpreting experience at this stage of dementia have been evidenced that warrant further development. A challenge associated with implementing the new model of day care is to achieve a partnership approach fostering communication which includes care recipient, care provider, and families. Findings from the study suggest that this approach contributes to a positive quality of life for individuals in the advanced stage of dementia and supports family carers, although further work is needed.

## RECOMMENDATIONS

- Future dementia strategies reflect the contribution of enhanced multi-sensory stimulation interventions in supporting people with advanced dementia to live the best life possible.
- Future policy developments include enabling plans to make enhanced multi-

sensory stimulation available and accessible for persons living with advanced dementia across all care settings.

- Day care services offering enhanced multi-sensory stimulation are developed for people with advanced dementia to address the current gap in provision, with a clear understanding of the contribution from all partners.
- Sufficient and appropriate day care practitioners (staff and volunteers) are equipped to safely deliver selected multi-sensory interventions as part of person-centred care for individuals with advanced dementia.
- Developments in enhanced multi-sensory stimulation day care are designed to support family caring through partnership approaches as part of palliative care.
- Guidance is made available for family carers in the delivery of selected multi-sensory stimulation techniques for relatives with advanced dementia.
- The potential for enhanced multi-sensory day care to prevent or delay admission to long-term care for individuals with advanced dementia should be explored.
- Further work is undertaken to determine referral and admission criteria for multi-sensory dementia care, based on tools such as the FAST scale and PAL checklist, in order for a timely transition to the new service to occur.

## SECTION 1 OVERVIEW OF THE MODEL AND APPROACH

### INTRODUCTION

As dementia advances and the complexity of care needs rises, there is a gap in the provision of appropriate services for people who are living at home. The increasing numbers of people in the later stages of dementia and associated need for care at home, create the imperative to develop dementia capable services. Practice and user based evidence indicates that standard day care services struggle to provide the high levels of support required for people with advanced dementia. Family caring is compromised by the absence of alternatives suggesting that new models are required. Set against this backdrop, a programme of sensory interventions as part of a new model of day care was developed and piloted within south west Scotland, consistent with a longstanding Scottish public policy framework of shifting the balance of care (Scottish Government,2009). This sets the context for outcome improvements and resource efficiencies by keeping people living at home for longer. Individuals living at home whose dementia had advanced to a stage that their needs could not be met by the standard day care service would in most cases be discharged from day service. This response is inadequate for both the person with dementia and the carer, as the alternative to day care tends to be home support, fewer hours of which can be provided than day care within the allocated budget. This section presents the aim and objectives of the pilot study and overviews the new Enhanced Sensory Day Care model including the design and delivery.

## PILOT STUDY AIM

- To collaboratively evaluate and refine an Enhanced Sensory Day Care Model for individuals with advanced dementia.

## PILOT STUDY OBJECTIVES

1. To achieve an experienced-based understanding, and description of the Enhanced Sensory Day Care model in practice.
2. To understand and measure the contribution of this model to the quality of life of individuals with advanced dementia.
3. To evaluate the contribution of the Enhanced Sensory Day Care model to family caring including recognition of any influence on place of care (i.e. if it is possible to determine if people with dementia were supported to remain at home for longer due to the continuation of day care provision as dementia progressed).
4. To explore the impact of the new model from the staff and volunteer perspective.
5. To identify areas of refinement for the model to support the wider implementation and continuation of the service.

## ENHANCED SENSORY DAY CARE MODEL – AN OVERVIEW

Alzheimer Scotland Enhanced Sensory Day Care is a sensory-based, non-pharmacological programme intended to optimise the well-being of people in the later stages of dementia, where a decrease in ability is typically seen. It seeks to make connections with the person through a programme that incorporates some, or all, of the five senses of the body: sight, smell, sound, touch and taste.

Whilst each individual with dementia taking part received interventions that were considered appropriate to their preferences and wishes, the following are examples of sensory interventions available:

- Sight: photographs, effect of light, using specific photograph books developed to maximise the ability to see and understand the pictures.
- Smell: food, scents of perfume or aftershave, flowers, scented oils.
- Sound: specific use of personal music through MP3 players, retro radio, singing, musical instruments, noise-making soft toys,
- Touch: massage, elements of personal care, doll therapy, use of soft toys,
- Taste: food, finger food, ice-cream,
- Physical movement will involve using mirroring techniques and taking advantage of reflex responses.

#### DELIVERY OF THE ENHANCED SENSORY DAY CARE MODEL

The service-users were people with dementia whose day care needs could no longer be met by their current standard day care service, due to progression of their dementia. Enhanced Sensory Day Care was piloted within an existing Alzheimer Scotland day care centre which delivered the new service on Thursdays and Sundays. On these days the service was dedicated to Enhanced Sensory Day Care, offering this to a maximum of five people with advanced dementia.

The days ran from 10am-4pm with care provided by a small team of staff, supported by volunteers. Staff and volunteers were trained to the enhanced level on the Scottish Government Promoting Excellence framework (Scottish Government, 2011) and received additional in-house training in the delivery of sensory interventions.

Family carers were also offered training following the admission of their family member to the study.

The training for staff and volunteers consisted of:

- Information about the end stages of dementia, including difficulties with nutrition and changes in eating and drinking.
- What is meant by a palliative care approach.
- Developing life story work, to ensure understanding of the importance of individualised and meaningful activity.
- The importance of non-verbal communication.
- Specific interventions to be used (as above) such as music, gardening, effect of light and noise, reminiscence, gentle massage and use of oils.

## DESIGN AND STUDY PROCEDURES

Table 1 summarises the design and procedures in relation to each of the five key objectives.

Table 1 Objectives and data source

Objective	Data source
1. Description of model	<ul style="list-style-type: none"><li>• Admission process – FAST<sup>1</sup> and PAL<sup>2</sup> criteria</li><li>• Observational log - ongoing</li></ul>
2. Contribution to quality of life of person	<ul style="list-style-type: none"><li>• QUALID<sup>3</sup> questionnaire – weeks 0 and 12</li></ul>

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<sup>1</sup> Functional Assessment Staging scale

<sup>2</sup> Pool Activity Level checklist

<sup>3</sup> Quality of Life in Late Stage Dementia Scale



with dementia	<ul style="list-style-type: none"> <li>• Documentary photography - ongoing</li> </ul>
3. Impact on family carers and place of care	<ul style="list-style-type: none"> <li>• Semi-structured interviews with emotional touchpoints at week 12</li> </ul>
4. Staff and volunteer perspectives	<ul style="list-style-type: none"> <li>• Self-efficacy questionnaire<sup>4</sup> – at weeks 0 and 12</li> <li>• Semi-structured interviews with emotional touchpoints at weeks 0 and 12</li> </ul>
5. Refinement of model and recommendations	<ul style="list-style-type: none"> <li>• Brief feedback interviews with staff/volunteers and family carers at 9 months</li> </ul>

#### ETHICAL AND MANAGEMENT APPROVAL

Ethics approval was granted by the University of the West of Scotland prior to commencement, with the original submission being accepted. Permission to undertake the evaluation and to access family carers of people with dementia who attended the service and staff/volunteers was provided by Alzheimer Scotland.

Whilst most service-users with dementia were already known to the service, referrals were also accepted from health or social work.

Consent and information procedures (Appendices A, B, C, D, E) ensured that individuals were voluntarily participating in the evaluation with full knowledge of any risks or benefits. In addition to agreeing to their own involvement, written consent was given by the welfare guardian or nearest relative for photographs to be taken

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<sup>4</sup> A 10 question questionnaire, each question involved a seven point Likert scale.

during the Enhanced Sensory Day Care sessions with copies given to family members.

Additionally, the research team attempted to reasonably foresee any difficulties; all were experienced researchers with an understanding of the emotional vulnerability of carers of people with dementia.

## SECTION 2: LITERATURE REVIEW

### INTRODUCTION

This section of the report begins with a contextual overview of the changing demographics and an indication of the rising demand for appropriate care services and models of care, including day care, for people with advanced dementia. This is framed within the Scottish policy context where the imperative is to enable people to live the best life possible, and to support family caring. The narrative literature review explores the contemporary move towards recognition that dementia is a progressive, life-limiting condition and of the rationale for embracing the principles of palliative care in advanced dementia.

### BACKGROUND

There are estimated to be over 750,000 people with dementia in the UK; 88,000 of whom live in Scotland (Department of Health, 2010; Scottish Government, 2010). This figure is projected to double in the next 30 years (Department of Health, 2010). Dementia is viewed as a major health problem worldwide and substantial political effort is being mobilised to prioritise treatment of the disease (G8 UK, 2014). Dementia is a progressive and life-limiting illness and this progression can be conceived as a series of three stages: early or mild; middle or moderate; advanced or severe (Alzheimer's Society UK, 2013). At any one time, a proportion of people living with dementia will be in the advanced or severe stage of the disease. Although it should be recognised that symptoms, rate of progression, and longevity are all specific to the individual, the course of the disease is also considered predictable, especially in the advanced stages (Mitchell et al., 2009). People with advanced dementia typically lose mobility, speech, and the ability to chew and swallow safely,

resulting in nutritional deficits and infections. Risk of urinary infections increases with reduced mobility and recognition of the need to void, and this risk is compounded by use of indwelling catheters. Lack of ambulation also increases the risk of developing pressure sores that can cause sepsis (Volicer, 2013). Death is usually triggered by pneumonia (Kuhn, 2013; Volicer, 2013). It has been estimated that over 100,000 people with dementia die every year in the UK (Bayer, 2006), with recent research from Alzheimer's Research UK highlighting that Alzheimer's disease and other forms of dementia are now the third leading cause of death in the UK and the leading cause of death for women in England and Wales, according to Office for National Statistics figures (ONS, 2014). With the numbers of people with dementia increasing, it is forecast that by 2025, one in three people over the age of 60 will have dementia when they die (Brayne et al., 2006). The most recent place of death figures for Scotland show that 12,000 people died in care homes (including private hospitals) (National Records for Scotland, 2013), and the majority of people in care homes (up to 90% by some estimates) have dementia (Lithgow et al., 2012). The number of people dying with or of dementia will increase as the number of people developing the disease, and the diagnosis rate, increases. Prognosis for people in the 'end stage' of the illness can be 2 or even 3 years (Shuster, 2000).

#### PALLIATIVE AND SUPPORTIVE CARE IN DEMENTIA

Given that the progression of dementia cannot be prevented by current treatments, it has been suggested that care for individuals with the disease should be guided by the principles of palliative care (Kuhn, 2013; Volicer, 2013). A palliative care approach, from the point of diagnosis, involves a shift in the goals of care from an emphasis on prolongation of life to an emphasis on improving quality of life,

maintaining function, and maximising comfort (van der Steen et al., 2013). The emphasis which palliative and supportive care places on the holistic care of the patient and his or her family bears similarity to the model of person-centred care pioneered in dementia studies and practice (Downs, 2009). While it is widely suggested that people with dementia could benefit from a palliative approach to their care, this has been slow to develop across Europe and beyond (Davies et al., 2014). Some of the reasons identified for this include: the limited evidence base about the efficacy of a palliative care model in dementia when compared to traditional care (Sampson et al., 2005); the decline in the person with dementia's ability to communicate their wishes and needs (Bayer, 2006); a lack of training for healthcare professionals supporting people with dementia (Lawrence et al., 2011); and a general lack of awareness that dementia is a life-limiting illness (Bayer, 2006; Davies, et al., 2014). Yet, the quality of end of life care for people with dementia is frequently reported to be insufficient (Marie Curie/Alzheimer's Society, 2014). Recent UK dementia policies (Department of Health, 2009 (Objective 12), 2010; Scottish Government, 2010) responded to research findings and identified improving end of life care for people with dementia as a key priority. Scotland's National Dementia Strategy (2013) specifically supports: the earlier identification of palliative care needs among people with dementia; the promotion of advance care planning; and the development and roll out of the Electronic Palliative Care Summary which enables health information about patients to be updated on a daily basis and made available across a variety of services.

In 2013, the first European guidance on providing palliative care to this patient group was published which included an 11-domain framework (van der Steen et al., 2013). Domain 1 confirmed the applicability of a palliative care approach to the treatment of people with dementia. Indeed, the guidance recommends such an approach throughout the disease trajectory rather than being exclusively focused on the advanced stage (van der Steen et al., 2013). One of the highest research priorities identified through the Delphi study<sup>5</sup> was 'the optimal treatment of symptoms and providing physical comfort' (Domain 7). This priority can perhaps be explained by research evidence showing that pain is experienced by at least one third of nursing home residents with advanced dementia in the last year of life and frequently goes undetected and undertreated (Frampton, 2003; Kovach et al., 2001; Mitchell et al., 2009; McAuliffe et al., 2009; Scherder et al., 2005).

#### MULTI-SENSORY STIMULATION THERAPY

The physical comfort and relief of the behavioural and psychological symptoms associated with advanced dementia prioritised in the Delphi study (van der Steen et al., 2014) can be treated using both pharmacological and non-pharmacological interventions. Non-pharmacological interventions should, theoretically, be recommended before pharmacological methods, and thus there is an impetus to strengthen the evidence base on their clinical effectiveness (Howard et al., 2001). Non-pharmacological interventions include psychosocial therapies such as: reality orientation (Wallis et al., 1983), music therapy (Aslakson, 2010; Svansdottir &

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<sup>5</sup> The Delphi technique is a widely used and accepted method for consensus-building by using a series of questionnaires delivered using multiple iterations to collect data from a panel of experts. It is a group communication process which aims to achieve a convergence of opinion on a specific real-world issue.

Snaedal, 2006); aromatherapy (Burns et al., 2011); doll therapy (Higgins, 2010); animal-assisted therapy (Bernabei et al., 2013); validation therapy (Toseland et al., 1997); reminiscence therapy (Lai et al., 2004); Montessori-based activities (Orsulic-Jeras, 2000); and multi-sensory stimulation (Baker et al., 2003, Stacpoole et al., 2014, van Weet et al., 2005). All of these interventions can be offered by healthcare providers in a variety of care environments and do not require any input from palliative care specialists. They all involve a shift in focus to go beyond basic nursing or task-focused care (Lawrence et al., 2011) to promoting more meaningful activity which has the potential to enhance quality of life (Volicer, 2013).

Research into the effectiveness of multi-sensory stimulation specifically provides a mixed picture. These interventions rely in stimulating the primary senses of sight, hearing, touch, taste and smell. The rationale for their use lies in providing a relaxing sensory environment that places fewer demands on intellectual abilities but capitalises on the residual sensorimotor abilities of people with advanced dementia (Buettner, 1999; Hope, 1998), encouraging expressions of awareness (Clare et al., 2013). In other words, multi-sensory stimulation is about finding a balance between sensory overload and sensory deprivation (Kovak, 2000).

In Livingstone and colleagues' systematic review (2014), 13 studies of 'sensory interventions' ranging from those focused purely on touch to those which involved tactile, light and auditory stimulation were scrutinised for their effect on patient agitation specifically. Agitation may be caused by environmental factors (noise, temperature, restraints) physical factors (hunger, thirst, infection, pain), or emotional distress. Overall, they found that sensory interventions significantly improved emergent agitation, symptomatic agitation, and severe agitation during the time the

intervention took place, but that therapeutic touch had no added advantages and that there was insufficient evidence about any long-term effects or effects in settings other than care homes (Livingstone et al., 2014:20). However, not all sensory interventions are designed solely to target agitation. They can also be used to promote comfort and pleasure. Two types or models of multi-sensory stimulation have become particularly well known or ‘popularised’ in recent years within dementia care provision, and these are the Snoezelen<sup>6</sup> and Namaste care initiatives. Both are explained below as examples of existing sensory approaches. As with all the studies identified in Livingstone and colleagues’ review (2014), both the Snoezelen and Namaste models have only (so far at least) been used in residential care settings with a lack of evidence in day care settings.

#### SNOEZELLEN

The first popular model of sensory care was Snoezelen. Originally pioneered in the Netherlands in the 1970s for people with learning disabilities, it had its use extended to people with dementia in the 1990s (Chung & Lai, 2009; Moffat et al., 1993).

Snoezelen commonly involves a specialised room filled with a variety of stimuli. Descriptions of these various stimuli include: vibrating chair and foot stool; mirror ball; coloured light projector; disc projector and effects wheel; fibre-optic spray; bubble tube set within mirrors; relaxation CDs (e.g. bird sounds); aromatherapy atomizer and fragrant oils; soft toys; and rubber balls (Anderson et al., 2011).

A Cochrane review undertaken in 2002, and updated in 2009, evaluated two empirical studies into the effectiveness of Snoezelan for people with dementia

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<sup>6</sup> Snoezelen is a registered trademark of ROMPA.



(Chung & Lai, 2009). The first was Baker and colleagues' (2003) multi-sited randomised control trial involving patients in the UK, the Netherlands and Sweden which found that session-based multi-sensory stimulation was no more effective than non-multi-sensory activities in improving the mood, behaviour and cognition of patients with moderate to severe dementia. The second study, conducted by Van Weert and colleagues (2005) in nursing homes in the Netherlands, showed a significant 'treatment' effect to 24 integrated Snoezelan care with respect to the level of both apathetic and aggressive behavior, and depression, among residents. The study was reported to show significant changes in well-being (mood, happiness, enjoyment, sadness) and adaptive behavior (responding to speaking, relating to caregiver, normal-length sentences). However, Chung & Lai's (2009) Cochrane review concludes that both of these studies are methodologically flawed. They argue that both trials were conducted in stages with an attempt to achieve the optimal sample size, rather than including the attrition rate in the sample size calculation prior to the study. They also argue that the two trials lacked rigor in aspects of subject recruitment; the randomization process; and a non-uniform use of instruments across participating centres. Finally, both trials reported results of the sub scales/items of the outcome measures, thus orienting towards individual symptoms rather than the overall performance of behaviours and mood. They conclude the review by stating that there is no evidence of the efficacy of Snoezelan on the behaviour, mood and interaction of people with dementia.

## NAMASTE

The second popular sensory model is Namaste (a Hindi greeting meaning 'to honour the spirit within'), originally pioneered in America by Joyce Simard (1997). According

to Simard & Volicer (2009:29), Namaste care helps staff in an institutional setting to provide quality services that are 'holistic and meet the physical and emotional needs of their residents'. They suggest that basic nursing care can be made more meaningful if undertaken with a 'loving care approach' (Simard & Volicer, 2009:29). In this way, Namaste is not so much a shift beyond task-focused care (Lawrence et al., 2011) but rather makes completion of the activities of daily living into a sensory activity. Like Snoezelen, Namaste care is usually given in a separate room where the conditions can be modified and controlled, for example, by lowering the lights, playing soothing music, or infusing the room with the scent of lavender (Simard & Volicer, 2009). People are made comfortable with pillows and soft blankets, are offered high calorie drinks (e.g. fruit juice) and puddings (e.g. ice-cream, cake), and are given the option of interacting with lifelike stuffed animals or dolls. Other stimuli mentioned as part of Namaste care include: chattering false teeth; blowing bubbles; animated puppets; watching nature videos; moisturising legs and feet; and carers wearing funny wigs and glasses 'to get a laugh from residents' (Simard & Volicer, 2009). Both Snoezelen and Namaste care incorporate other psychosocial therapies which themselves have generated their own body of research literature e.g. doll therapy, light therapy, and music therapy. While not discussed here, Livingstone and colleagues (2014) provide an overview of the effectiveness of all of these different activities in terms of their effects on agitation specifically.

While there has been discussion of, and support for, Namaste care in the trade press (Duffin, 2012) and anecdotal evidence of the model's efficacy, the first robust evaluation by Stacpoole and colleagues (2014) shows that Namaste care can reduce behavioural symptoms in people with advanced dementia provided that strong leadership, adequate staffing, and good nursing and medical care are evident in the

institutions where the intervention is adopted. Outcome measures for this study were the Neuropsychiatric Inventory (nursing home version) which measures 10 neuropsychiatric symptoms, and the Doloplus-2 behaviour pain assessment scale for the elderly. Both measures were completed by the research team in discussion with care staff. One of the likely effects of multi-sensory stimulation, whether in the form of Snoezelen or Namaste care, or some combination of the two, is that engaging with sensory stimuli facilitates interaction and communication between the person with dementia and the person providing their care (Spaull, 1998). When people with advanced dementia develop communication problems, care-givers can become reluctant to initiate conversations. Using sensory stimuli could therefore provide a new focus for shared activity, promoting interaction and moments of awareness (Clare et al., 2013). Multi-sensory stimulation also enables individualised and one-to-one attention to be given to the individual with dementia. As Cohen-Mansfield and colleagues (2011) identified, one-to-one social interaction, within a group setting, is the most potent stimulus for engagement. Multi-sensory stimulation can also be used as a means to facilitate discussion between professional and family carers. In the Namaste programme reported by Stacpoole and colleagues (2014) for example, families were supported to acknowledge the progression of their relative's dementia within the positive context of seeing staff prioritising their quality of life. It is possible, then, that creating multi-sensory enclaves away from daily routines and 'usual care' holds possibilities for enhancing care-giving relationships. It is also important to recognise the broad spectrum of potential benefits which can accrue from engaging in sensory interventions, rather than a narrowly construed set of outcomes.

As a person's dementia progresses, the amount of informal caregiving required, of necessity, increases. Family carers can feel an increasing sense of burden (Papastavrou et al., 2007), are themselves at risk of mental and physical illness (Schulz et al., 1995), and sometimes experience social isolation (Brodaty & Donkin, 2009) and financial difficulties (Rimmer et al., 2005). While some commentators are critical of the carer-burden model because it foregrounds the negative aspects of caring rather than recognising the positive aspects which can result (Sanders, 2005), there is a broad policy consensus in Scotland (Scottish Government, 2010) and elsewhere that carers need to be supported by outside agencies in order to sustain their caring role. Indeed, in Scotland, 'support for carers' is pillar 6 of the 8 pillar model of dementia care (Alzheimer Scotland, 2012). Day care offers an important source of care for individuals with dementia (Brataas et al., 2010) in addition to support and respite for family members; an existential 'break' (Chappell et al., 2001) and the opportunity to connect with a different world from that of care-giving (Cuesta-Benjumea, 2011). In Scotland, Alzheimer's Scotland (2012), which is only one provider of day care services, offer over 1000 day care sessions a week and support more than 1,700 people a week through either day care or one-to-one services.

The elements that make up an ideal supportive caring environment have been studied by Nolan and colleagues (2006) at the University of Sheffield. The SENSES framework which they developed provides an analytic model to help understand the ways in which 'good' caring relationships can be created and maintained within the context of a particular service. Nolan and colleagues argue that enriched care

environments can only exist when all parties (patients; family; paid carers; staff; students) experience six identified 'senses'. These are a 'sense' of:

1. Security (feeling safe);
2. Belonging (feeling part of the community);
3. Continuity (recognition of life history);
4. Purpose (engaging in purposeful activity);
5. Achievement (taking part in meaningful activities and feeling satisfied with the results);
6. Significance (to feel that what you do is valued).

These six 'senses' are seen as prerequisites for good relationships within the context of care and service delivery. All groups need to experience these 'senses' if best care is to result. In other words, while person-centred care is focused on the individual with dementia, relationship-centred care (facilitated by paying attention to the six identified senses) focuses on all parties involved in the care of the person with dementia.

Another useful framework for thinking through all of the influences on the care-giving relationship is the concept of 'clinical significance' proposed by Schulz and colleagues (2002). The four dimensions of this model are:

1. Social significance (which includes public attitudes towards people with dementia);
2. Social validity (the day-to-day experience and perceptions of daily life);
3. Quality of life (of the person with dementia); and
4. Symptomatology (the neuropsychiatric symptoms associated with dementia).

Both the SENSES framework and the concept of clinical significance are designed to encourage researchers and practitioners to think broadly about all the different influences on the caring relationship and how these interrelate.

Day care has the potential to be an enriched care environment fostering relationship-centred care and attending to all four aspects of clinical significance. However, there are concerns that the traditional day care model cannot meet the needs of persons in the advanced stages of the disease for example, staffing ratios mean that if a person requires one-to-one support then other attendees may not receive the support needed. Similarly, if the person with advanced dementia is withdrawn or asleep for periods of time, then the needs of other attendees can lead to the person with advanced dementia not getting individualised attention at optimum times. This has resulted in calls to develop 'enhanced stage-specific services' to support individuals attending day care in the later stages of dementia (Silverstein et al., 2011). If individuals with advanced dementia are no longer able to attend day care, this will result in family carers receiving less support outside of the domestic setting. It is considered likely that without adequate respite and support caregiver stress will grow, increasing the likelihood of the person with dementia being admitted to a care home (Rockwell et al., 2014). Such a move is not always in the best interests of the person with dementia, often leading to increased confusion due to having to adapt to an unfamiliar environment (Mace & Rabins, 2001) and an increased risk of mortality (Aneshensel et al., 2000). The social care bill for care home places is also significantly more than supporting people in their own home (Chappell et al., 2004). Mittleman and colleagues' longitudinal research (2006), for example, showed that offering support to spousal caregivers of people with dementia in the form of individual counselling, support group participation, and telephone support delayed

nursing home placement (Mittleman et al., 2006). In its Carers Strategy (2010-15), the Scottish Government has shown a commitment not only to supporting carers through better information services, offering short breaks, and carer training, but also moving resources from institutional care to care at home through its 'Shifting the Balance of Care' programme. Within this, there is a vital role for day care to play in delivering relationship-centred care and an 'enriched' care environment.

### Summary

1. There is a gap in the provision of appropriate day services to meet the needs of people with advanced dementia who are living at home.
2. Arguments to create new models of day care based on the principles of palliative/supportive care are persuasive for people with advanced dementia.
3. The complexity of needs experienced in advanced dementia limits opportunities for self-realisation, and the growing evidence base for use of multi-sensory stimulation, while showing mixed results, is compelling.
4. Conceptual models of family caring signal the importance of partnership approaches with family members at this advanced stage of the condition.

### SECTION 3: DESCRIPTION OF THE ENHANCED SENSORY DAY CARE MODEL IN PRACTICE

This section will explain the design and methods used in confirming that service-users met the criteria of being in the advanced stage of dementia and will provide an overview of the new model in practice.

#### OBJECTIVE

To confirm the stage of dementia of those attending the service and to achieve an experienced-based description of the Enhanced Sensory Day Care model in practice.

#### STAGE OF DEMENTIA

Assessment Staging (FAST) scale) was used to assess the stage of dementia of each potential service-user prior to admission to the service (see Appendix F). FAST is an assessment measure that determines functional deterioration in people with dementia even in the most advanced stages (Sclan and Reisberg, 1992). A second survey instrument or framework (Pool Activity Level (PAL) checklist) was used to assess whether sensory activities would be appropriate for potential service-users (see Appendix G). This instrument has been shown to demonstrate validity and reliability when used with older people with dementia and that it can be transferred to a range of care settings (Wenborn et al. 2008).

The FAST scale and PAL checklist were used in all cases completed by the referring practitioner from within the existing day care service in discussion with the individual's main carer/s.

The FAST scale has seven stages:

1. normal adult



2. normal older adult
3. early dementia
4. mild dementia
5. moderate dementia
6. moderately severe dementia
7. severe dementia

At Stage 6 which is classified as 'moderately severe dementia' the person with dementia may begin to forget the names of family members or friends. They may require more assistance with activities of daily living, such as bathing, toileting, and eating. Patients in this stage may also develop delusions, hallucinations, or obsessions and show increased anxiety and may become distressed or angry. They may begin to sleep during the day and stay awake at night. Stage 7 is severe dementia. In this stage, all speech is lost. Patients lose urinary and bowel control and lose the ability to walk.

The PAL checklist lists the following nine activities:

1. bathing/washing
2. getting dressed
3. eating
4. contact with others
5. groupwork skills
6. communications skills
7. practical activities (crafts, domestic chores, gardening)
8. use of objects

9. looking at a newspaper/magazine

A person's ability to undertake each of these activities can be scored in one of four ways:

P (Planned level of ability) e.g. an individual can wash independently and eat independently using the correct cutlery

E (Exploratory level of ability) e.g. an individual needs soap put on flannel and one step at a time directions to wash, and eats using a spoon or with food cut up

S (Sensory level of ability) e.g. relies on others to wash but will wipe own face and hands if encouraged, only uses fingers to eat and drink

R (Reflex level of ability) e.g. totally dependent and needs full assistance to wash and relies on others to be fed.

The number of 'P's, 'E's, 'S's and 'R's recorded for each individual are totalled indicating the predominant activity level of the person with dementia.

## ANALYSIS

Description of a typical day at the Enhanced Sensory Day Care was elicited from the observational log and the constructed account was subsequently verified by day centre staff. Table 2 shows how each Enhanced Sensory Day Care service-user scored on both scales:

Table 2 – Service-users' scores on FAST scale and PAL checklist prior to admission to Enhanced Sensory Day Care

Service-user ID	Fast Scale Score	Pool Activity Level (PAL) Checklist
A	6	Sensory (P-0, E-1, S-5, R-2)
B	6/7	Reflex (P-0, E-1, S-4, R-4)
C	6	Sensory (P-3, E-1, S-5, R-0)
D	6	Sensory (P-0, E-2, S-6, R-1)
E	5/6	Sensory (P-1, E-2, S-4, R-0)
F	6	Sensory (P-0, E-3, S-6, R-1)

As the table above indicates, five of the original six service-users who signed up to the project were classified as having either moderately severe or severe dementia. One service-user was classified as having moderate to moderately severe dementia. All service-users had, or were beginning to have, difficulties with activities of daily living and were becoming increasingly dependent on their carers. According to the activity levels recorded on the PAL checklist, five of the six service-users were recorded as having a predominantly Sensory level of engagement in activities, while one service-user was found to have a Reflex level of ability for most activities. However, recorded ability for all the different activities were not uniformly Sensory and did vary, as indicated by the 'P', 'E', 'S' and 'R' scores listed in brackets in the

table. This shows that there was significant variation in abilities across all the activities which might have implications for undertaking joint activities in the day care.

## DEVELOPING A DESCRIPTION OF THE MODEL IN PRACTICE

### ATTENDANCE PATTERN

The Enhanced Sensory Day Care service ran on a Thursday and a Sunday. For one service-user's family, Sunday was viewed as a family day and they therefore did not want their relative attending on that day. However, by declining Enhanced Sensory Day Care on Sunday, this left the family with only Enhanced Sensory Day Care on a Thursday, which when compared to the three days originally offered in the standard service, was considered a reduction in service. A solution was agreed whereby the service-user could attend Enhanced Sensory Day Care on a Thursday while continuing to attend the standard day care service on two other days, giving the family three days of respite. While dual attendance at the standard and the enhanced service had not been envisaged when the Enhanced Sensory Day Care pilot was set up, it was agreed that this compromise would be the best way to support the family whilst enabling participation in the new service. However, the fact of non-exclusive attendance at Enhanced Sensory Day Care needs to be borne in mind when analysing the findings (see Section 4, for example) as any changes observed in the behaviour of the person with dementia over the intervention period may not be solely attributable to benefits derived from attending the enhanced sensory service.

### REFERRALS AND ATTENDANCE

It took longer than expected to receive appropriate referrals from external agencies, despite leaflets being produced and circulated widely and staff attending team meetings to inform others. This could be attributed to hesitancy among professionals

to refer to a pilot (i.e. temporary) service that they may not consider to be in the best interests of their clients, due to concerns about the need to establish a different care provision should the pilot operation cease. By the time the study ended, the Enhanced Sensory Day Care was running at full capacity with five service-users.

At the beginning of the pilot project when only three service-users were attending, there were weeks when, as a result of the individual with dementia being poorly or being away on holiday, there was only one person in attendance with up to three staff and volunteers. Whilst one-to-one interaction was seen as a benefit of the service, ratios such as this were considered disproportionate to the level of care required. It was subsequently decided that the service would be over-allocated to maximise capacity on each Enhanced Sensory Day Care session, while allowing for absences.

During the study period, two people with dementia attending the service died. For a service of this kind which is designed specifically for the needs of individuals with advanced dementia, a high mortality rate can be expected.

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#### TYPICAL DAY AT THE CENTRE

Before the service-users arrived, staff (typically 2 on any given day although not always the same 2) and volunteers (usually minimum of 2) spent time rearranging the standard day care lounge. High back chairs were moved from their usual place around the edge of the room into a circle in the middle of the room. A partition screen depicting a beach scene was used to partition the room. Lava lamps were switched on and various soft toys, rubber balls and brightly coloured cushions were placed around the room. Staff spent time planning the sensory activities to be offered that day.

On any one day, there could be between one and five service-users present. Individuals arriving were greeted by name and were seated and offered a tea or coffee. Once service-users were settled and assessed for any physical ailments or pain, staff/volunteers gently suggested either an individual or a group activity. An individual activity might be to listen to music which was personal to the individual via headphones. A group activity might be to hit a balloon back and forth across the room, engaging hand-eye co-ordination. For a comprehensive list of sensory activities engaged in, see Table 3. If a service-user showed any discomfort or reluctance to engage in a chosen activity, the activity was changed. Some service-users would be sleepy on arrival. Staff/volunteers would make gentle attempts to rouse the individual, but if unsuccessful, would allow them to sleep whilst maintaining physical contact, perhaps through holding their hand or brushing their hair.

At lunchtime each service-user was given individual support from a member of staff/volunteer while they ate. Different food was offered during enhanced sensory day care sessions compared to the standard day care provision. There was an emphasis on finger food and on soft, easy to eat foods, such as mashed potato, ice-cream, and rice pudding. There was a leisurely pace to lunch, as enhanced service-users can find chewing and swallowing difficult and for some it can be a slow process requiring sustained encouragement.

After lunch, more sensory activities were then initiated. These included: looking at picture books; hand massage and nail painting; baking, icing and decorating buns, among other activities. Activities were suggested according to the perceived mood of the individual. Some service-users were sleepy after lunch, and sometimes relaxing music was played as people slept. Family carers began arriving to collect their

relative around 4pm and were given an update on the day's activities by staff or volunteers. This debrief helped to build a trusting relationship between the staff/volunteer and the family carer. It also had the potential to give the family carer ideas for sensory activities they could try at home. Finally, service-users who arrived by taxi returned home by taxi, accompanied again by a member of staff/volunteer. For these service-users, the day's activities were written up in a notebook which was handed to their relative/s along with a short verbal debrief. In this way, family carers were always kept abreast of activities and responses. Meanwhile, back at the day centre, the room was returned to its typical configuration and all room adornments and accessories stored away.

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#### DESCRIPTION OF SENSORY ACTIVITIES

Sensory activities were selected by staff in order to stimulate one or more of the five senses: sight, smell, sound, touch and taste. Table 3 below describes all of the activities which staff/volunteers undertook with service-users and the senses they were designed to engage.

Table 3 - Description of all sensory activities attempted with Enhanced Sensory Day Care service-users

<b>Name of Sensory Activity</b>	<b>Description of Sensory Activity</b>	<b>Senses Engaged</b>
Listening to music	Played either through speakers to all service-users (at different volume levels depending on mood) or to individual service-users via	Sound

	headphones. Music selected according to knowledge of musical tastes of service-user	
Musical instruments	A maraca was used by service-users and staff/volunteers	Sound, touch, sight
Dance	Supported to dance in response to music	Sound, touch, sight
Hand and nail care	Nails filed, hands massaged with scented lotion, nail polish applied if desired – colour chosen by service-user	touch, sight, smell
Veranda	Sitting out on the veranda to look at greenery and watch activities on the riverbank	Sound, sight, smell
Sweeping the veranda	Helping staff and volunteers to sweep the veranda clear of leaves	Sight, sound
Walking	Walking with service-users around the day care centre and the local vicinity	Sight, sound, smell
Brushing hair	Brushing service-users' hair as a form of head massage to encourage relaxation	Touch
Magnetic darts	Throwing plastic magnetic darts at a magnetic dart board to engage service-users' hand-eye co-ordination	Touch, sight



Target practice – ball and net	Throwing a sponge ball into a free standing net to engage service-users' hand-eye co-ordination	Touch, sight
Scent box	Helping service-users to smell the different essential oils	Smell
Ball games	Encouraging service-users to pass a ball back and forth between each other to encourage interaction	Touch, sight
Baking and decorating fairy cakes	Helping service-users to stir the cake mixture, arrange bun cases, put the mixture into bun cases, and decorate the cooked fairy cakes with icing and sprinkles. Service-users could also eat the cooked fairy cakes	Sight, smell, touch, taste
Domestic tasks	Helping to lay a table, fold napkins, wash and dry dishes	Sight, touch
Passing balloon with rice inside	Encouraging service-users to hit the balloon back and forth to facilitate interaction	Sight, touch, sound
Picture books	Using photo books developed to maximise the ability to see and understand the pictures	Sight, touch
Soft toys	Soft toys, such as a lifelike cat, were stroked and	Sight, touch

	cuddled and their fur brushed.	
Singing toy birds	Small soft toy birds which tweet when touched were held and stroked by service-users.	Sight, sound, touch
Rosebud the doll	A lifelike doll was held, cuddled and interacted with	Sight, touch
Flower arranging	Fresh cut flowers were arranged in a vase and service-users encouraged to touch and smell them	Sight, smell, touch
Paper flower making, making butterflies	Craft sets for paper flower making and making butterflies were used with service-users to engage hand-eye coordination. Artificial scents were sometimes applied to the paper flower.	Sight, smell, touch
Fabrics, patchwork quilt	A collection of different brightly coloured fabrics and a patchwork quilt were shown to service-users who were encouraged to touch them	Touch, sight
Electric fire with fake flames	The fire in the day centre had a sensory element	Sight
Family album	Family albums supplied by relatives were used to	Sight

	encourage reminiscence	
DVD of Scottish music	Played to engage the interests of a service-user who was particularly interested in Scottish music	Sight, sound
Lava lamp	Service-users could watch the lamp at their leisure	Sight
Reminiscing	Staff/volunteers engaged in conversation with service-users about their family history and key events in their lives	Sound
Playing cards	Large format playing cards were used to interact with service-users	Touch, sight

In order to stimulate service-users' sense of taste, the following foods were offered which were considered particularly sensory:

- Chocolates
- Fruit salad or sliced fruit
- Jelly
- Rice pudding
- Angel Delight
- Milk pudding
- Ice lollies
- Ice-cream

In the advanced stage of dementia there is often a concern with encouraging the consumption of high calorie foods in order to counteract the weight loss that can be experienced.

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#### DOCUMENTARY PHOTOGRAPHY

An important aspect of the evaluation of the Enhanced Sensory Day Care service was the aim to visually evidence the experiences of the individual service-users. Given that the research team did not have access to the first person voice of the person with dementia, the documentary photography enabled us to see some of the reactions of service-users to the sensory interventions and to draw some conclusions from that. This inevitably involves some interpretation of the images, supported by the staff/volunteer entries in the Observational Log.

The photographs were all taken by staff/volunteers in the moment of care.

Staff/volunteers were seeking to capture, via digital camera, activities which worked well and which elicited a good response from service-users. Photographs were not taken when activities did not work well, although staff and volunteer feedback (see Section 6) suggested that there were very few occasions when this was the case.

The documentary photographs shown on the following pages are illustrative of some of the sensory activities undertaken with service-users during the Enhanced Sensory Day Care sessions. The images capture a sense of the engagement in, and pleasure derived from, the activities themselves and from the one-to-one attention which supported the activity. Permission has been given to use the following images within this report:



Image 1 – an Enhanced Sensory Day Care support worker gives a service-user a hand massage, and the touch is mirrored by the service-user. There is a deep focus by the carer and the person in the moment, as they make direct and personal contact. There appears to be an attempt at reciprocity on the part of the woman with dementia as she reaches out to touch the caregiver in return for the massage. This could be interpreted as a sign of approval or perhaps an attempt to attract attention and make eye contact.

Image 1 shows an Enhanced Sensory Day Care support worker giving a service-user a hand massage. At the same time, the service-user is mirroring her touch, demonstrating that she is engaged in the touch-based care she is receiving.

According to staff/volunteer reports, hand care (massage, nail care, polishing) was a popular activity among service-users. Image 2 shows the service-user smiling, which suggests that she was enjoying the activity and the interaction it prompted.



Image 2 – as the caregiver completes the massage the Enhanced Sensory Day Care service-user smiles at staff/volunteer taking the photograph. There is a sense of being involved in a new interaction. She seems to say ‘see me’, and her responsive and natural smile is a reaction expected when a person is photographed.

Another activity which impressed staff/volunteers in terms of the engagement it elicited from service-users was making, decorating and eating fairy cakes. This activity involved a number of different senses: sight, touch, taste, and smell. It also involved hand-eye co-ordination, and as a shared activity it prompted interaction between service-users and between staff/volunteers and service-users.

The sequence of photographs below shows the different components of this activity:



Image 3 – A service-user has a look of concentration as he mixes the fairy cake mixture in a bowl using a whisk. The bowl is positioned near the body to ensure maximum control of the equipment. He concentrates on stirring the mixture and shows deliberateness in this moment captured.



Image 4 – a service-user smiles at the person taking the photograph, perhaps suggesting pride in having successfully helped to add the cake mixture to the cases, ready to go into the oven. This is about satisfaction in a job well done and pleasure at being recognised as having achieved such an expert result. She responds to the camera with a smile that engages with the person taking the picture, maintaining eye-to-eye contact and indicating awareness.





Image 5 – an Enhanced Sensory Day Care service-user mixes the icing in a bowl with a wooden spoon. Again, she appears concentrated on the activity and there is hand-eye co-ordination involved in the activity. The position of the right hand is familiar to expert bakers, positioning the bowl and using just enough pressure to steady it. Her attention and relaxed hands suggest that she has paused for a moment to check the texture of the mixture. This is not simply stirring food in a bowl.



Image 6 – a service-user is helped by a member of the day care staff to ice a fairy cake. This activity involves touch and hand-eye co-ordination, even with assistance. He is using both hands in an attempt to engage with the activity.





Image 7 – another service-user is helped by a member of staff to decorate a fairy cake with sprinkles.



Image 8 – a service-user concentrates as she adds sprinkles to the fairy cakes showing embodied memories of this long-term activity is focussed and she shows an awareness of the appropriate position of the tub of sprinkles in relation to the top of each of the cakes. These are movements that may well be partly a body memory from her early life and relates to the concept of embodiment, identified as an ‘expression of need, agency and will’ (Downs, 2013: 271).

Making fairy cakes had a number of different components and stimulated a number of different senses. The photographs show that it was an activity which service-users were able to concentrate on and in some cases appeared to bring pleasure (Image 4).

Images 9 and 10 show an Enhanced Sensory Day Care service-user engaged in a game of throw and catch with a soft ball. In Image 9, the service-user is shown to reach her hands out in anticipation of catching the ball. In Image 10 we see that she has successfully caught the ball. This activity involves hand-eye co-ordination as well as flexibility in reaching out and catching the ball. In Image 10, the service-user appears to be smiling, suggesting that engaging in the activity brought her some pleasure.



Image 9 – a service-user reaches her hands out in anticipation of catching a soft ball. Her face is animated and she looks in the direction of the caregiver. The position of her hands shows a readiness to catch the ball. On the table are brightly coloured Frisbees, which provide a prompt to the sport-based activity. This multi-sensory approach of visual stimuli, auditory, touch and movement is key to this sensory programme. A recent review of physical activity for the person with dementia shows limited research available in this area (Bowes, 2013).



Image 10 – a service-user catches the soft ball and leans back in satisfaction. She looks pleased at achieving her goal of catching the ball.

In another ball related activity, Image 11 shows a service-user leaning forward and picking up tennis balls from the table, which required concentration and hand-eye coordination. He then attempted to aim and throw them at the target held up by the support worker. If he was successful in hitting the target, the ball would stick. This activity appealed to the following senses: sight, touch, and sound.



Image 11 – a service-user picks up balls from the table in preparation for throwing them at a brightly coloured target. The room is well lit to allow maximum opportunity for success. His posture shows active forward movement and he acts purposefully to reach for the ball with only a verbal prompt. He has no direct assistance to move, reach or complete the action. Such purposeful movement is recognised and developed by Perrin (2008) in developing meaningful activity.

Service-users also enjoyed playing with a range of musical instruments. Image 12 shows an Enhanced Sensory Day Care service-user shaking a tambourine, engaging the senses of sound, touch and sight.





Image 12 – a service-user plays a tambourine showing real joy in her expression, watching the instrument closely as she performs. Other musical instruments are on the table next to her to act as visual prompts to the activity. This link between emotion and music is core to a study by Drapeau et al. (2009) who found that music could elicit emotional response even when the face and voice do not create a response.

Music chosen to fit service-users' taste was played using an iPod. Image 13 shows an Enhanced Sensory Day Care service-user tapping the table while she listens to her favourite music. An activity designed to stimulate the sense of sound, also stimulated the sense of touch and sight as she tapped the table. This service-user was also known to sing along to music she heard, and to get up and dance on occasion (with support from staff/volunteers).



Image 13 – a service-user listens to music on an iPod. Her lips are slightly open as though she is humming, her hands on the table beating out the rhythm of the music. She is sitting upright and actively looking at the other person with her at the table. The iPod and earphones appear to be undetected and do not intrude on her experience. Interestingly, at this stage of dementia it might be thought that introducing new technology might be a challenge for the person with advanced dementia. Clearly this is not always the case.



Image 14 – a service-user has a rest in a comfortable chair. His posture is relaxed and his eyes are closed. His feet fall away in gentle rest. Kovak (2000) who developed a 'sensoristasis' model of care has identified that the person with dementia at this stage requires periods of calm in order to respond to periods of purposeful activity. In effect, there should be periods of sensory stimulating, then sensory calming.

In advanced dementia, people can often be very sleepy. Enhanced Sensory Day Care allowed service-users to sleep without disturbance and to feel comfortable while doing so. Soft toys were very popular; here (Image 15), one service-user cuddles a toy seal. This activity engages the senses of sight and touch.



Image 15 – a service-user cuddles a soft toy, this is a baby seal. This approach has been used successfully in doll therapy and seal Paro. (Heerink, 2011). Her expression is calm and relaxed and her hands support the body and limb of the toy showing a response to managing its safety and preventing it falling to the floor.

## Summary

1. Five of the six service-users were classified as having either moderately severe or severe dementia. One service-user was classified as having moderate to moderately severe dementia (FAST scale).
2. Five of the six service-users were recorded as having a predominantly Sensory level of engagement in activities, while one service-user was found to have a Reflex level of ability for most activities (PAL checklist).
3. The family of one service-user did not want her to attend on a Sunday due to this

being considered a 'family day'. As a consequence, the family were given the option of continuing to attend two days of standard day care. Not exclusively attending Enhanced Sensory Day Care may have affected the results of the different measures used in the pilot study.

4. It took longer than expected to receive appropriate referrals from external agencies, which could be attributable to hesitancy among professionals to refer to a pilot (i.e. temporary) service.
5. A range of sensory activities were introduced, an observational log kept and documentary photos taken, to record service-users responses.



## SECTION 4: CONTRIBUTION TO QUALITY OF LIFE OF PERSON WITH DEMENTIA BASED ON CARER PERCEPTION

This section explores family carer perception of the quality of life for their relative based on the QUALID quality of life tool and staff/volunteer reported observations of how service-users responded to the interventions.

### OBJECTIVE

To evaluate the contribution attending the Enhanced Sensory Day Care makes to the quality of life of the person with dementia.

### METHODS

- 1) The Quality of Life in Late Stage Dementia (QUALID) scale (see Appendix I) (Weiner, 2000) was used to measure perception of quality of life of service-users as reported by the family carer. The QUALID tool has 11 sections with ratings including how often has the person: smiled; cried; appeared uncomfortable; or appeared emotionally calm and comfortable over the preceding seven days. The possible scores range from 11 to 55, with 11 representing the highest quality of life. The QUALID checklist was completed with family carers at week 1 and again after the person had attended the Enhanced Sensory Day Care service for 12 weeks.
- 2) Observational information about how service-users responded to the sensory interventions was provided by staff and volunteers in two emotional touchpoint group interviews (see Section 6 for details of this method) and also recorded in an observational log.

## METHOD OF ANALYSIS

The QUALID scores at week 1 and week 12 were collated in an Excel spread sheet and bar charts produced. Observational information about sensory activities which had been deemed particularly successful were identified in the verbatim transcripts of the two group emotional touchpoint interviews and in the observational log.

## FINDINGS

### QUALID SCALE – FAMILY CARER REPORTS

QUALID questionnaires were completed by family carers for four service-users, A, B, C and F at week 1 and week 12. Family carers of Service-user D and E did not complete a week 12 questionnaire. One service-user (D) had died in the three month period and his relative no longer felt able to participate in data collection. Family carers of another service-user (E) were also not able to complete a questionnaire at week 12 because during the three-month period their relative had moved out of the family home into a dementia assessment ward.

The respondent in all cases was the family carer who was familiar with the person with dementia's general behaviour. In one case, two family carers (husband and daughter) of one person with dementia gave joint responses to the questionnaire. Table 4 below shows the change in scores on each quality of life indicator for each of the four service-users who were able to complete the questionnaire at week 12. The lower the score, the higher the perceived quality of life. Figure 1 illustrates the change in total score at weeks 1 and 12. It should be noted that, in line with QUALID criteria, respondents were all instructed to score the questionnaire only according to the observed behaviour of the person in the past week.

Table 4 - Results of each quality of life indicator from the QUALID checklist at weeks 1 and 12 for each Enhanced Sensory Day Care participant

Quality of Life Indicator	Participant A		Participant B		Participant C		Participant F	
	1	12	1	12	1	12	1	12
A: Smiles	1	1	1	1	3	3	2	1
B: Appears Sad	1	1	1	1	1	1	3	1
C: Cries	1	1	1	1	1	1	5	1
D: Has a facial expression of discomfort - appears unhappy or in pain (looks worried, grimaces, furrowed or turned down brow)	2	1	1	1	4	1	2	2
E: Appears physically uncomfortable - he/she squirms, writhes, frequently changes position	1	1	5	1	2	3	1	1
F: Makes statements or sounds that suggest discontent, unhappiness or discomfort (groans, screams)	1	2	1	1	1	1	1	1

G: Is irritable or aggressive (becomes angry, curses, pushes or attempts to hurt others)	1	4	1	1	1	1	1	1
H: Enjoys eating	2	1	5	1	1	1	1	1
I: Enjoys touching/being touched	1	1	1	1	1	1	2	2
J: Enjoys interacting or being with others	1	1	1	1	3	1	2	1
K: Appears emotionally calm and comfortable	1	2	1	1	1	1	1	1
<b>TOTAL</b>	<b>13</b>	<b>16</b>	<b>19</b>	<b>11</b>	<b>19</b>	<b>15</b>	<b>21</b>	<b>13</b>

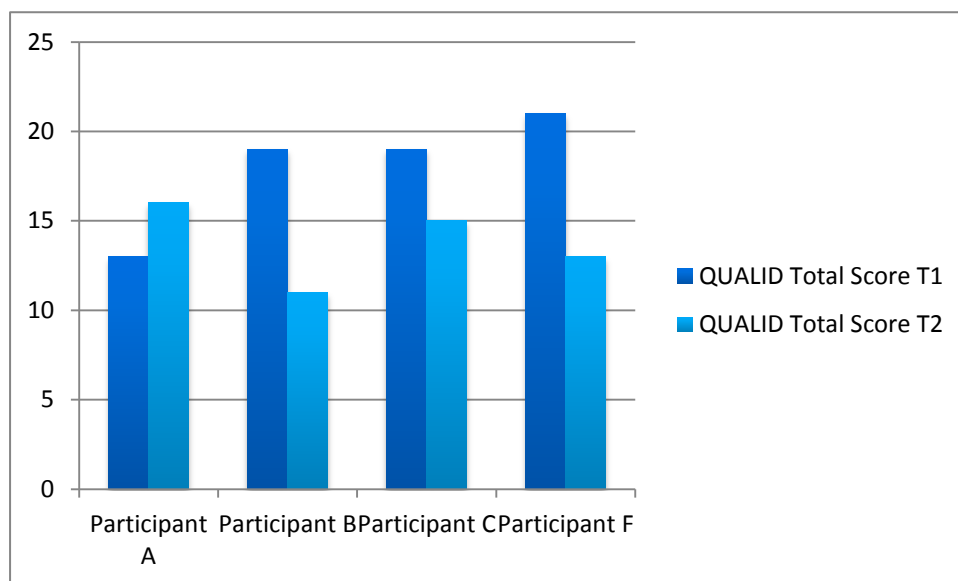


Figure 1 - DSDC service-users' QUALD scores at week 1 and week 12

In all cases, according to the researcher's judgment, the answers given by respondents appeared valid in that they understood the question being asked and responded in line with their relative's behaviour in the past seven days. For validation purposes, and to ensure consistency, two members of the research team completed the QUALID independently of each other.

As Figure 1 illustrates, the overall scores decreased for three of the four service-users indicating that their quality of life was perceived to be higher in the week of the second interview after 12 weeks than the interview in week 1. For one participant, their quality of life was perceived to be lower at the second interview.

- Participant A: had fewer facial expressions of discomfort (looking worried, grimacing, showing a furrowed or turned down brow) and appeared to enjoy eating more. However, the participant more often made statements or sounds suggesting discontent, unhappiness or discomfort, appeared slightly less emotionally calm and comfortable at times, and was irritable or aggressive without cause less than once each day.
- Participant B: appeared much less physically uncomfortable (squirming, writhing, frequently changing position) and appeared to enjoy eating much more at 12 weeks.
- Participant C: had facial expressions indicating discomfort (looks worried, grimaces, furrowed or turned down brow) less often (rarely or never) at week 12 than at week 1 (nearly half of each day). The participant also appeared to enjoy interacting with people more. However, at week 12 he also appeared slightly more physically uncomfortable (squirming, writhing, or frequently changing position)

- Participant F: was perceived to smile more often and appear sad and cry less often at week 12. There was also perceived to be a small improvement in the participant's enjoyment when interacting with others.

It should also be noted that due to the progressive nature of dementia, the condition may have advanced over the 12 week period which could have impacted on the indicators.

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#### STAFF OBSERVATIONS OF EFFECTS ON QUALITY OF LIFE

Staff and volunteers made various observations, either during the emotional touchpoint group interview at 12 weeks (see Section 6 for details of this method) or in the observation logbook, about sensory activities which service-users appeared to have particularly enjoyed or demonstrated a positive response to. Activities were often deemed to have elicited a positive response if service-users were able to vocalise their appreciation in some way or, indeed, to vocalise anything at all in some cases. A number of service-users spoke very few words, if any, and any interaction which prompted more words or an attempt by them to communicate was deemed encouraging.

Some service-users appeared to respond well to the doll (Rosebud). One service-user was recorded as saying to the doll "what a bonny tot". Another cuddled and nursed the doll and kissed its forehead. On this activity, a member of staff commented in the group interview:

*The dolls were amazing [...] one participant wasn't speaking much, and you called me in, and he was, I think he was actually having a conversation with this baby.*

Service-users also participated in making fairy cakes and all the different sensory aspects to this activity were deemed to provide a lot of stimulation for people. Some were witnessed chatting to each other whilst undertaking the activity and, upon tasting the fairy cake, one person commented “they are good”. Service-users also appeared to enjoy sitting out on the veranda at the day centre with members of staff where they could have some fresh air and watch activities going on beside the river. One service-user spontaneously commented on what he saw: “there’s a wee boy on his bike” while another waved at passers-by.

Other examples reported by staff and volunteers of communication from service-users included when a service-user recognised and said “butterflies” while they were touching a quilt with pictures of butterflies on it or when another service-user was looking at some large format photography books, they pointed at a picture of a boy smoking and said: “that boy should not be smoking, he’s too young”. When a service-user was being given a hand massage with scented moisturiser, they were heard to say that it “smelt nice.”

Undertaking some of the sensory activities appeared to enable staff members and volunteers to form a bond with service-users. As one staff member commented during the group interview:

*The first time I worked with this lady I read in her notes that she really relaxed if she has her hair brushed so before we’d even had a chat or exchanged a few words I just sat there brushing her hair for her and I realised that was a little wee magic moment there because she just fell asleep.*

Service-users were reported to spontaneously reach out and hold hands with staff on occasion which was taken as an indication of a desire for touch and comfort. A number of service-users also appeared to particularly enjoy listening to music and

using musical instruments. They were perceived to show their enjoyment by singing along, clapping, whistling, tapping their feet to the music or tapping the table with their hand in time with the music. Finally, the 'sensory' food, in this case ice-cream, was found to help one service-user who was finding it difficult to swallow that day. The service-user enjoyed the ice-cream and he appeared more alert after eating it.

In general, staff and volunteers felt that service-users were being helped to communicate more as a result of the one-on-one attention and the inclusive and stimulating activities. One volunteer who had worked previously in standard day care with a service-user expressed surprise that she was still able to communicate verbally:

*P4 : The most surprising thing for me about the people who've been here is [service-user]'s speech cause I ...*

*P2: Amazing*

*P4: I honestly thought [service-user] had lost the speech*

*P1: Yes*

*P4: You know, I thought she couldn't say any words 'cause I'd only seen her at ordinary day care and I'd never heard her say a single word.*

Other staff and volunteers clearly attributed the increase in communication to the one-to-one attention they were able to give services-users:

*P1: it's not like a miracle but it's, it's just the extra*

*P2: time*

*P1: numbers game that we can play here which is better ratio, it really works.*

Staff also noted that improvements in communication were recognised by family carers:



*It's nice to hear the families saying that they didn't have a lot of communication before but now they're getting more communication back from them and talking more.*

## **SUMMARY**

10. Quality of life was perceived to be higher for three of the four service-users after 12 weeks. For one participant, their quality of life was perceived to be lower after 12 weeks.
11. Staff and volunteers perceived that the Enhanced Sensory Day Care Service improved service-users' quality of life due to the increase in communication they perceived from the service-user.
12. Staff and volunteers attributed improved communicative abilities on the part of service-users with the one-to-one attention they were able to give them as a result of the lower staff-user ratio.
13. Shared sensory activities, such as brushing service-users' hair or giving them a hand massage, facilitated 'magic moments' in the caring relationship.

## SECTION 5: IMPACT ON FAMILY CARERS AND PLACE OF CARE

### EMOTIONAL TOUCHPOINTS INTERVIEWS

This section details the design and methods used to determine the impact on family carers and place of care.

#### OBJECTIVE

To explore the contribution of the Alzheimer Scotland Enhanced Sensory Day Care Model to family caring for people with advanced dementia.

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#### METHOD

Individual emotional touchpoint interviews were conducted with family carers of EDSC service-users after 12 weeks of attendance. The emotional touchpoint method was devised by researchers at the NHS Institute for Innovation and Improvement and is a visual framework method designed to:

1. encourage people to talk about their emotional responses to events
2. identify co-created solutions to problems in healthcare practice (Dewar et al. 2009).

The first aim of the method is based on the assumption that, generally, people do not have a rich emotional vocabulary (Freshwater 2004), and that offering examples of emotional words can help people to describe more accurately what the experience felt like in a way that moves beyond statements like 'good', 'fine' or 'difficult'. The second aim of the method is to counteract the tendency in healthcare for solutions to be imposed by management, rather than generated by the people who themselves use the service.

Touchpoints are representative of the key moments identified as being crucial in the experience of receiving or delivering a service. They can be bigger moments that people instantly recall as affecting them emotionally, or smaller moments that left an impact on the individual. Potential touchpoints are created in advance of the interview with scope to change or add new ones. In this pilot study, family carers were presented with two general touchpoints during their interview: *Learning New Ways to Care* and *Future Care*. Both were devised to be sufficiently open to incorporate a number of different aspects of the caring experience. Carers were advised that they could also identify their own personalised touchpoints which were felt to be of personal significance throughout their experience of being a carer for their relative. Participants were then asked to identify emotions which they associated with each touchpoint. Emotions were selected from a predetermined set of emotion words (see Table 5) which had been decided in advance by the research team, although carers were informed that they could also identify their own emotions which would be written on blank cards.

<b>Broadly 'positive' emotions</b>	<b>Broadly 'negative' emotions</b>
Fortunate	Let down
Pleased	Overwhelmed
Supported	Guilty
Relieved	Worried
Hopeful	Unsupported
Happy	Frustrated
Safe	Powerless

Table 5 – the emotion words identified in advance by the research team and presented to family carers as possible responses to the touchpoints

The above emotion words were displayed to participants and then physically placed on the touchpoint as a visual aid to facilitate further discussion (See Figure 2 below):



Figure 2 - touchpoint 'learning new ways to care' with some of the emotion words placed on it to act as a visual aid.

Each participant was then invited to discuss the emotions they had associated with the touchpoint. Where appropriate, they were also asked to discuss how things could have been different, particularly if the emotion identified was a negative one.

Four of the five interviews (two relating to the same Enhanced Sensory Day Care service-user) were conducted individually in the participant's own home, while the person they cared for was at day care. One interview was conducted in the home of the co-carer. All were tape-recorded and transcribed verbatim.

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## METHOD OF ANALYSIS

The emotion words identified by family carers were extracted and presented in a table (see Table 6). The verbatim transcripts of the interviews were read and re-read in a process of deep familiarisation. Comments and suggestions about the service

were identified and collated according to topic e.g. continuing the sensory activities in the home. Once collated, the most salient points were extracted, illustrated by quotes which were found to be particularly illuminating, or which had emotional resonance for the researcher (which is a facet of the emotional touchpoint method). The data was not subject to a process of co-analysis (between researcher and participant) as advised in the emotional touchpoint method. This was due to not wanting to overburden carers with evaluative tasks when their spare time was very limited. However, they were asked for proposed solutions to any problems they identified, and the findings presented below incorporate these suggestions.

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## FINDINGS

Brief emotional touchpoint interviews were conducted with five family carers of four people with dementia who attended the Enhanced Sensory Day Care service. Of the eight family carers originally involved in the study, one carer did not want to take part in the interview at 12 weeks because the person she cared for had died and she no longer felt able to participate. The other two carers declined to participate because their relative had been withdrawn from the service as a result of having to move into a dementia assessment ward. Overall participants felt supported in their present care arrangements and anticipated being supported in the future by the day centre staff, the care staff who currently visited them at home, and other family members. While there was some diversity in the views expressed, carers were very appreciative of the day care service.

The emotions identified by participants in response to the general touchpoints used during the interviews are listed in Table 6:

Table 6 - emotion words selected and comments made by participants in response to two emotional touchpoints

Service-user ID	Pseudonym	Carer Pseudonym	Relationship	Touchpoint: Learning new ways to care	Touchpoint: Future Care
A	Jane	Robert	Husband	Encouraging, helpful, and frustrated (with Jane occasionally)	Not worried
		Liz	Daughter	Supported, and pleased that Jane is comfortable, content, and safe	Not worried; Supported
B	Mavis	Anne	Daughter	Fortunate, hopeful, relieved, supported and happy that Mavis is safe	n/a (as Mavis died during the 12 weeks)
C	Geoffrey	Jean	Daughter	Supported, fortunate, pleased that Geoffrey is safe, sometimes frustrated.	Worried, overwhelmed (by caring responsibilities), supported, guilty
F	Gwen	Donald	Husband	Happy, supported	Supported

The touchpoints and emotion words used in the interview acted as a visual prompt, but were not fully engaged with by participants who were, in general, willing to share their story and their emotions without the need for the visual prompts. In cases where the individual was not very forthcoming about their emotional response, the emotion cards were not thought to help in eliciting one. Generating the touchpoint in the

interview encounter itself might have resulted in a more complete story forming around that touchpoint. However, this runs the risk that the participant will feel pressure to come up with a touchpoint on the spot, and presents difficulties with cross-case analysis if all touchpoints are different. Overall, participants seemed at ease talking about their emotions and were able to present a picture of their caring role, which included making suggestions about how they could be better supported. The emotional touchpoint method did not appear to enhance the quality of the data generated or significantly improve the interview encounter when compared to the data generated by the in-depth interview (see part 2 of this Section). However, it may be a limitation that the emotional touchpoint method was not followed to the extent of co-producing solutions to issues raised by participants.

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#### TOUCHPOINT 1: LEARNING NEW WAYS TO CARE

This touchpoint was intended to prompt discussion of whether carers had used any of the sensory stimulation activities at home with their relative and how they felt about this. However, in discussions around this touchpoint, carers focused more on what day care meant to them. As shown in Table 6, people felt ‘happy’ and ‘supported’ by the day care service because it gave them a break from their caring responsibilities. They also felt ‘fortunate’ and ‘pleased’ that they could be assured that their relatives’ needs were being attended to in a caring environment. Some carers felt it was important that day care offered their relative the opportunity to interact with other people who had the same condition as them. When prompted to comment on what they thought about the enhanced sensory service specifically, participants again registered support. In some cases, this was because carers

worried that if the enhanced service did not exist, then their relative would not have the option of day care at all, that she/he would be 'put out':

*At the one [dad] was at, he was no longer getting very much out of it because you need to have a degree of being able to mix in and stay awake and he was spending most of his time asleep [...] We were feeling guilty about him taking up a place there (Jean, daughter of Geoffrey).*

As Jean's comment shows, there was some anxiety expressed among carers about the lack of day care options for people in the later stages of the disease who were perhaps incontinent and spending a lot of time asleep.

When carers were prompted to comment on whether the sensory stimulation activities had produced any noticeable changes in their relative, Anne made the following comment about subtle changes she had noticed in her mother:

*She would be trying to walk and do things that she wouldn't normally do [...] She would be wanting to hold things herself and she'd take the cups sometimes and she was just happier within herself and she wanted to, because of the way they did it, she wanted to intermingle more.*

Liz, on the other hand, had noticed that her mum seemed 'relaxed' when she returned from Enhanced Sensory Day Care:

*[Mum is] a little bit calmer and comes in smiling most of the time (Liz, daughter of Jane)*

Another carer, Donald, had noticed that his wife Gwen seemed a bit 'lost' and 'quiet' the day after attending the service, which he attributed to the attention she received while she was there:

*I think she missed these people and that's only my thought on it because she comes back and it's only her and me. It's like my son – if you took him to a party when he was small and that, he enjoyed it so much that he didn't want there to be an ending, he wanted to go on and on having fun, and I think maybe with Gwen that's the situation.*



In Donald's view, Gwen's mood on the day following Enhanced Sensory Day Care was to do with the interaction and stimulation she had received whilst there. Other carers also commented on the individual attention their relative received at Enhanced Sensory Day Care which they viewed as beneficial, given their relative's level of dependency.

So whilst there was acknowledgement of subtle changes and relatives 'having fun' or being 'calmer' after attending Enhanced Sensory Day Care, there was an acknowledgement that it was 'very difficult to know' or evaluate if there were any benefits to the sensory activities, because their relative was unable to tell them:

*We are very happy with [dad] going there, it's just not easy to say 'yeah, he's having a great time' (Jean, daughter of Geoffrey).*

There was also a recognition by some that there was a process of natural deterioration occurring which also made it difficult to assess any changes in well-being resulting from the Enhanced Sensory Day Care service.

Finally, carers were prompted to talk about whether they had tried any of the sensory activities at home as a result of training received at the Centre, and how they felt about engaging with their relative in a 'sensory' way. Training mentioned by carers was on nutrition and oral hygiene. In relation to the nutrition training, one carer mentioned feeling 'frustrated' because the theoretical techniques for encouraging swallowing had not worked when she tried them at home and she wished that someone had been able to demonstrate the techniques on her dad. The same carer mentioned that despite an emphasis placed on nutrition, when the service first started she felt that food with low nutritional value had been provided such as white bread and tinned soup. However, she acknowledged that this issue had since been

rectified. The training on oral hygiene was mentioned by one carer who said she 'didn't learn much there'. Despite the fact that carers had not received any specific training on the use of sensory activities, all mentioned that they engaged in some kind of sensory activities with their relatives at home, whether that involved playing music, singing, using soft toys, puppets, or giving cuddles or hand massage. Robert described what he did at home with Jane:

*I try to read to her and she quite likes music and I put on the music [...] the music sort of stimulates her. I think it's good for everyone, it's a therapy isn't it because sometimes it makes people come alive.*

Anne mentioned a soft toy which had comforted her mother:

*We gave her a little penguin, it was like a baby, even in the hospital she was getting disturbed so the ladies picked it up and gave it to her to cuddle.*

Anne was also convinced of the value of touch and her mother's positive response to being touched:

*The touch, they need that, it's human, it's warmth, it's basic. My mother loved her hair. Do anything with her hair and she would go from being a monster to being a wee darling!*

So while carers seemed to value the fact that their relative was being provided with sensory stimulation at day care, they reported that they had already been doing some sensory activities at home. It did not appear that they had increased the amount of sensory stimulation they were giving their relative since their relative began attending Enhanced Sensory Day Care.

A final comment made by one relative with regards to the sensory activities undertaken in the Enhanced Sensory Day Care service was that she felt her father had been 'type-cast' as someone who enjoyed picture books, whilst she felt that there were a number of other sensory activities which he might respond well to. In

fact, comments from the observation log show that Geoffrey responded well to the doll Rosebud, but, according to his daughter Jean, 'it never seems to have appeared again.' Jean suggested that there were perhaps too many sensory props available in the room, and that there was a chance that staff forgot about the variety of things available.

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## TOUCHPOINT 2: FUTURE CARE

This touchpoint was used to elicit a discussion about whether carers anticipated continuing to care for their relative at home, and reflections on end of life care. Carers' choice of emotion words (see Table 6) reveal that while some were worried, others were not and there was a general sense of feeling supported. Robert was someone who said that he didn't worry about the future:

*I take one day at a time [...] I don't worry about it, but I know there's different stages to go through'.*

In Robert's comment we can see he did acknowledge that his wife's condition would change in the future, and that the current care arrangements, which were felt to be working, may not work in the future. His daughter, Liz, with whom he shared caring responsibilities, commented:

*We do talk as a family as to what the next step would be when the next phase comes along. And both my brother and I and my dad do feel that we want to keep Mum at home if we possibly can. I mean, if Mum had a stroke then it may be difficult, but I think that we would work with it until we are beaten.*

Liz, like other carers of relatives who attended the Enhanced Sensory Day Care service, was determined that all efforts would be made as a family to care for her mother at home and avoid having to admit her to a care home. For some, this was a response to reading news reports and hearing anecdotal reports about poor care

received in care homes. Some also worried about the guilt which might arise from such a move:

*Neither my sister nor I would live with how guilty we would feel if we left him in a home and even if people say 'but he'll be well looked after', he's not going to be as well looked after as he is here (Jean, daughter of Geoffrey).*

Carers generally felt that they would rather incrementally increase the amount of outside support they were bringing into the house before they would consider a care home.

Another source of worry for some was what would happen to their relative once the enhanced pilot service came to an end and whether that might mean that day care was no longer an option for them. It was felt that this would precipitate a need to bring more care into the home so that the carer could continue to receive respite.

## IN-DEPTH INTERVIEWS

### OBJECTIVE

The intention here was to compare the experience of family carers whose relatives attend a standard day care provision, where there is a focus on group activities, with carers whose relatives experience the Enhanced Sensory Day Care Service, where there is a focus on giving one-to-one attention.

### METHOD

In-depth semi-structured interviews were conducted with family carers in both services. The short interview guide is reproduced in Figure 3:

- How does day care fit with the rest of your relative's week/activities?
- What is working well?
- What could be done differently?
- Would you describe the service as supportive?
- What, to your mind, is the best way to support family caring?
- Have you been given opportunities to make suggestions about day care?
- How do you envisage your relative's care a month or a year from now?
- How does thinking about your relative's future care make you feel?
- How do you envisage being supported in your caring role in the future?

Figure 3- interview schedule for carers whose relative attend standard and sensory day care services

Although it was originally anticipated that recruitment of family carers whose relative attended standard day care would take place in the same Alzheimer Scotland day centre where the Enhanced Sensory Day Care was operating, this did not prove to be possible as staff could not identify suitable family carers who would be willing to be interviewed. Recruitment subsequently took place at two other Alzheimer Scotland day centres in Scotland. The research team aimed to balance the number of carers interviewed for standard day care services with the enhanced sensory service i.e. a minimum of 5 interviews.

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## ANALYSIS

A thematic analysis was carried out on the full interview transcripts of standard service carers and enhanced sensory service carers. This was undertaken in an inductive way, generating themes or codes from the data and then subjecting the

verbatim transcripts to a coding process (Strauss & Corbin 1990). This was undertaken using NVivo data management tool. It was decided that after the synthesis of useful contextual data, such as people's current care arrangements, the focus would move to an in-depth exploration of three key themes: respite; potential barriers to attending day care; and views on care homes.

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## FINDINGS

Seven interviews, including one dyad (where two family members were interviewed together) were carried out with carers of people with dementia who attended a standard day care service in a different part of Scotland run by the same provider. Six of these interviewees were relatives and one was a friend who had power of attorney. One participant was now classified as a former carer as his wife had died, which meant that the account he gave was retrospective. Five family carers were interviewed of four people with dementia who attended the Enhanced Sensory Day Care service. All interviews were carried out in person, either at the carer's own residence, the residence of the person they cared for, or in the day centre. In three cases, the person with dementia was present in the house, usually in another room, for the duration of the interview. Interviews lasted between 20 minutes and one hour and were recorded and transcribed verbatim. Table 7 lists the standard day care carers and their pseudonyms which are used in the subsequent analysis:

<b>Service-User ID</b>	<b>Pseudonym</b>	<b>Carer Pseudonym/s</b>	<b>Relationship</b>
Service-User 1	Penelope	Katherine	Daughter
Service-User 2	Marjorie	Julie	Friend
Service-User 3	Rosemary	David	Husband
Service-User 4	Eleanor	Jonathan	Son
Service-User 5	Elizabeth	Phillipa	Daughter
Service-User 6	Doris	Fred	Husband
Service-User 7	George	Geraldine and Leslie	Daughter and Son-in-law

Table 7 - Standard day care service-user ID, pseudonym, carer pseudonym, and relationship to service-user

As evident in the emotional touchpoint interviews with family carers of people with advanced dementia, family carers of people attending the standard day care services were quick to comment that they found the service very 'helpful' and 'supportive' and trusted that their relative was being well looked after and was happy to go to the day

care. It was not possible to carry out a PAL checklist or complete a FAST scale with the person attending the standard service, so their stage of dementia was not known, or how this compared to the Enhanced Sensory Day Care sample. However, it can be deduced from comments made by carers about their relative's ability levels that, in general, the person with dementia was at the 'moderate' rather than the 'advanced' stage. When asked about what their relatives did while attending day care, the following activities were mentioned: Tai Chi; craft activities; having hair and nails done; doing the crossword; snakes and ladders; bagatelle; singing and dancing; and football reminiscence. Relatives attended day care between one and three times a week. Care packages varied, with some families managing on day care and family caring alone, and others had professional carers coming into the house two or three times a day for short periods, usually at meal times.

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#### THE BENEFITS OF DAY CARE

As discussed earlier in this section, family carers of people attending the Enhanced Sensory Day Care found it difficult to judge if their relative was receiving any benefit from day care because of their communication and memory difficulties. This was also found to be the case for relatives of people who attended the standard service, some of whom acknowledged that they did not really know what their relative did at the day care. All carers were able to judge whether their relative appeared to enjoy day care, and they judged this through their expressed willingness to go to day care and their mood on return from day care.

*I don't know, I don't go and see what she does there, I can only go by how it helps me and what feedback I get from Mum [...] the bus arrives in the morning and she's keen to get on the bus to go. I know that she's aware of where she's going and I know when she comes back she's aware for a short period, and then she'll quickly forget [...] so I know all those things. I don't know what actually happens when she's there (Jonathan, carer of Eleanor).*



Some carers were informed of what their relative had done that day because it was noted down in a book which was transferred between staff and carer each week. Information was considered helpful for providing a sense of their relative's day, and even in so far as it gave details about whether they had used the toilet or not. While some carers acknowledged that they might not know *exactly* what their relative had done at day care, they felt that, while they were there, their relative was content:

*I feel my mum's situation is such that as long as she can have a lot of positive moments, 'cause she lives very much in the moment, so the day care centre is a good moment as it were* (Katherine, carer of Penelope)

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## RESPIRE

The responsibility of caring for the person with dementia raised different emotions for people, including frustration and occasionally a feeling of being overwhelmed by the administration, appointment making, and amount of evaluations which accompanied the caring role, notwithstanding helping with activities of daily living such as dressing, washing and eating. For instance, carers spoke about the difficulties of trying to go on holiday. They spoke of meticulously putting care arrangements in place prior to their departure, only to get a telephone call once they had reached their destination saying that their mother or father had been found 'wandering' on a main road or had 'absconded' from their care home. This inability to get away for an extended break without worrying about what was happening to their relative at home caused carers significant stress. Although day care did not allow carers a holiday as such, it did offer them a 'little break' from their responsibilities. For example, day care helped Robert to manage the frustration he sometimes felt, or sense of being 'trapped', when he did not have any time to himself:

*I like looking after her but at the same time it can be difficult, well, for anyone really. You want to do the best you can for her although it's very difficult at times, especially when there's no real communication (Robert, carer of Jane).*

These comments were echoed by Fred. His respite came in the form of fishing, and day care enabled him to get away for long enough stretches of time to engage in this hobby.

*You start getting weary after 12 hour days, like really frustrated during the day, but when they take her away to day care, phew, then I know I don't even have to think about it like because they're thinking about it.*

Other comments on the respite which day care offered ranged from it enabling people to engage in paid employment, to it allowing them to 'get back to the real world' or to 'draw breath and reflect'. Certainly, the benefits of being freed from caring duties for a significant period of time was central to people's dependency on day care.

While Fred managed not to think about Doris while on his fishing trips, Donald struggled to switch off from thinking about his wife Gwen who attended the Enhanced Sensory Day Care:

*Sometimes I sit here, you know, she's always on my mind. I keep saying, I wonder what she's doing at this moment.*

Donald explained that he and Gwen had been together all their lives and that they had never really been apart. Like Donald, Jonathan also initially struggled to switch off and enjoy his periods of respite, but in his case it was because of the guilt he felt at having to rely on others to help him care for his mother.

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## POTENTIAL BARRIERS TO ATTENDING DAY CARE

While carers wanted their friend/relative to continue to attend day care for as long as possible, some had already experienced problems finding a service which would accept their relative, while others were fearful about possible future barriers to continuing with day care. Marjorie had recently been 'suspended' from attending her usual day care because she showed signs of severe agitation while she was there. Julie, Marjorie's friend, was told that she had been swearing at people, and refusing to sit down etc.:

*She wasn't participating. She was anxious, she wanted to go out [...] They're finding it difficult to cope with her now so she stopped going in the last week.*

The loss of day care was a concern to Julie because although Marjorie had live-in carers, she felt that day care provided her with activities which the carer wouldn't be able to engage her in, like having a communal sing-song. Julie wondered if the reason behind Marjorie's agitation while at day care was to do with the fact that she had been 'spoilt' through having one-to-one care the rest of the time. In Marjorie's case then, it was severe agitation which was the barrier to attending day care.

For Anne, whose mother Mavis had attended the Enhanced Sensory Day Care, her worries had centred on whether Mavis was going to be asked to leave or 'put out' of her standard day care because she was too sleepy to engage in regular activities. Anne said she found it 'depressing' when the book filled out by staff said 'she's piddling all the time and she's sleeping all the time.' Concerns about the suitability of day care for people in the later stages of dementia were shared by other carers whose relatives had not yet reached that stage:

*A lot of these day cares say, well, we take just frail elderly they call it, and slight to moderate dementia, and you think, what happens when they pass that, you know? [...] you just wonder if there is a point where they then say, 'oh, she's past day care' (Phillipa, carer of Elizabeth)*

Another potential barrier, along with agitation, incontinence, and not being 'active' or 'awake' enough, was the practicalities of actually travelling to the day care. David, for example, had faced this barrier when his wife Rosemary's condition deteriorated:

*She was desperately slow and [Alzheimer Scotland] are going round with a bus to pick up 8 or 10 people and Rosemary was taking about half their time to get herself [in the bus].*

David's solution to this problem was to drive Rosemary to day care himself.

However, as her mobility decreased he had to lift her into the car, and at one point Rosemary fell and David, unable to lift her up again, had to phone for help. It was around this time that David was advised to move Rosemary into a care home to avoid any future, more serious falls.

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## CARE HOMES

The final key theme identified was how carers felt about the prospect of their relative moving into a care home. Earlier in this section comments from carers of people attending Enhanced Sensory Day Care were explored with regards to this issue.

Looking across all carers, similar sentiments were expressed, along the lines of 'I know her better than anyone' and 'no one will look after them as well as you will'.

There was a sense that when people were family, they had a shared history and they knew their relative's likes and dislikes and their social networks. Fears were also expressed that their relatives might be neglected or mistreated in a care home:

*Knowing that it can take an hour and a half to feed [Dad] breakfast I don't believe that in any care home they would spend that amount of time (Jean, carer of Geoffrey).*

And:

*I think they would sedate her more. I don't know, I just feel that they'd just be sitting round a room (Julie, carer of Marjorie).*

While some people said that they would increase the professional help they were receiving at home before they contemplated moving their relative into a care home, other people felt that they were already at their limit. Katherine, for example, said she felt she was already at the limit of what she could 'comfortably cope with' in terms of the current care arrangements and that if her mother's care needs increased or 'when she starts not knowing who I am', she would have to move her into a care home. She acknowledged that in an 'ideal world', she would look after her mum 24/7 but she had her own family and did not think it would be fair to them. She also anticipated that it might bring a 'sense of relief because the responsibility has shifted slightly.'

Another complicating factor when contemplating a move to a care home was the relative's willingness to move. For Geraldine and Leslie, the reluctance of Geraldine's dad George to go into a care home even for a week of respite suggested to them that, if it came to it, their only option would be to section George and move him into a home against his will, which they were very reluctant to do:

*L: [George] will only go into a home if*

*G: his memory completely goes*

*L: there is a court action taken out that the control comes out of him.*

While the link between the fact of attending day care and avoiding admission to a care home was implied by some, Jonathan, carer of Eleanor, drew an explicit connection:

*[Day care] makes a huge difference socially to her well-being, and it plays a huge part in, you know, her being able to still live in her own home.*

## SUMMARY

1. Overall participants whose relatives attended a standard day care service felt supported in their present care arrangements and anticipated being supported in the future. Carers expressed appreciation for the day care service.
2. Family carers of relatives attending Enhanced Sensory Day Care (n=5) worried that if the enhanced service did not exist, then their relative would not have the option of day care at all (because of their propensity to sleep a lot, or because of incontinence) and that she/he would be 'put out' of day care.
3. Family carers of relatives attending Enhanced Sensory Day Care were not given the option of attending many training sessions on sensory care. However, some already engaged in sensory activities with their relatives.
4. Both family carers of relatives attending Enhanced Sensory Day Care (n=5) and of relatives attending standard day care (n=7) valued the respite which day care offered, allowing them time to 'get back to the real world' or to 'draw breath and reflect'.
5. Both Enhanced Sensory Day Care and standard day care family carers expressed concerns about the prospect of having to move their relative into a care home, fearing that 'no one will look after them as well as I will'.

## SECTION 6: STAFF AND VOLUNTEER PERSPECTIVES

### OBJECTIVE

To assess staff and volunteer beliefs about their ability to deliver the enhanced sensory service and to examine their experiences of delivering the service.

This section presents process and findings from self-efficacy questionnaires completed by staff and volunteers to determine their confidence and knowledge in administering an Enhanced Sensory Day Care service to people with advanced dementia. Findings from emotional touchpoint group interviews at weeks 1 and 12 are presented.

### METHOD

1. Self-efficacy questionnaires (see Appendix J) were completed with staff and volunteers at the start of the study (week 1 - January 2014) and again after 3 months (week 12 – April 2014). Self-efficacy in this instance relates to the staff member's or volunteer's beliefs and personal judgements about their ability to be competent and capable in given situations (Bandura, 1997). It is associated with one's beliefs about one's own competence and ability to respond or act appropriately. The concept has been widely used within studies of caring including caring for people with dementia (Steffen et al., 2002, Fortinsky et al., 2002). Unlike self-esteem and self-mastery, which are conceived as relatively stable constructs, self-efficacy often changes within the same individual over time and in response to specific experiences (Bandura, 1997).
2. Emotional touchpoint group interviews (x2) were conducted with staff and volunteers (see Section 5 for an explanation of the principles behind this

method). Those assembled were presented with three touchpoints which had been agreed in advance by the research team: *being with people with advanced dementia*; *communicating with the person* and; *selecting appropriate sensory interventions*. These touchpoints were intended to be sufficiently open to incorporate a number of different aspects of the staff/volunteer experience. Staff and volunteers were advised that they could also identify their own personalised touchpoints i.e. specific events, activities, or ‘moments’, which were felt to be significant to them in their job of caring for people living with advanced dementia. Staff/volunteers added the following touchpoint: *building a new team* due to the nature of the new service – whilst all staff currently worked or volunteered for Alzheimer Scotland they did not work in the same day service or day centre and not all knew each other. All had volunteered to work in the new service. Participants were then asked to identify three or more emotion words which they associated with each touchpoint. Emotion words were selected from a predetermined set of words although those attending were informed that they could also identify their own emotions in addition to those written down on the cards.

## ANALYSIS

A T-test was performed on the self-efficacy questionnaire results. This method was chosen in order to show the change in staff and volunteers’ perceived competence to deliver the enhanced sensory service. A T-test allows for the fact that a different number of people completed the self-efficacy questionnaires at week 1 than did at week 12.



The emotion words selected by staff in response to each emotional touchpoint at weeks 1 and 12 were listed in a table (Table 8) and photographs taken. Additional comments made by staff/volunteers during the group interview were collated and summarised according to the touchpoint themes.

## FINDINGS

At week 1, a total of 16 staff/volunteers completed self-efficacy questionnaires and attended one of two emotional touchpoint group interviews. At week 12, eight staff/volunteers completed self-efficacy questionnaires and attended one of two emotional touchpoint group interviews. The known reasons for this attrition were: participants' conflicting work schedules; and some role changes in the intervening 12 weeks. Other reasons remain unknown.

## SELF-EFFICACY QUESTIONNAIRES

The table and graph below show the changes in self-efficacy scores for staff and volunteers between January and April 2014. While staff and volunteer belief in their ability to undertake all activities with service-users with advanced dementia had improved after 12 weeks, the improvement was most marked across the sensory activities.

	Time 1 (n=16)		Time 2 (n=8)		T-Test Sig.
	Mean	Std. Deviation	Mean	Std. Deviation	
Q1. Life story	4.94	1.81	6.25	.89	.067
Q2. Interact	5.00	1.41	6.13	1.13	.063
Q3. Meals	5.44	1.15	6.00	1.20	.277

Q4. Interventions	3.81	1.60	5.88	.84	.003
Q5. Physical	3.75	1.69	5.88	.84	.003
Q6. Smell	4.13	1.67	5.63	.74	.025
Q7. Touch	4.19	1.60	5.75	.71	.016
Q8. Taste	4.06	1.73	5.75	.71	.015
Q9. Hearing	4.25	1.61	5.88	.84	.014
Q10. Sight	4.25	1.57	5.63	1.06	.037

Table 8 – mean scores and standard deviation from the mean across the scores for each of the activities at week 1 and week 12)

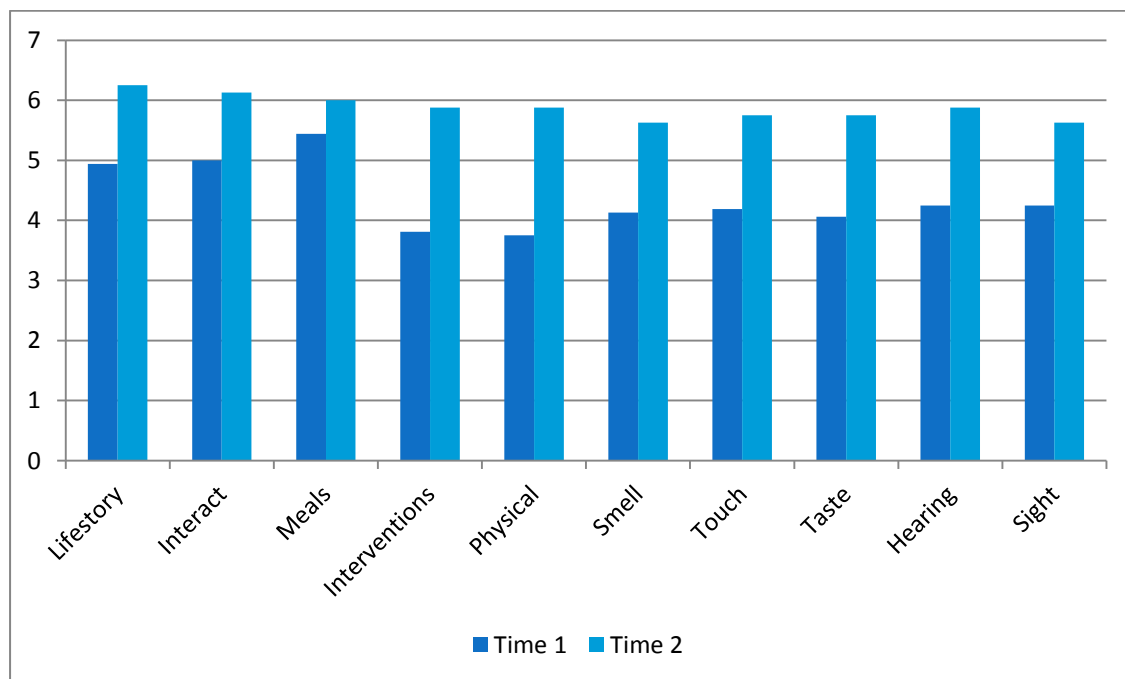


Figure 4 – bar chart showing changes in self-efficacy mean scores between weeks 1 and 12

## EMOTIONAL TOUCHPOINTS

### BUILDING A NEW TEAM

#### January 2014



Full list of emotion words chosen by staff/volunteers:

1. Capable	2. Enthusiastic
3. Up beat	4. Interested
5. Hopeful	6. Valued
7. Encouraged	8. Wonderful
9. Curious	10. Pleased
11. Safe	12. Happy
13. Appreciative	14. Thankful
15. Motivated	16. Nervous
17. Supported	18. Excited
19. Keen	

#### April 2014



Full list of emotion words chosen by staff/volunteers:

1. Capable	2. Enthusiastic
3. Up beat	4. Appreciated
5. Hopeful	6. Valued
7. Encouraged	8. Wonderful
9. Curious	10. Pleased
11. Included	12. Happy
13. Keen	14. Proud
15. Supported	16.

Figure 5 – photos of a selection of the emotion words and a list of all the emotion words selected by staff/volunteers at emotional touchpoint interviews in January and April 2014 in response to the touchpoint ‘Building a new team’

At week 1, staff and volunteers spoke of feeling enthusiastic, excited, motivated and that they appreciated being given the opportunity to contribute to the new service.

Others were hopeful that the team would be strong and that this would help to make the new service a success. One member of staff said she felt upbeat about the new service and what the team could offer:

*Quite often in a normal day care we had people really advanced into the illness and it was difficult to manage that as well as having people in the early stages. So having a separate thing to focus on them, to me, that's why I put upbeat.*

Other staff agreed with this view:

P1: *even 'wonderful' because it is wonderful that it is actually being addressed, and there's a big need for it, which there hasn't been before.*

P2: because normally we would have to discharge somebody from the system and then they would either stay at home with the carer and a bit of a care package or go into long-term care, so it's good that they're actually getting that chance to live in the community for longer in their own surroundings as well where they are more familiar with everything.

However, some staff/volunteers also said that they were apprehensive because they had not worked with people in the team before, and one volunteer said that she felt nervous about what she would be able to contribute 'as a lay person'. Concern was also expressed about 'isolating' people with advanced dementia from a more mixed group, as well as about potential emotional effects on staff and volunteers.

At week 12, it was clear that staff and volunteers felt confident in the team they were working with: 'I'd say it's a really good team to be honest. I think they picked the best people.' Emotion words such as proud, wonderful, super, sensible, valued, enthusiastic, encouraged, happy, pleased, capable were selected: 'I think we value each other and we're, we're really, really, really good at asking, bouncing ideas,

things like that.' When asked about the personality type which suited working in Enhanced Sensory Day Care, being 'calm' was viewed as important:

P1: *you've all, you've all got a ...*

P5: *calm*

P1: *certain calm I think's a really good word, you've all got this calmness with you and that was really important for me. I think that's what makes a lot of the atmosphere apart from the lights and stuff.*

In terms of communication among team members, the team leader made the following observation:

*Yeah, there's very little communication actually goes on sometimes. You can just make eye contact or make a sign and we know, we know what's going on which is the sign of a good team, I would say (...) You don't need to say 'right, you need to do this' and 'you go over there', 'I'll do this'. We don't do that.*

## COMMUNICATING WITH PEOPLE WITH ADVANCED DEMENTIA

### January 2014



Full list of emotion words chosen by staff/volunteers:

1. Frustrated	2. Happy
3. Compassionate	4. Comfortable
5. Surprised	6. Bewildered
7. Embarrassed	8. Thankful
9. Respected	10. Capable
11. Enthusiastic	12. Safe
13. Concerned	14. Distressed
15. Interested	16. Hopeful
17. Calm	18. Cautious
19. Motivated	20. Flustered
21. Apprehensive	22. Empathy
23. Eye contact	24. Patient
25. Knowing the person	26. Nervous

### April 2014



Full list of emotion words chosen by staff/volunteers:

1. Happy	2. Comfortable
3. Surprised	4. Concerned
5. Enthusiastic	6. Hopeful
7. Interested	8. Wonderful
9. Satisfied	10. Fortunate
11. Competent	12. Upbeat
13. Encouraged	

Figure 6 – photos of a selection of the emotion words and a list of all the emotion words selected by staff/volunteers

At week 1, staff/volunteers reported different feelings in response to this touchpoint.

Some emphasised the need for patience and calm:

*if you're quite stressed and anxious yourself that may rub off on them, so to be calm, you know when you're speaking to them, rather than be uptight.*

Others selected emotion words such as comfortable, empathetic, compassionate:

*I put compassionate just because I feel for these people quite strongly so to be compassionate about it rather than being negative.*

However, some selected emotion words indicating a level of apprehension. One member of staff selected the word 'embarrassed':

*I just get embarrassed if I can't understand what they are trying to say to me. I'm worried that I'm not doing the right thing for them.*

Other members of staff chose the word 'bewildered'

*I always thought I could communicate relatively well with people but at times I'm just gonna look and think – "what now", you know. Is it up to me to be doing something or have I misread something? And there will be, you know, just sort of unknown for 2 or 3 minutes, not even for 2 or 3 minutes.*

Another member of staff felt cautious '*that I'll not pick up on signs, because if I can't speak to them and they are in distress, will I spot it?*'

At week 12, staff/volunteers selected emotion words which suggested they felt much more confident in communicating with people with advanced dementia, as they perceived a real benefit to the service they were running. They spoke of feeling comfortable, happy, interested, hopeful about the effect it was having on service-users' well-being, and satisfied and fortunate to be doing the job: '*I get such a wee spark when somebody's able to communicate back to me.*'

While the word 'concerned' was also selected, on the grounds that *'there are some weeks when you're never quite sure'*, in general, staff/volunteers felt confident that their communication strategies were working:

*I had a chat with a lady today, we didn't really use words, but we were chatting to each other, so I put like little, little victories if you like.*



## BEING WITH PEOPLE WITH ADVANCED DEMENTIA

### January 2014



Full list of emotion words chosen by staff/volunteers:

1. Trusted	2. Worried
3. Cared for	4. Privileged
5. Happy	6. Honoured
7. Hopeful	8. Understanding
9. Compassionate	10. Patient
11. Up beat	12. Sense of belonging
13. Safe	14. Responsible
15. Comfortable	16. Calm
17. Capable	18. Powerless
19. Interested	20. Competent

### April 2014



Full list of emotion words chosen by staff/volunteers:

1. Trusted	2. Happy
3. Honoured	4. Compassionate
5. Comfortable	6. Capable
7. Competent	8. Thankful
9. Relaxed	10. Confident
11. Assured	12. Surprised
13. Pleased	14. Enthusiastic

Figure 7 - photos of a selection of the emotion words and a list of all the emotion words selected by staff/volunteers at emotional touchpoint interviews in January and April 2014 in response to the touchpoint 'Being with people with advanced dementia'

At week 1 staff/volunteers expressed mixed views about being with people with advanced dementia. While some selected emotion words such as capable, confident, privileged, others selected apprehensive and anxious:

*I always doubt myself thinking that, and reflect back on what I do and think is there any way I could have done that different that would have had a different outcome, a better outcome for the person with dementia. And I sometimes think I think too much about that, but I always think, you know, is there anything I could have done differently that could have had a different outcome?*

Some staff/volunteers anticipated being supported by the team if they felt unsure.

They also spoke about the skills required to be with someone with advanced dementia; that you needed to be calm, patient, understanding and to build trust with each of the service-users:

*if somebody feels trusted either helping with eating or taking them to the toilet, if they trust the person that's taking them I think that's a big thing.*

The word hopeful was also selected by some:

*I'm hopeful that every reaction that people do in this type of day care will go some way to improving that quality of life for the person and their carer, so I'm hopeful at this time that that's what we're going to achieve every day that somebody is here.*

At week 12, three months later, staff/volunteers chose emotion words such as comfortable, happy, enthusiastic, compassionate, trusted, honoured, assured, competent, capable. One of the staff leaders commented:

*I was sitting here looking at these words thinking and I can remember some of the [earlier] comments from staff and we were a lot of us 'scared', 'curious' and I know from working with you all in a team, those things won't even come into your head now.*

Staff/volunteers also spoke of being thankful for being given the opportunity to work in the service, and of being happy and pleased that it was working well.

## SELECTING APPROPRIATE SENSORY INTERVENTIONS

### January 2014



Full list of emotion words chosen by staff/volunteers:

1. Agitated	2. Compassionate
3. Happy	4. Curious
5. Concerned	6. Worried
7. Comfortable	8. Bewildered
9. Encouraged	10. Thankful
11. Enthusiastic	12. Capable
13. Safe	14. Interested
15. Scared	16. Hopeful
17. Vulnerable	18. Cautious
19. Motivated	20. Experimenting
21. Practice	

### April 2014



Full list of emotion words chosen by staff/volunteers:

1. Brave	2. Compassionate
3. Happy	4. Curious
5. Surprised	6. Satisfied
7. Comfortable	8. Wonderful
9. Pleased	10. Up beat
11. Enthusiastic	12. Capable
13. Trusted	14. Interested
15. Hopeful	16.

Figure 8 - photos of a selection of the emotion words and a list of all the emotion words selected by staff/volunteers at emotional touchpoint interviews

At week 1, staff/volunteers selected emotion words such as interested, comfortable, curious, hopeful, and safe. One member of staff said they felt enthusiastic:

*about trying different things and working with [service-users] to find things that are going to help and passing that on to carers as well so that they can take that home with them and do the same thing at home.*

However, some concern was expressed about keeping family carers engaged with a sensory approach and not overwhelming them with suggested activities. Some staff/volunteers also said that they felt concerned, scared and cautious:

*that we are able to identify the best thing for the person at the end of the day because if we get it wrong they can have such a bad day which goes onto a bad evening. Maybe that's just lack of training.*

*I think because its new as well there's an element of that, you know, you are scared, you know, to say or do something in case it's not right. Whereas it's different in day care, isn't it, when we've got them earlier on.*

At week 12, three months into the delivery of the Enhanced Sensory Day Care service, staff/volunteers said they felt capable, competent – because they had seen that the interventions worked – curious and interested to see if they were shown to be having an effect, trusted, upbeat, and brave at trying new things. One member of staff said she found the training ‘thought-provoking’ and commented:

*I feel quite comfortable and quite competent taking them to the toilet now. Before I mean it was no, no, it's learning new tricks to, how to get her to the toilet, how to get her to eat.*

## SUMMARY

1. Sixteen staff/volunteers completed self-efficacy questionnaires and attended one of two emotional touchpoint group interviews at week 1, eight at week 12.
2. Staff/volunteer confidence in their ability to interact with a person who has little or no verbal communication and to choose appropriate sensory interventions increased over the 12 weeks, with improvement being most marked across the sensory activities.
3. In group interviews before the pilot project started, some staff/volunteers expressed concern that they would feel 'embarrassed' or 'bewildered' when communicating with people with advanced dementia and some said they felt concerned, scared and cautious about using the sensory interventions.
4. Three months into delivering the Enhanced Sensory Day Care service, staff/volunteers said during group interviews that they felt the service was working well, that service-users were responding well to the activities and the one-to-one attention and that, in general, they felt capable and competent delivering the sensory interventions.

## SECTION 7: DISCUSSION

### SUMMARY

During the course of the pilot study there were some issues in service delivery which have affected the study and the subsequent data. Whilst most are process driven, and as such were out of the control of the research team, their impact will be acknowledged before discussion of the importance of place of care, suitability of standard day care as dementia progresses, sensory activities as an intervention and the contribution made to family caring.

### LIMITATIONS

There have been a number of process limitations identified as part of introducing a new service that have been identified by the pilot study. It took longer than expected to receive appropriate referrals from external agencies, despite leaflets being produced and circulated widely, and staff attending team meetings to inform others. This could be attributable to hesitancy among professionals to refer to a pilot (i.e. temporary) service which they may not consider to be in the best interests of their clients. Another issue for some families was that the Enhanced Sensory Day Care service was run on a Sunday which for some was seen as a family day and they were therefore reluctant for their relative to attend on that day. By declining Enhanced Sensory Day Care on Sunday, this left them with only Enhanced Sensory Day Care on a Thursday, which compared to the three days originally offered in the standard service, was considered a loss of respite. A solution was eventually negotiated for one service-user to be able to attend both the Thursday Enhanced Sensory Day Care and two other days of the standard day care service. While dual attendance had not been envisaged when the Enhanced Sensory Day Care pilot was

set up, it was agreed that this compromise would be the best way to support this family while enabling participation in the new service.

A further limitation in the day-to-day operation of the pilot service was that there was often low attendance at the service due to people being ill, going into hospital, or going on holiday. At times there was a staff/volunteer to participant ratio of 5:2 which was disproportionately high.

Additionally, significant organisational changes were ongoing at the host organisation and a number of managerial staff ceased working at the day centre. This resulted in a lack of continuity in terms of oversight of the project and in terms of maintaining a focus on project objectives.

Process limitations were at times difficult to differentiate from scientific limitations in the methodology. Albeit an enabling tool, the emotional touchpoint approach is a relatively brief means of facilitating individuals to describe their experiences. It is not designed for an in-depth discussion but as a starting point. To offset this potential limitation, the research team completed an in-depth questionnaire triggered by using emotional touchpoint techniques.

The research methods were designed to be as unobtrusive as possible on practice in the day centre, hence the use of observational logs by day centre staff. However, the challenge was that the logs, by necessity, were recorded afterwards and not in the moment of care. It became apparent that staff were recording what the person did rather than clearly stating the sensory interventions and the response. Consequently the format of the logs was changed after the pilot began to enable more accurate recording.

In recognition of the limitation of retrospective logs, documentary photography was introduced to record activities in the moment of care. This has resulted in some less than ideal images in terms of quality but nonetheless the photographs convey vividly the depth of understanding through visualising the experience of the Enhanced Sensory Day Care for people with advanced dementia.

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#### PLACE OF CARE

The Scottish Government (2010) is committed to 'shifting the balance of care' from institutional care to care at home wherever possible. This is in line with research evidence which suggests that a move to a care home is not always in the best interests of a person with dementia as it can lead to increased confusion (Mace & Rabins, 2001) and an increased risk of mortality (Aneshensel et al., 2000). This study was designed to evaluate a new model of day care for people with advanced dementia, to see what part it could play in enabling family carers to feel supported whilst continuing to care for their relative at home. Looking across the sample, of the six service-users whose families agreed to participate in the research, three were continuing to live at home at the end of the study, and two had died while still resident within their family home in the intervening weeks. Only one service-user of the six, then, was unable to continue living at home having been admitted to the dementia assessment ward, and care arrangements were transitional. According to Enhanced Sensory Day Care staff, this was due to the individual having a series of seizures, becoming combative, and resisting help with activities of daily living such that her family carers felt that they could no longer manage looking after her at home. She had only been attending Enhanced Sensory Day Care for a few weeks before her admission to hospital. Whilst overall these findings are encouraging, it



must be emphasised that the small numbers involved in the study mean that the findings may not be representative.

In the semi-structured interviews with family carers of service-users attending both Enhanced Sensory Day Care (n=5) and standard day care services (n=7), some indication was given as to carers' preference for continuing to look after their relative at home. Sentiments such as 'I know her better than anyone' and 'no one will look after him as well as I will' were commonly expressed, indicating that carers judged that their relative would have a better quality of life being looked after by them. In a brief feedback interview at the end of the project, one carer commented:

Knowing that it can take an hour and a half to feed him breakfast I don't believe that in any care home they would spend that amount of time. (Jean, daughter of Geoffrey)

News reports and anecdotes from friends about poor care received in care homes also made them reluctant to consider such a move. However, a desire to care for their relative at home was accompanied by the qualifier 'as long as', signalling that their ability to do so was dependent on the right support being in place.

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#### STAGE OF DEMENTIA AND SUITABILITY OF STANDARD DAY CARE

Individuals recommended to the Enhanced Sensory Day Care service were all assessed as being in the advanced stage of dementia, according to the Functional Assessment Staging (FAST) scale (stage 6 or 7) and Pool Activity Level (PAL) checklist (scoring 'sensory' across the majority of activities listed). The individuals attending the service had little speech, tended to sleep a lot, and needed assistance with many of the activities of daily living such as eating and toileting. In the later stages of the disease the sleep-wake cycle can become disturbed (Klaffke & Staedt,

2006), and people's alertness can decrease (Edman et al., 2003) meaning people are less likely to be able to engage in activities requiring attention, such as 'usual' day care activities like snakes and ladders or dominoes. Some service-users lost mobility while attending Enhanced Sensory Day Care and others came to require more support with walking. In sum, this was a service characterized by high levels of dependency.

Interviews with family carers of people attending the Enhanced Sensory Day Care revealed that some carers had been worried (and stressed) after having received indications from staff at the standard day care service that their relative was no longer benefiting, raising doubts about how long they could continue to attend. Reports from day care staff that their relative, in the words of one carer, had been 'piddling all the time and sleeping all the time' did not fill carers with confidence that their relative was deemed to still be benefitting. This was one reason for carers' gratitude and in some cases disbelief - 'are we really getting this?' – that they had been offered Enhanced Sensory Day Care because it meant there was a service which was tailored to meet their relative's high level of dependency. Concerns then shifted from whether their relative would be 'put out' of standard day care, to whether they would be 'put out' of the Enhanced Sensory Day Care service when the pilot came to an end.

One outcome of the study so far is the acknowledgement by both Alzheimer Scotland and Social Services that they need to work more closely together to communicate better with families when standard day care is no longer meeting a person's needs. Aligned to this, Alzheimer Scotland has modified its service agreement with family carers so that when people first enter day care, it is made

clear to them that they are not being offered an indefinite service and that there might come a time when their relative needs to transition to a different type of service.

As the pilot Enhanced Sensory Day Care evolved over the study period, questions were raised about the suitability of extending the service to people who were classed as being at 'stage 5' of the FAST scale i.e. to people with 'moderate' dementia.

During the emotional touchpoint group interview with staff and volunteers three months into the service, some expressed the view that people in the moderate stages of the disease could benefit from more sensory based interaction. One family carer also said that she wished that the service had been available for her relative earlier in the disease progression because of the additional benefit he could have received. Stacpoole and colleagues' research into the Namaste programme (2014) found that in care homes where there was open access to the Namaste room, people with moderate dementia who went into the room appeared to show a benefit, although these people were not officially participants in the research. If multi-sensory stimulation is considered a form of palliative and supportive care, then the recent Delphi study by Van der Steen and colleagues (2014) recommends that palliative care be delivered from the point of diagnosis rather than be targeted solely at those in the advanced stage of the disease. However, additional comments made by staff and volunteers during brief feedback interviews at the end of the study period did add some qualifiers to the recommendation that the service be extended to those in the 'moderate' stage of the disease. Some urged that attention needed to be paid not so much to the 'stage' of dementia of the service-users referred to the service, but to the 'personality' and to how that individual would fit in with the existing mix of service-users. The mood of the room was considered to be very important to facilitating a

sensory approach. There were also indications that the age of service-users needed to be considered when making referrals because this could also affect the interpersonal dynamics between service-users.

Finally, when service-users were transitioning to the Enhanced Sensory Day Care service, there were indications that family carers' expectations of what the service entailed and what the transition meant in terms of the progression of the disease needed to be well managed by staff. Because there is less mix of abilities in the day care room, family carers observing the service are made more aware of the stage of their family member's dementia leading to reluctance from the family to accepting this type of bespoke service. For example, the carer of one service-user suggested that he did not think the service was appropriate for his wife (who was in her 60s) because she needed more stimulation and the other service-users' dementia was more advanced. Staff interpreted this as evidence that the family was in a process of transition in coming to terms with their wife/sister's changed needs, and did not endorse the husband's view that there was great disparity between his wife's abilities and stage of illness and those of the other service-users.

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#### SENSORY ACTIVITIES

As detailed in Section 3, a wide variety of sensory activities were undertaken with service-users, ranging from hand and nail care to cuddling the lifelike baby doll, Rosebud. A variety of sensory equipment had been purchased at the study outset and staff and volunteers were free to decide when and how such equipment was deployed each session. One carer queried whether perhaps there was too much equipment, comparing it to a 'sweetie shop', and wondered if as a consequence staff forgot about the full range of what was available. The observational log (Appendix H)

was designed to enable staff to record the interventions used alongside observations of how service-users responded and reflections on all the different senses stimulated by each intervention. At the start of each Enhanced Sensory Day Care session, staff and volunteers would discuss which sensory activities they would try out that day, ideally with reference to what had been tried and been shown to work previously. One member of staff, in their brief feedback interview, questioned whether staff had perhaps started to 'stand still' or had 'got a wee bit stale' in terms of trying out new sensory techniques in the Enhanced Sensory Day Care. In their study of Namaste care programmes running in care homes, Stacpoole and colleagues (2014) also questioned whether after an initial flurry of interest, staff had subsequently lost interest, and invested less time in the sensory care. Observational logs from the Enhanced Sensory Day Care service show that with some service-users, the same activities tended to be tried again and again, perhaps in response to a positive response being elicited. One carer reported that she would have liked staff and volunteers to try out a greater variety of sensory activities with her relative, rather than relying on activities that he had enjoyed in the past. Whilst the range of equipment available and the open structure of the sessions gave staff and volunteers the freedom to be creative in their sensory engagement with service-users, it is possible that engaging in more frequent collective review of activities and taking part in more training sessions might help to sustain staff and volunteer interest in delivering a sensory service specifically.

The self-efficacy questionnaires completed by staff and volunteers after three months showed that confidence in delivering the Enhanced Sensory Day Care service had increased. The group interviews held at the same time confirmed this and also indicated that staff and volunteers perceived service-users to be deriving

benefit from the sensory activities. It should be acknowledged that only staff and volunteers who were considered to have the right temperament were selected by the manager to work in the Enhanced Sensory Day Care service. In other words, there was prior selection of people who were amenable to delivering a slower pace of care. For some staff and volunteers, the main perceived benefit of the service was the ability to spend quality one-on-one time interacting with service-users while in a group context. Cohen-Mansfield and colleagues (2011) found that engagement with sensory care was optimised through one-to-one social interaction within a group of between 2-14 people, with a moderate level of ambient sound. This supports findings from this study that it was the way in which sensory activities were delivered which was perceived to be effective, not just the fact that the activity was, in itself, sensory.

This study was not designed to assess the efficacy of multi-sensory interventions as compared to usual care, which was the aim of many of the studies discussed in the literature review in Section 2 (Baker et al., 2003; Livingstone et al., 2014; Van Weert et al., 2005). If such a test was to be undertaken, a randomised controlled trial would be the gold standard to aim for in terms of research design. Chung and Lai (2009), in their Cochrane review, argue that, in future, such studies need to employ a rigorous methodology if findings are to be considered reliable. Attention needs to be paid, for instance, to standardising the intervention offered (type of interventions selected; length of session) to enable comparison between studies. The sensory interventions offered in this pilot were not standardised but were person-centred and often improvised by staff and volunteers according to individual need and mood on the day. As Stacpoole and colleagues (2014) found in their study, sensory activities were often used to structure 'empty time' when the service-users were not engaged in personal care or mealtimes. One of the benefits of not conducting an efficacy study

was that a more fluid and responsive approach could be taken and rather than 'empty time' there was time for the individual to rest and take advantage of the relaxing nature of some of the tailored interventions.

While there were indications that staff could benefit from regular (though not necessarily frequent) training sessions in sensory techniques, if only to sustain creative thinking around and engagement in trying out different interventions, there were also indications that family carers with relatives in Enhanced Sensory Day Care could have been offered more training sessions in sensory techniques. Some carers had not attended any training, and some indicated that they had not found the training sessions which they had attended particularly useful because they struggled to apply the 'theoretical' techniques which they had learnt in the session to their relative back at home. There was an acknowledgment from the Alzheimer Scotland Day Centre that carer training sessions had not been organised in a way that was envisaged at the outset, which was perhaps a result of management changes at the centre. However, interviews with family carers suggested that even before their relative had started attending the Enhanced Sensory Day Care service, they had engaged with them in a sensory way, ranging from using puppets to holding hands and giving cuddles. Some carers said that they would like the opportunity to attend more training sessions. Some also perceived small changes in their relative since attending the Enhanced Sensory Day Care service, such as: attempting to do things that they wouldn't normally do, or appearing 'a little bit calmer'. These were interpreted as positive changes resulting from a different model of care and as being indicative of the quality of the care being offered to their relative.

## QUALITY OF LIFE

This study used the validated QUALID questionnaire to measure changes in service-users' quality of life after three months of attending the Enhanced Sensory Day Care service, as perceived by their family carer. Results show that quality of life was perceived to have improved in three out of four service-users. However, these results must be interpreted with caution. This is because of: 1/ the small sample size; 2/ the potential issues with proxy responses (as detailed in Section 4) and; 3/ the fact that the QUALID takes a 'snapshot' of how a person has been behaving during the previous week while behaviour patterns can fluctuate from week-to-week. Another more general difficulty with assessing improvements in the quality of life of service-users with advanced dementia is that there is an ongoing process of natural deterioration which could obscure or offset any benefits accrued from attending Enhanced Sensory Day Care.

While advising caution, the encouraging results from the QUALID questionnaire were supported by the other data collected. As already stated, staff and volunteers perceived that service-users benefitted from the one-to-one interaction which was possible because of the lower staff to service-user ratio in the Enhanced Sensory Day Care service. Some family carers also endorsed this view – 'it's quality', reported one family carer. The 'magic moments' which were recorded in the observation logbook by staff and volunteers testified to how some felt that their relationship with service-users was improved through a more sensory approach to care:

The first time I worked with this lady I read in her notes that she really relaxed if she has her hair brushed so before we'd even had a chat or exchanged a few words I just sat there brushing her hair for her and I



realised that was a little wee magic moment there because she just fell asleep.

Such magic moments could be argued to facilitate relationship-centred care (Nolan et al., 2002) in that they improve the relationship between the care-giver and the care recipient. In this way, it is perhaps more accurate to discuss quality of lives rather than quality of life, as Post (2001) has suggested. In the above example, the sensory activity – hair brushing – was used to provide a sense of continuity with what the staff member already knew the service-user enjoyed, combined with a sense of purpose while engaging in the activity, and a sense of achievement at meeting the objective – for the service-user to feel relaxed and calm. The trust required from both carer and care recipient to engage in the activity implies a sense of security and belonging, and the professional carer's reflection on the experience as a 'magic moment' shows that he felt a sense of significance in the bond he had managed to establish with the service-user through the activity. In this brief example, all six senses which form part of Nolan and colleagues' 'Senses' framework can be identified, helping to create an 'enriched' care environment. This is an important contribution to raising the standards of dementia care services which are often portrayed in the media as impoverished.

Other ways in which staff inferred that the service 'worked' was the perception that there was an increase in communication from care recipients. In the group interview, one volunteer who had worked previously in standard day care with a service-user expressed surprise that she could still say words as she had not heard her do so whilst attending standard day care. The individual's family carer, however, commented that:

they were surprised and saying 'oh your mum can read that and do that' and I was like 'she's been doing it for a while'.

In other words, we suggest that this apparent improvement might be explained by the creation of an enabling communication environment and the additional time which staff had to spend with service-users one-on-one which meant that they were more likely to notice their residual capacities, rather than that their communicative capacities increased. Another aspect to this is that while attempts by service-users to communicate using residual capacities were interpreted positively by staff, this does not necessarily show an improved quality of life but is perhaps more an indication that verbal communication as an element of personhood is highly valued and prompts recognition from staff.

A final point on the contribution the Enhanced Sensory Day Care service can make to service-users quality of life is actually brought to light in Stacpoole and colleagues' (2014) Namaste care study. Staff in the care homes where the Namaste programme was implemented reported that residents with advanced dementia who took part in the programme gained weight, that they experienced fewer falls and 'incidents', and that infection rates fell. These are perhaps other aspects of quality of life where improvements could be measured in future iterations of the Enhanced Sensory Day Care service.

#### CONTRIBUTION TO FAMILY CARING

The experience of dementia impacts on the whole family. Each relationship has pre-existing dynamics, strengths and vulnerabilities to the challenge which dementia presents (Morhardt & Spira, 2013). While many of these dynamics lie outside the scope of influence of external service providers, some relationship dynamics can be

influenced, for example, by offering good examples of care and a whole-family approach to offering support.

Evidence from this study – both the service evaluation from Enhanced Sensory Day Care and the interviews with family carers in standard day care services – show that overall family carers felt supported by both standard and Enhanced Sensory Day Care day care services, albeit with different experiences of stage of dementia in both services. Family carers reported that day care provided ‘a lot of positive moments’ for their relatives and that despite not always knowing exactly what activities their relative engaged in whilst at day care (because they were unable to tell them afterwards), they felt confident that they derived benefit from attending. One carer, whose relative attended a standard day care, summed up this sentiment when he commented: ‘I think the best way to help a carer is to help the person they’re caring for.’ For carers across the sample, day care was also highly valued for the respite or short break from caring it afforded them. Some carers reported feeling ‘trapped’ or feeling ‘frustrated’ spending all day with their relative. Day care allowed carers the possibility of connecting with a different world from that of care-giving or an ‘alternative’ self from that of care-giver (Cuesta-Benjumea 2011), whether this involved going on a fishing trip or doing the gardening.

Some family carers expressed worry for the future, decisions about place of care and the day-to-day responsibility of caring appearing to weigh heavily upon them. Some whose relatives were in the moderate stage of the disease and were still attending standard day care, worried about the type of service provision available ‘down the line’ for people in the advanced stage. Other family carers reported that they tried not to worry about the future and instead took ‘one day at a time’, managing challenges

or changes required in care as and when they arose. This same temporal orientation was expressed by carers in Nolan and colleagues study (1996). However, in order to be able to take 'one day at a time' it is necessary that carers feel supported (by other family members and professional services) and that there are additional care options should things change in the future.

Revisiting Nolan and colleagues' SENSES framework, carers across the sample highlighted different senses as being of importance in their perception of the contribution made by day care to their caring role. Day care was generally perceived to provide a sense of security, belonging, and continuity for carers in terms of offering a service which they could trust and a familiar environment where their relative would be safe. They hoped that the activities undertaken at day care would provide their relative with a sense of purpose; however, given that some carers admitted that they did not know what their relative did at day care, this did not appear to be as important to them as safety or continuity of care. Other senses which we interpret as being less important to carers in terms of what day care offered them was a sense of achievement and significance. These senses were possibly more important in terms of their own care-giving and in terms of the time they spent alone with their relative.

One of the hopes for the Enhanced Sensory Day Care service was that family carers would be trained in and would feel confident to try out sensory activities with their relatives at home. It was anticipated that encouraging a sensory mode of engagement and communication might help to maintain the relationship with the person with dementia at a time when their verbal communication was declining. The findings of this study show that while there was little training on, or additional uptake

of, sensory activities in the domestic setting, family carers did value the sensory engagement they already had with their relatives and in some cases reported that such engagement did bestow a sense of *significance*:

My mum loves having her hair brushed. She maybe not be communicating with you and you'll start brushing her hair and you say "can you lean forward so I can get the back" and she'll lean forward.

Given that in the advanced stages of dementia, a person has less ability to communicate verbally and is dependent on their carer for all activities of daily living, having ways of facilitating moments of contact and connection between caregiver and care-recipient in order to generate a sense of *significance* and *achievement*, are important for maintaining relationship-centred care.

## CONCLUSION

Of the six service-users who participated in this pilot study, two died during the three month evaluation period. This is consistent with evidence in the literature (Mitchell et al., 2009; Shuster 2000) that people with advanced dementia should be considered to be nearing the end of their life. The Scottish Government (2009) has stated that palliative and end of life care should include everyone in the last year of life which 'means increasing the number of patients and carers with their palliative and end of life care needs identified, assessed and planned with families and carers (and kept under review)' (Scottish Government 2009, p25). Palliative care involves shifting the emphasis of care from prolongation of life to an emphasis on quality of life, maintaining function, and maximising comfort (van der Steen et al., 2014). In considering how the Enhanced Sensory Day Care service responded to the palliative needs of service-users, the focus on trying to maintain function and provide comfort through sensory activities was certainly one way. Perhaps another way in which the

Enhanced Sensory Day Care service was a palliative/supportive service is the holistic care which it offered to relatives.

However, there were perhaps missed opportunities for staff and volunteers to enter into open communication with family carers about the fact that their relative was nearing the end of life. Staff and carers did not indicate that open discussions of this nature had taken place, nor did they comment on any training they had undergone. Although it could be that conversations about end of life care and advance care planning had been held between family carers and other healthcare professionals (e.g. GP) or social workers, this should not necessarily be taken for granted. The move to a different type of day care service, Enhanced Sensory Day Care, represents a transition in care for an individual whose condition is deteriorating and whose needs are increasing. Transitioning to this service, then, might represent an opportune moment to raise issues with carers around end of life and advance care planning. In order for staff and volunteers to have the confidence to initiate such conversations with family carers they would require additional training, but would also need to acknowledge themselves that the Enhanced Sensory Day Care service is a palliative care service. This would enable a palliative/supportive care approach to be adopted when engaging with family carers as much as when engaging with service-users who are potentially in the last year of their life.

The pilot study has demonstrated the viability and potential benefit of Enhanced Sensory Day Care as a model for the supportive care of people in the advanced stage of dementia. Whilst outcome determinants with people in the advanced stage of dementia are understandably challenging, creative approaches to the methodology and to interpreting experience at this stage of dementia have been

evidenced that warrant further development. A challenge associated with implementing the new model of day care is to achieve a partnership approach fostering communication which includes care recipient, care provider, and families. Although further work is needed, findings from the pilot study suggest that such a partnership approach contributes to a positive quality of life for individuals in the advanced stage of dementia and supports family carers.

## SECTION 8: RECOMMENDATIONS

1. Future dementia strategies reflect the contribution of enhanced multi-sensory stimulation interventions in supporting people with advanced dementia to live the best life possible.
2. Future policy developments include enabling plans to make enhanced multi-sensory stimulation available and accessible for persons living with advanced dementia across all care settings.
3. That day care services offering enhanced multi-sensory stimulation are developed for people with advanced dementia to address the current gap in provision with an understanding of the contribution from all partners.
4. Sufficient and appropriate day care practitioners (staff and volunteers) are equipped to safely deliver selected multi-sensory interventions as part of person-centred care for individuals with advanced dementia.
5. Developments in enhanced multi-sensory stimulation day care are designed to support family caring through a partnership approach during this essentially palliative phase.
6. Guidance is made available for family carers in the delivery of selected multi-sensory stimulation techniques for relatives with advanced dementia.
7. That the potential for enhanced multi-sensory day care to prevent or delay admission to long-term care for individuals with advanced dementia be explored.
8. That further work is undertaken to determine referral and admission criteria for multi-sensory dementia care, based on tools such as the FAST scale and PAL checklist, in order for a timely transition to occur.



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## **Enhanced Sensory Day Care Service Evaluation**

### **Information Sheet - Family Carer**

#### **Background**

The Day Centre is piloting a new sensory approach to day care on Thursdays and Sundays each week. This is designed to improve the well-being and quality of life of people with dementia in its advanced stages. Staff from the University of the West of Scotland will be evaluating this new service. As a family/informal carer you are invited to take part and this leaflet gives you information about what is involved. The evaluation will help to understand what is working well and not so well as part of this new enhanced sensory day care model. Staff and volunteers at the day centre will also take part in the study.

#### **What is Enhanced Sensory Day Care?**

The Enhanced Sensory Day Care service is a non-medical programme based on the five senses of sight, sound, smell, touch and taste. For example, this might include looking at photographs, smells associated with favourite foods and familiar scents, listening to music, handling objects that will bring back memories, and food tasting.

After attending training in how to deliver these activities, staff and volunteers will select appropriate sensory activities for each person with dementia whilst they attend the day care session. You will also be offered training to continue some of these interventions at home.

The aims of the service evaluation are:

- to measure improvement in the quality of life of people with dementia and the carers of people with dementia.
- to examine this Enhanced Sensory Day Care service in practice to find out if it may be of value to use in other day services in Scotland.
- to make any changes based on the findings from the staff, volunteers and carers who are involved in the delivery of the sensory care within day care services and care at home.

### **Who is conducting and funding the study?**

The study is being undertaken by a team of experienced researchers from the Alzheimer Scotland Centre for Policy and Practice based at the University of the West of Scotland. The new service is funded through the Dumfries and Galloway NHS 'Putting You First Fund' and the evaluation is funded by Alzheimer Scotland.

### **If you agree to participate in the study what will you be asked to do?**

You will be asked to help in two ways:

1. Complete a short questionnaire (called QUALID) indicating the quality of life of your relative. You will be asked to complete this questionnaire at the time of your relative's admission to the new

Day Care service and again after 12 weeks of attending the new service.

2. After approximately 12 weeks (or sooner if your family member leaves the service) take part in an interview which, with your permission, will be recorded. It will be conversational with one of the researchers who will ask you a short series of questions. The researcher will use a tool called 'emotional touchpoints' to help you to express your feelings about the sensory day care model. This is a series of cards with feelings and emotions on them which you will choose depending on how you are feeling.

The interview will take approximately 30-45 minutes to complete. This will be typed up and your name, and the names of other individuals who may have been mentioned, will be removed. This interview will also take place after your family member has been at the Day Care service for 12 weeks or sooner if they stop attending earlier. You will be invited to choose the most convenient time and place for the interview which might be within your home or at the Day Centre.

With your permission, the Day Care staff will take up to three photographs of your relative each day when they are showing a positive response to a sensory intervention. You will be invited to view these and select any that you would like copies of and any that you think can be shared with the project team. You do not have to agree to photographs being taken. Even if you agree you can change your mind later and keep these as private pictures.

### **What will happen to the results of the service evaluation?**

An evaluation report will be prepared for Alzheimer Scotland and findings will be shared at conferences. We also hope to write articles to share the findings within professional and academic journals. No names will be used of those who take part.

### **What should you do if you would like to take part?**

If you are happy to take part in the evaluation you should let the Day Care staff know and they will tell the project team. You will be asked by the Day Care staff how you would like the evaluation team to contact you. We will arrange a time and place to meet you so that they can answer any further questions you may have about the study. You will be asked to sign a consent form and given a copy of this for your records.

As well as this evaluation of the new day care service there is a separate research project being carried out by the University of the West of Scotland which involves a more in-depth interview with family carers. You may be asked at a later stage if you wish to be involved in this research.

## Service Evaluation Team

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### Contact details:

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Hamilton, ML3 0JB

Telephone: 01698 283100

If you have any concerns about this evaluation and would like to speak to someone independently  
please contact:

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**Appendix B**

**Consent form  
(Family Carer)**

**Title of Project:** Enhanced Sensory Day Care Service Evaluation (Project A)

**Name of carer (will be removed or anonymised)**

.....

**Date** .....

**Please initial the boxes to the right to show your consent. Leave blank any box that you do not agree with. You may change your mind later, in which case please speak to a member of staff at the Day Centre in the first instance.**

1. I confirm that I have read and understand the project information sheet. 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 am a voluntary participant in the evaluation of the day service and that I am free to stop taking part at any time.

☐

3. If I decide to withdraw I understand that I do not need to give a reason for this and the care of my relative/friend will not be affected if I do so.

☐

4. I give permission to the project team to access information about my relative/partner/friend held by the Day Centre.

☐

5. I give permission for Day Centre staff to take photographs of my family member and understand that these will be shared with me. I can then decide which, if any, I would like the project team to use when they talk about the evaluation.

☐

6. I understand that findings from the study may be published in professional journals, and included at conferences. Publications and talks will not identify me.

☐

7. I agree to complete a short questionnaire with a staff member or a UWS researcher at the time of my family member/friend starting to attend the new day care service.

☐

8. I agree to take part in an interview and short questionnaire with UWS staff after approximately three months of my family member starting the new day care service, or sooner should they stop attending.

☐

9. I agree to this interview being recorded

☐

10. I understand that I will be invited to attend a workshop with staff and other carers after approximately 7-9 months

☐

11. I agree to (anonymised) quotes being used from the interview and workshop

☐

I agree to take part in the study.

☐

Name of carer .....

Date .....

Signature .....

Name of evaluation team member taking consent .....

Date .....

Signature .....

One copy of this form will be retained by the participant, one by the evaluation team and one in the Centre records of the individual



## Appendix C

Name of carer (will be removed or anonymised)



### Consent form – Research (Project B)

#### Family Carer

**Title of Project:** Family Caring: the Contribution of Day Care and Enhanced Sensory Day Care

**Please initial the boxes to the right to show your consent. Leave blank any box that you do not agree with. You may change your mind later, in which case please speak to a member of staff at the Day Centre in the first instance.**

1. I confirm that I have read and understand the research project information sheet. 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 am a voluntary participant in the Family Caring research project and that I am free to stop taking part at any time.

☐

3. If I decide to withdraw I understand that I do not need to give a reason for this and the care of my relative/friend will not be affected if I do so.

☐

4. I agree to take part in an interview with research staff where I will talk about how I feel using 'emotion' cards.

☐

5. I agree to this interview being audio recorded.

☐

6. I agree to anonymised quotes being used from the interview

☐

7. I understand that findings from the study may be published in professional practice or carer journals, and presented at conferences. Publications and talks will not identify me.

☐

8. I agree to take part in the research interview.

☐

Name of participant .....

Date .....

Signature .....

Name of researcher taking consent .....

Date .....

Signature .....

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

## **Appendix D**

### **Family Caring: the Contribution of Day Care and Enhanced Sensory Day Care**

#### **Information Sheet - Family Carer (Enhanced Sensory Day Care) Research Project B**

### **Background**

Day Care is one of the services available to people with dementia. As the condition advances the benefits derived from attending day care may change. It is therefore important that we understand the contribution of standard day care services and compare this to new models of day care such as Enhanced Sensory Day Care which focuses specifically on meaningful activity based on the five senses. This model is currently being tested in one Scottish Day Care Centre. We will be talking to family members of people who have attended different types of day care.

### **What is the aim of the study?**

1. To find out how sensory day care provision contributes to family caring in advanced dementia
2. To understand the experiences of attending different types of day care from the perspective of family/informal carers.

### **Who is conducting and funding the study?**

The study is being undertaken by a team of experienced researchers from the Alzheimer Scotland Centre for Policy and Practice based at the University of the West of Scotland. The study is funded by NHS 'Putting You First Fund' and Alzheimer Scotland.

### **Why have you been invited to consider taking part in the study?**

As your relative has recently attended or is currently attending the pilot Enhanced Sensory Day Care Services in Dumfries and you are involved as a family member in their care at home, your experiences would be very relevant to our study.

### **What if I am already helping with the evaluation of the pilot service?**

This is not a problem as you can do both at the same time. By agreeing to take part in this separate research study you will be involved in a slightly longer interview where you will have more time to explain your experiences of the new Enhanced Sensory Day Care approach and share your thoughts about day care.

### **If you agree to participate in the study what will you be asked to do?**

You will be asked to take part in one individual interview with a researcher from the University of the West of Scotland. If you have

already agreed to take part in the service evaluation you will still only attend one interview. It just means that we will talk to you in more detail.

The interview, with your permission, will be audio recorded. The researcher will use an approach known as 'emotional touchpoints'. You will be asked to choose from:

1. a series of cards known as 'touchpoints' with key issues or statements on them.
2. an additional set of cards with emotion words on them. This will help you to talk about your experience of day care and to focus on the things that are important to you in terms of how you feel, or were feeling.

Using the touchpoints and the emotional words will help you to tell a story about your experiences. You will be prompted to tell us what has gone well and things that improved or could have improved the experience of day care.

The interview will take approximately 40-60 minutes to complete and with your permission we will record this. The interview will be typed up and your name, and the names of other individuals who may have been mentioned, will be removed. You will be invited to choose the most convenient time and place for the interview which might be within your home or at the Day Centre or at your nearest University of the West of Scotland campus.

### **What will happen to the results of the research?**

A report of the findings will be prepared for Alzheimer Scotland and findings will be shared at conferences and seminars. We also hope to write articles to share the findings within professional and academic journals. No names will be used of those who take part.

### **What should you do if you would like to take part?**

If you are happy to take part in the research study or would like more information you should let the Day Care staff know and they will tell the research team. You will be asked by the Day Care staff how you would like the researchers to contact you. The researcher will arrange a time and place to meet you so that they can answer any further questions you may have about the study. You will be asked to sign an additional consent form to the one you signed for the service evaluation and given a copy of this for your records and we will agree arrangements for the interview.

### **What happens if I change my mind?**

If you change your mind at any time, either about withdrawing or about taking part in the study this is absolutely fine. It is also possible to rearrange interviews if your plans change but we would ask for as much notice as possible if you are cancelling or postponing interview appointments.

Thank you for considering helping with this study we appreciate the time and thought given to our research invitation.

### **University of the West of Scotland Research Team:**

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If you have any concerns about this evaluation and would like to speak to someone independently please contact Professor Pauline Banks, School of Health, Nursing and Midwifery, University of the West of Scotland, Caird Building, Hamilton, ML3 0JB

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## **Appendix E**

# **Family Caring: the Contribution of Day Care and Enhanced Sensory Day Care**

## **Information Sheet - Family Carer**

### **Research project B (standard day care)**

#### **Background**

Day Care is one of the services available to people with dementia. As the condition advances the benefits derived from attending day care may change. It is therefore important that we understand the contribution of standard day care services and compare this to new models of day care such as Enhanced Sensory Day Care which focuses specifically on meaningful activity based on sensory interventions. This model is currently being tested in one Scottish Day Care Centre. We will be talking to family members of people who have attended different types of day care.

#### **What are the aims of the study?**

1. To find out how day care provision contributes to family caring in advanced dementia
2. To understand the experiences of attending different types of day care from the perspective of family/informal carers.

#### **Who is conducting and funding the study?**



The study is being undertaken by a team of experienced researchers from the Alzheimer Scotland Centre for Policy and Practice based at the University of the West of Scotland. The study is funded by NHS 'Putting You First Fund' and Alzheimer Scotland.

**Why have you been invited to consider taking part in the study?**

As your relative has recently attended or is currently attending day care and you are involved as a family member in their care at home, your experiences of day care would be very relevant to our study.

**If you agree to participate in the study what will you be asked to do?**

You will be asked to take part in one individual interview with a researcher from the University of the West of Scotland. The interview, with your permission, will be audio recorded. The researcher will use an interview approach known as 'emotional touchpoints'. You will be asked to choose from:

3. a series of cards known as 'touchpoints' with key issues or statements on them,
4. an additional set of cards with emotion words on them. This will help you to talk about your experience of day care and to focus on the things that are important to you in terms of how you feel, or were feeling.

Using the touchpoints and the emotion words will help you to tell a story about your experiences. You will be prompted to tell us what has gone well and things that improved or could have improved the experience of day care.

The interview will take approximately 40-60 minutes to complete and with your permission we will record this. The interview will be typed up and your name, and the names of other individuals who may have been mentioned, will be removed. You will be invited to choose the most convenient time and place for the interview which might be within your home or at the Day Centre or at your nearest University of the West of Scotland campus.

### **What will happen to the results of the research?**

A report of the findings will be prepared for Alzheimer Scotland and findings will be shared at conferences and seminars. We also hope to write articles to share the findings within professional and academic journals. No names will be used of those who take part.

### **What should you do if you would like to take part?**

If you are happy to take part in the research study, or would like more information, you should let the Day Care staff know and they will tell the research team. You will be asked by the Day Care staff how you would like the researchers to contact you. The researcher will arrange a time and place to meet you so that they can answer any further questions you

may have about the study. You will be asked to sign a consent form and given a copy of this for your records and we will agree arrangements for the interview.

### **What happens if I change my mind?**

If you change your mind at any time, either about withdrawing or about taking part in the study this is absolutely fine. It is also possible to rearrange interviews if your plans change but we would ask for as much notice as possible if you are cancelling or postponing interview appointments.

Thank you for considering helping with this study we appreciate the time and thought given to our research invitation.

## University of the West of Scotland Research Team:

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## **Appendix F**

# **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.

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

STAGE	SKILL LEVEL
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.

**STAGE••\_\_\_\_\_**

\*Scored primarily on the basis of information obtained from a knowledgeable informant and/or caregiver.

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## Appendix G

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"I believe that people can live well with dementia when they are cared for by people with specialist skills"

*Jackie Pool*

### Pool Activity Level (PAL) Checklist

Name:

Completed By:

Date:

Users of the PAL Instrument will need a PAL book. To order the PAL book please [click here](#)

Ensure you are familiar with the instructions before completion.

#### Completing the Checklist

- Thinking of the last 2 weeks, tick the statement that represents the person's ability in each section.
- If in doubt about which statement to select, choose the level of ability that represents their average performance over the last 2 weeks.
- You must select one statement for each section.
- Selections are totalled at the bottom of each column.

#### Key

**P** = Planned level of ability

**E** = Exploratory level of ability

**S** = Sensory level of ability

**R** = Reflex level of ability

1. Bathing/Washing	P	E	S	R
-1 • Can bathe/wash independently, sometimes with a little help to start.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
• Needs soap put on flannel and one step at a time directions to wash.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
• Mainly relies on others but will wipe own face and hands if encouraged.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
• Totally dependent and needs full assistance to wash or bathe.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Getting dressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



-1	<ul style="list-style-type: none"> <li>Plans what to wear, selects own clothing from the cupboards; dresses in correct order.</li> </ul>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	<ul style="list-style-type: none"> <li>Needs help to plan what to wear but recognises items and how to wear them; needs help with order of dressing.</li> </ul>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	<ul style="list-style-type: none"> <li>Needs help to plan and with order of dressing, but can carry out small activities if someone directs each step.</li> </ul>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	<ul style="list-style-type: none"> <li>Totally dependent on someone to plan, sequence and complete dressing; may move limbs to assist.</li> </ul>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>3. Eating</b>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-1	<ul style="list-style-type: none"> <li>Eats independently and using the correct cutlery.</li> </ul>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	<ul style="list-style-type: none"> <li>Eats using a spoon and/or needs food to be cut up into small pieces.</li> </ul>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	<ul style="list-style-type: none"> <li>Only uses fingers to eat food.</li> </ul>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	<ul style="list-style-type: none"> <li>Relies on others to be fed.</li> </ul>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>4. Contact with others</b>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-1	<ul style="list-style-type: none"> <li>Initiates social contact and responds to the needs of others.</li> </ul>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	<ul style="list-style-type: none"> <li>Aware of others and will seek interaction, but may be more concerned with own needs.</li> </ul>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	<ul style="list-style-type: none"> <li>Aware of others but waits for others to make the first social contact.</li> </ul>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	<ul style="list-style-type: none"> <li>May not show an awareness of the presence of others unless in direct physical contact.</li> </ul>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>5. Groupwork skills</b>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-1	<ul style="list-style-type: none"> <li>Engages with others in a group activity, can take turns with the activity/tools.</li> </ul>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	<ul style="list-style-type: none"> <li>Occasionally engages with others in a group, moving in and out of the group at a whim.</li> </ul>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	<ul style="list-style-type: none"> <li>Aware of others in the group and will work alongside others although tends to focus on own activity.</li> </ul>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	<ul style="list-style-type: none"> <li>Does not show awareness of others in the group unless close one-to-one attention is experienced.</li> </ul>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

6. Communication skills					
-1	• Is aware of appropriate interaction, can chat coherently and is able to use complex language skills.				
	• Body language may be inappropriate and may not always be coherent, but can use simple language skills.				
	• Responses to verbal interaction may be mainly through body language; comprehension is limited.				
	• Can only respond to direct physical contact from others through touch, eye contact or facial expression.				
7. Practical activities (craft, domestic chores, gardening)					
-1	• Can plan to carry out an activity, hold the goal in mind and work through a familiar sequence; may need help solving problems.				
	• More interested in the making or doing than the end result, needs prompting to remember purpose, can get distracted.				
	• Activities need to be broken down and presented one step at a time, multi-sensory stimulation can help hold the attention.				
	• Unable to 'do' activities, but responds to the close contact of others and experiencing physical sensations.				
8. Use of objects					
-1	• Plans to use and looks for objects that are not visible; may struggle if objects are not in usual/familiar places (eg. toiletries in a bathroom cupboard).				
	• Selects objects appropriately only if in view (eg. toiletries on a shelf next to the wash basin).				
	• Randomly uses objects as chances upon them; may use appropriately.				
	• May grip objects when placed in the hand but will not attempt to use them.				
9. Looking at a newspaper/magazine					
-1	• Comprehends and shows interest in the content, turns the pages and looks at headlines and pictures.				
	• Turns the pages randomly, only attending to items				

pointed out by others.					
<ul style="list-style-type: none"><li>• Will hold and may feel the paper, but will not turn the pages unless directed and will not show interest the content.</li></ul>					
<ul style="list-style-type: none"><li>• May grip the paper if it is placed in the hand but may not be able to release the grip; or may not take hold of the paper.</li></ul>					
<b>NB.</b> If the totals are evenly divided between activity levels, assume that the person is at the lower level but has the potential to move into the higher level.	<b>Totals</b>	0	0	0	0

The Activity Level identified for this person is:

Please click here for the relevant Pool Activity Level (PAL) Profile to assist you to plan how you will help the person with their activities.

## Appendix H

### Sensory programme: Engagement with senses through activities

Name *xxxx*

Date *xxxx*

You should focus on two activities which have taken place today; these can be activities that worked well or could have worked better. Use the headings below and provide as much information as you can. Try and complete it as soon as possible after the activity so you remember. Take some pictures as you go to make the story real. Use a separate side for each activity.

**What was the activity?** *Making an Easter Bonnet*

**What senses were used? What was the outcome of the activity?**

**Hearing** *There was background music on which x was whistling along to. x was also trying to tell us stories*

**Seeing** *x was able to pick items to decorate the hat with. x realised she was to decorate the hat and attempted to attach a large bunch of flowers. We helped her to do this by fixing the flowers on with a safety pin*

**Touching** *x touched a number of items before selecting the bunch of flowers but could not distinguish some of the items and tried to eat the chicks as they were small and bright yellow and probably looked like sweets*

**Smelling**

**Tasting**

**How did the person respond to the activity?**

*She placed the hat on her head and looked really pleased with herself and smiling when the photo was taken*

**How did it make you feel?** *A real sense of achievement because she looked so pleased with herself and it was all her own work!*

**What would you do differently (if anything) next time?** I think there were too many items on the table. I would introduce them one by one and not have them all on display. I would continue to resist the temptation to make the hat look prettier or neater for my own satisfaction.

## Appendix I

### QUALITY OF LIFE IN LATE-STAGE DEMENTIA (QUALID) SCALE ©

Name of carer/friend: (For administrative purposes only – name will be removed)

Name of evaluation team member:

Date of completion:

Which response best describes \_\_\_\_\_ over the past week?

- A. [S] smiles
1. spontaneously once or more each day
  2. spontaneously less than once each day
  3. only in response to external stimuli; at least once each day
  4. only in response to external stimuli; less than once each day
  5. rarely, if at all
- B. [S] appears sad
1. rarely or never
  2. only in response to external stimuli; less than once each day
  3. only in response to external stimuli; at least once each day
  4. for no apparent reason less than once each day
  5. for no apparent reason once or more each day
- C. [S] cries
1. rarely or never
  2. only in response to external stimuli; less than once each day
  3. only in response to external stimuli; at least once each day
  4. for no apparent reason less than once each day
  5. for no apparent reason once each day or more
- D. [S] has a facial expression of discomfort - appears unhappy or in pain (looks worried, grimaces, furrowed or turned down brow)
1. rarely or never

2. less than once each day
3. at least once each day
4. nearly half of each day
5. most of each day

E. [S] appears physically uncomfortable -he/she squirms, writhes, frequently changes position

1. rarely or never
2. less than once each day
3. at least once each day
4. nearly half of each day
5. most of each day

F. [S] makes statements or sounds that suggest discontent, unhappiness or complains, groans, screams)

1. rarely or never
2. only in response to external stimuli; less than once each
3. only in response to external stimuli; at least once each day
4. without cause less than once each day
5. without cause once or more each day

G. [S] is irritable or aggressive (becomes angry, curses, pushes or attempts to hurt others)

1. rarely or never
2. only in response to external stimuli; less than once each day
3. only in response to external stimuli; at least once each day
4. without cause less than once each day
5. without cause once or more each day

H. [S] enjoys eating

1. at most meals and snacks
2. twice a day
3. at least once a day
4. less than once each day

5. rarely or never

I. [S] enjoys touching/being touched

1. almost always; almost always initiates touching
2. more than half the time; sometimes initiates touching
3. half the time; never initiates touching, but doesn't resist touching
4. less than half the time; often or frequently resists touching/being touched
5. rarely or never; almost always resists touching/being touched

J. [S] enjoys interacting or being with others

1. almost always; almost always initiates interaction with others
2. more than half the time; sometimes initiates interaction with others
3. half the time; never initiates interaction, but doesn't resist interaction with others
4. less than half the time; often or frequently resists interacting with others
5. rarely or never; almost always resists interacting with others

K. [S] appears emotionally calm and comfortable

1. most of each day
2. more than half of each day
3. half of each day
4. less than half of each day
5. rarely or never

.....Total Score (sum of all items; scores range from 11 to 55 with lower scores representing higher quality of life)

#### Quality of Interview

(Administrator's judgement): 0

1

2

Interview appeared valid

Some questions about interview, but probably acceptable  
Information from interview of doubtful validity

0 Very familiar; provides daily care

1 Somewhat familiar; often provides some care

2 Not very familiar; only dispenses meds, minimal contact

#### Knowledge/familiarity

of caregiver with subject:



## Appendix J

Name of staff/ volunteer: (For administrative purposes only – name will be removed)

Name of evaluation team member:

Date of completion:

### Week 1 Self-efficacy Scale for Staff and volunteers

Instructions: In relation to working with individuals with advanced dementia please indicate your ability to do the following:

Please circle the appropriate number

1. Use a life story approach to identify meaningful activities for an individual

I cannot do this 1 2 3 4 5 6 7 I can do this

2. Be with and interact with a person who has little or no verbal communication

I cannot do this 1 2 3 4 5 6 7 I can do this

3. Assist the person who is having difficulties eating and drinking

I cannot do this 1 2 3 4 5 6 7 I can do this

4. Select appropriate sensory interventions

I cannot do this 1 2 3 4 5 6 7 I can do this

5. Use physical movements and mirroring techniques

I cannot do this 1 2 3 4 5 6 7 I can do this

6. Provide meaningful activities involving the sense of smell

I cannot do this      1    2    3    4    5    6    7    I can do this

7. Provide meaningful activities involving the sense of touch

I cannot do this      1    2    3    4    5    6    7    I can do this

8. Provide meaningful activities involving the sense of taste

I cannot do this      1    2    3    4    5    6    7    I can do this

9. Provide meaningful activities involving the sense of hearing

I cannot do this      1    2    3    4    5    6    7    I can do this

10. Provide meaningful activities involving the sense of sight

I cannot do this      1    2    3    4    5    6    7    I can do this

Thank you for completing this self-efficacy scale.

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