

Executive Summary

Enhanced Sensory Day Care

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



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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 by Alzheimer Scotland within South West Scotland.

Aim

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

What is Enhanced Sensory Day Care?

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

Enhanced Sensory Day Care is designed to support people with advanced dementia whose complex care needs cannot be met through standard day care services. To enable the pilot project, on two days per week, an existing Alzheimer Scotland Day Centre dedicated its facility to piloting the new model of care. Five places were offered to individuals with advanced dementia, with care provided by a team of staff and volunteers specifically prepared to deliver to the new sensory approach.

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 Alzheimer Scotland 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 day care service and again after three months of attendance.
- 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 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.
- In-depth semi-structured interviews using emotional touchpoints were conducted after 12 weeks. 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. This provided a comparison with family carers whose relative received the new enhanced service.
- At the end of the evaluation period, feedback interviews were conducted with staff volunteers and family carers at the Enhanced Sensory Day Care service to gain further information on what was working well and identify possible refinements to the new model.

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 shared 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 with 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 with 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 Alzheimer Scotland 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 during this palliative phase.
- Guidance and training is made available for family carers in the delivery of selected multisensory stimulation techniques for relatives with advanced dementia.
- 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.
- 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.



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