

*‘Small Changes Make a Big
Difference’:*
Empowering families living with
dementia to self-manage their lives

Dr Joan Murphy
Nicki Ewing
Final report to ALLIANCE April 2016



Contents

Background.....	3
What we expected to do	3
What we actually did	4
What difference we actually made	7
Challenges and changes	11
Learning for the future.....	13
What we would do differently	15
How we collected the information	16
The future	17
Acknowledgements.....	17
Appendices	18

Background

The Scottish Government's 2020 Vision states that Scotland *'will have a healthcare system where we have integrated health and social care, a focus on prevention, anticipation and supported self-management'*¹. Additional legislation and policy state that patients have the right to be involved in decisions and to have information presented to them in an accessible and meaningful way²³. Talking Mats is one way of putting policy into practice.

A key aspect of the work done by Talking Mats is to find ways to improve communication for families living with long term conditions. In particular dementia is a long term condition where deterioration in communication will eventually affect everyone. This makes it increasingly difficult to ensure that the person with dementia continues to be involved in decisions about their life.⁴

This report describes a project funded by Health and Social Care ALLIANCE Scotland. Training in the use of Talking Mats was given to families living with dementia and staff who worked with these families. The report highlights how this training helped people with dementia to communicate their views and be more involved in making decisions about their lives.

What we expected to do

Aims of the organisation:

Talking Mats is a social enterprise whose vision is to improve the lives of people with communication difficulties by increasing their capacity to communicate effectively about things that matter to them. Talking Mats uses a mat with symbols attached as the basis for communication. It is designed to help people with communication difficulties to think about issues discussed with them, and provide them with a way to effectively express themselves in a visual way that can be easily recorded. Talking Mats is an established communication tool, underpinned by robust research evidence. Further information is available on our website www.talkingmats.com.

¹ <http://www.gov.scot/Topics/Health/Policy/2020-Vision>

² Department of Health, 2009. Living well with dementia: A National Dementia Strategy. [Online] Available at:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168221/dh_094052.pdf

³ The Scottish Government, 2012. The Charter of Patient Rights and Responsibilities. [Online] Available at: <http://www.gov.scot/resource/0039/00390989.pdf>

⁴ Tyrrell, J., Genin, N. & Myslinski, M., 2006. Freedom of choice and decision-making in health and social care: Views of older patients with early-stage dementia and their carers. *Dementia: The International Journal of Social Research*, Volume 5, pp. 479-502.

Planned differences or changes that you want to make for the people you work with:

The deterioration of communication between people with dementia and their carers is one of the most distressing aspects of the illness and often has a negative impact on relationships^{5 6}. Unpaid carers are often left in a position of having to advocate on behalf of the person with dementia, but this can be difficult to do if the person's communication has deteriorated.

Building on what we have learned, we wished to work with family members, people with early stage dementia and staff in dementia resource centres to explore these issues of communication in more detail and then develop a model of training and support which could be implemented across dementia services in Scotland. This would provide carers with a practical tool which they could use in everyday life with the person with dementia to help them express their views and thereby improve everyday communication.

The main activities or services you provide to deliver your outcomes:

The project staff who delivered the training are experienced trainers and have a sound knowledge of communicating with families with dementia. We also have research knowledge and clinical skills in supporting self-management.

The project was carried out in two phases:

- A. Evaluation of Family Training Model with group of family carers, people with dementia and staff at an Alzheimer Scotland Resource Centre. Phase one was reported on in the mid project report.
- B. Delivery of training to Dementia Centres throughout Scotland, following evaluation and adaptation of the training in Phase 1. We planned to deliver the adapted training to seven Dementia Resource Centres in Scotland, involving families and staff and to evaluate the impact of the training.

What we actually did

We provided Talking Mats training for 26 family carers and 19 staff in 8 locations across Scotland. 24 people with dementia attended the training. Seven of the

⁵ Kitwood, T. (1997). Dementia reconsidered: The person comes first. Buckingham: Open University Press

⁶ Murphy J, Gray C M, Cox S, van Achterberg T, Wyke S (2010) The effectiveness of the Talking Mats Framework with People with Dementia. Dementia : International Journal of Social research and Practice 9(4) 454-472

centres where we delivered the training are run by Alzheimer Scotland and one is an independent advocacy resource.

As part of the preparation, we met with Alzheimer Scotland who provided valuable advice and guidance. We agreed that the training would be best delivered over 2 x 2 hour sessions - a simpler and shorter version of the standard training. They also provided contact details of centres who were interested in being involved in this project. It was originally anticipated that the carers would attend the training on their own but at the pilot training session some people with dementia came with their family member and we did not want to exclude them. As this pilot training went well, and the people with dementia seemed to benefit from attending the sessions, we decided to include people with dementia at all future sessions. This meant that the training was further adapted at each session depending on the needs of the attendees.

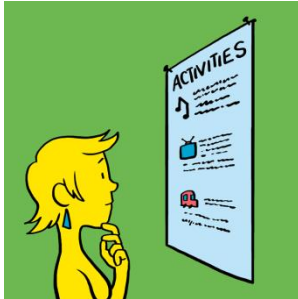
Session 1:

- Background on communication and introduction to Talking Mats
- DVD examples and reflection on communication
- Hands on practice
- Discussion of topics that could be used at home
- Planning for next session

We provided the 'Social Care' set of Talking Mats symbols⁷ for each family and staff members attending. This set was chosen as being the most suitable for helping families to self-manage their lives, by enabling the carer to find out the views of their relative about **activities, where they lived** and how they felt they were **managing day to day**. We explained to participants that this was a starter set and that symbols for further self-managements topics such as **health, mobility, self-care** were also available and would be explained at the second session.

⁷ The Symbols are designed and © to Adam Murphy 2015 and assigned to Talking Mats Ltd. in perpetuity. They may not be reproduced without permission.

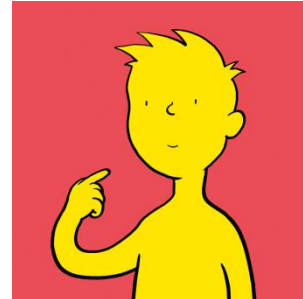
Social Care Symbol Set



Activities



Where you live



You

Each of the participants agreed to try out a Talking Mat at home / workplace using the above set and come back to the second session to provide feedback.

Session 2:

- Follow up session to share their own personal stories of using Talking Mats
- Discussion about how the framework can be used to support self-management in everyday life
- Discussion about other topics

We used a special set of symbols at the beginning of Session 2 to help participants reflect and comment on their experience of using Talking Mats (see page 16).

We used mind mapping to identify other topics that would be particularly useful for future use. Those who attended identified new activity topics: **trips out, sport, football, gardening, music, holidays**. Symbols for these topics will be developed by Talking Mats and given to each of the centres. The music symbols for example, can help staff compile musical memories, and the football symbols support the football discussion groups which are held at several of the centres.

Mind mapping also helped the families and staff see how they can develop their own symbols as needed.

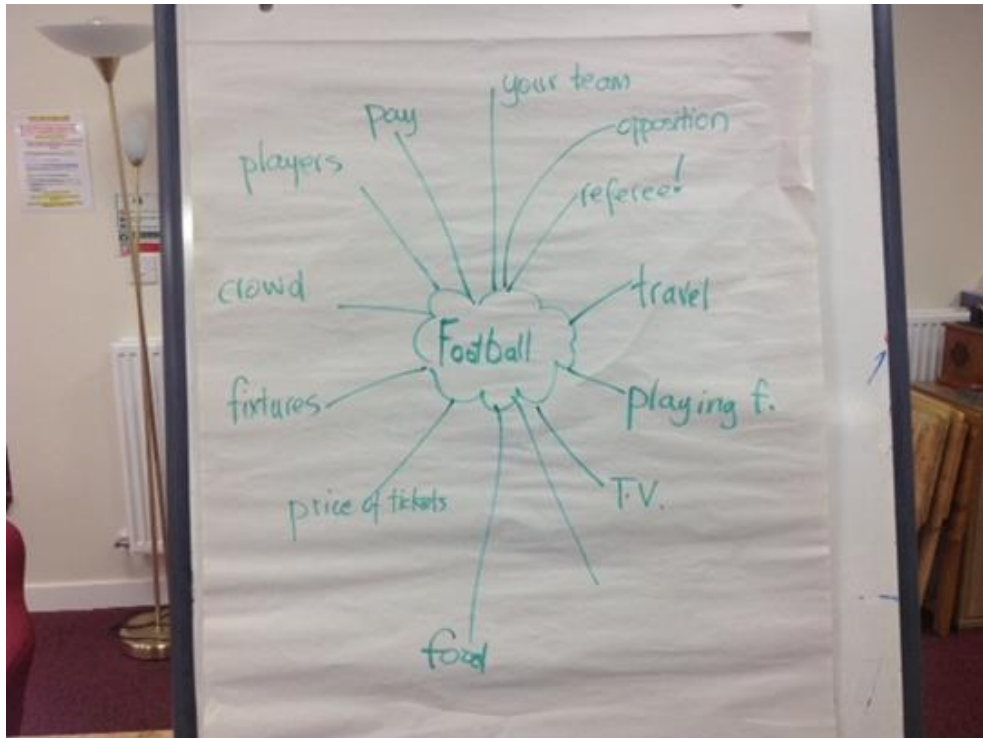


Figure 1 Football mindmap

We provided copies of research summaries for each participant: 'Using Talking Mats to help people with dementia communicate' and 'Talking Mats help involve people with dementia and their carers in decision-making'.

We also offered free attendance for 4 staff at a Talking Mats workshop on 'Capacity'.

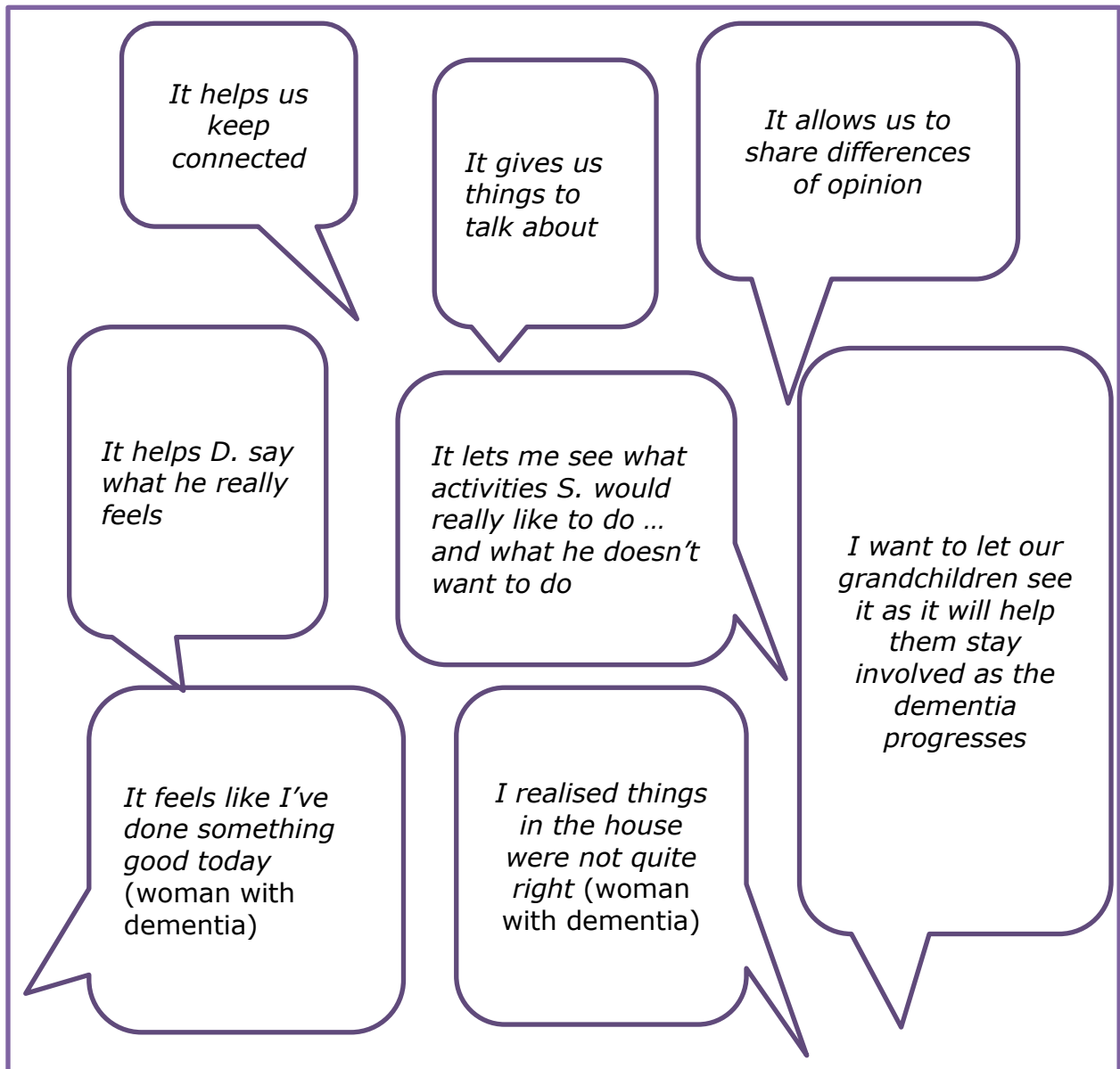
What difference we actually made

The overall responses from participants were positive. Participants said they found the training sessions enjoyable and useful and everyone who came to the second session said they thought they would use Talking Mats again in the future.

We have divided responses about the differences using Talking Mats made to the families and the staff.

Families:

Families identified issues relating to self-management that they had not previously been aware of. New insights emerged as the following comments illustrate.



For some family members an important outcome was that Talking Mats helped them see that their spouse was satisfied with many aspects of his/her life. They found this very reassuring as many assumed that the person with dementia was frustrated and discontented. The following short case studies give examples of how using Talking Mats helped with self-management.

1. When using Talking Mats on the topic of **Where you live**, G explained that he found it difficult to find his way to the toilet in the night. As a result his wife bought special senior night lights to help him which

solved their problem. As a result, night times improved for both of them.

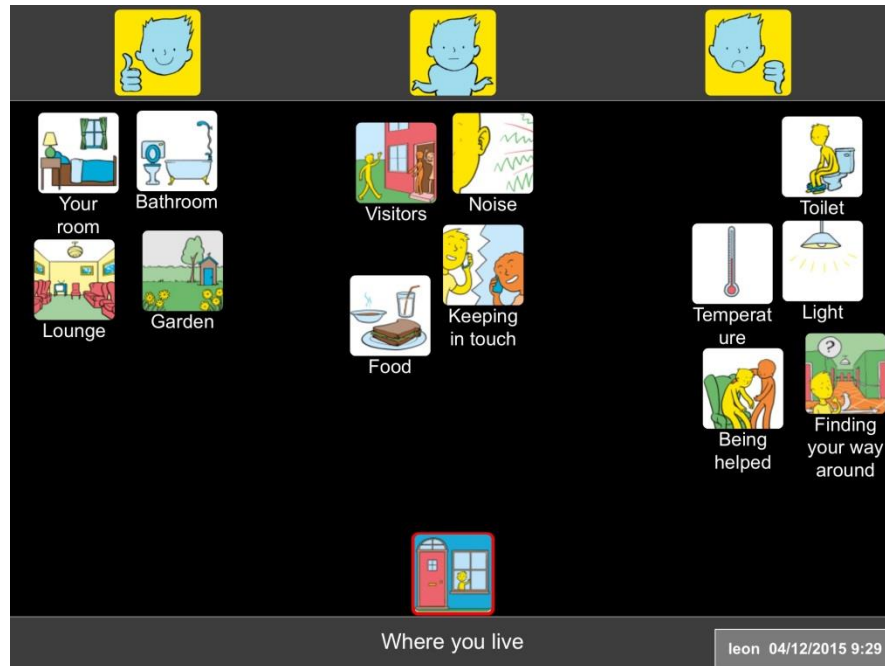


Figure 2 Where you live Talking Mat

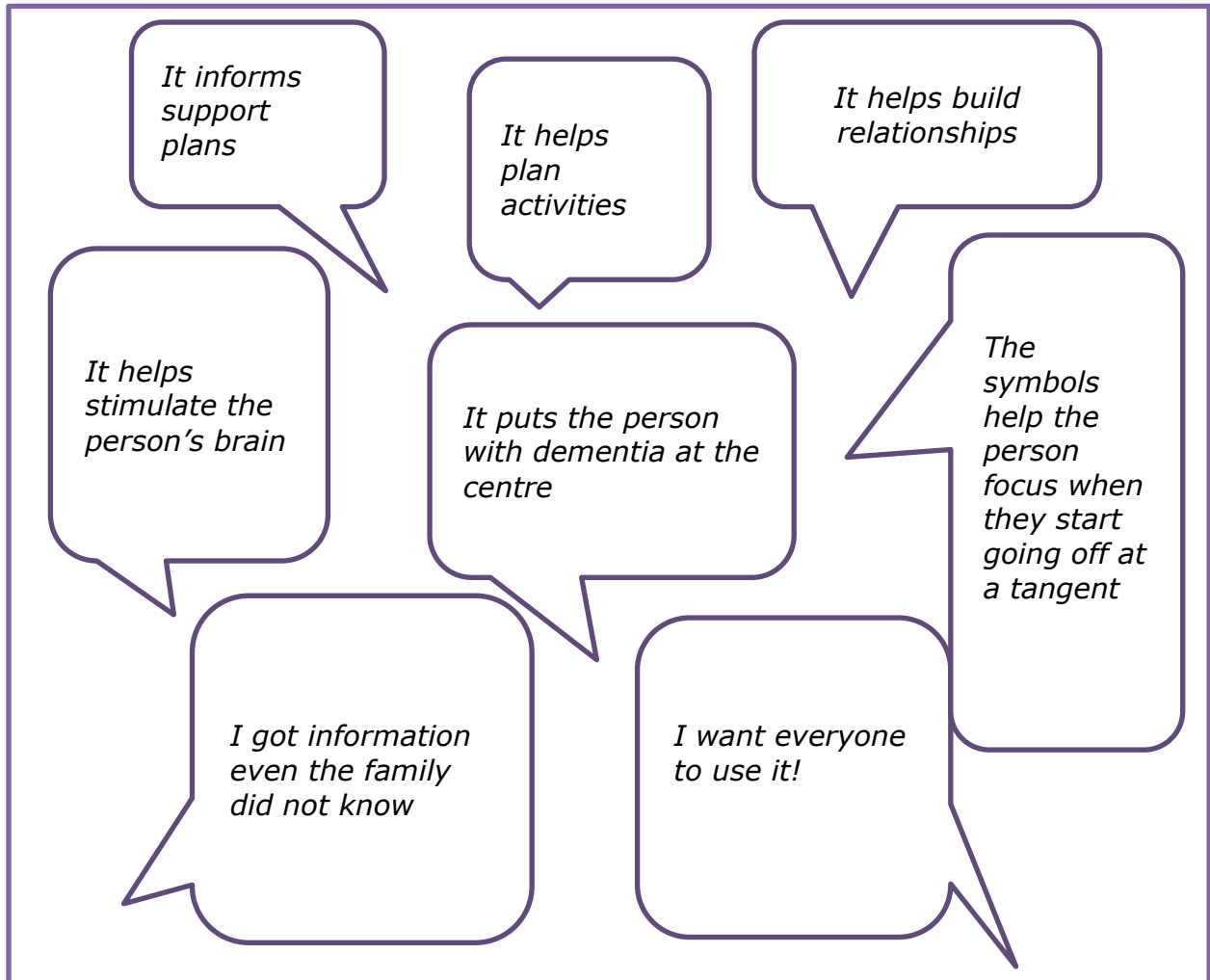
2. Another couple used the topic **You** which includes symbols on health issues. B, who has difficulty communicating, used the symbol for skin to indicate that he had an itch on his back which his wife had not been aware of. She realized that she would need to investigate it further.
3. One lady with early stage dementia used Talking Mats to think about her home. Her husband felt that everything was fine but for her it highlighted things that she felt she should put in place now as she had the insight to anticipate how things might progress. She felt they should get handrails put in on their stairs.
4. One couple did a Talking Mat on **Mobility**. P's wife was worried as P. was becoming increasingly reluctant to go outside for his evening walk. Using the mat, P was able to explain that his difficulty with walking was not due to a mobility problem but to his lack of confidence in finding his way in the street. The solution was that his wife now goes with him

These stories show how even small changes are important and can a positive impact on a person's quality of life.

Staff:

Staff were very pleased to be involved and to receive the Talking Mats training. They had heard about Talking Mats from other colleagues , some of whom had been previously trained.

The following are some of their comments at the follow up session:



One manager said that Talking Mats was especially useful to show the Care Inspectorate that they have genuinely included the person with dementia in discussions about their care. Another said 'It's a great tool to help staff do their job better' and several managers said that they wanted training for all their staff and more Talking Mats resources. Families also identified their wish for staff to be Talking Mats trained – 'I would like the support workers to be trained in using Talking Mats as I think it would help them understand my sister better.'

The following staff story illustrates the usefulness of Talking Mats.

N. works with a family who were struggling to talk to each other and to work with support services. They had frequent heated arguments which left everyone upset. N. visits every week and gradually introduced Talking Mats to E. who understood that she could express her feelings via the mats. She came to look forward to N's visits and would be waiting at the front door for N. to arrive. E's husband initially refused to come into the same room when N was working with E but he gradually would stand at the door and watch them use Talking Mats. N felt he was on the threshold of actually getting involved. She also noticed that arguments had reduced. N. told us that she found out important information that was missing from the Social Work Assessment. She felt that Talking Mats helped E. to calm down and that she was expressing a number of issues which were allowing her to self-manage her situation.

Headline achievement

By using Talking Mats, families living with dementia found out things they didn't know already and saw how even small changes helped them to manage their lives better.

Challenges and changes

Preparation:

There were challenges in arranging the training itself. 11 centres from the statutory and voluntary sector were approached but training was only carried out in 8 of these for the following reasons.

- One centre had arranged for family members of those with late stage dementia to attend. As the training was aimed at people with earlier stage dementia it was agreed with the manager not to go ahead with the second session.
- Two centres could not identify families who would benefit from the training
- Arranging the follow up sessions was also difficult due to weather, changes in staff both in Talking Mats and in some of the centres, Christmas holidays and changes in families' circumstances. Nevertheless, we exceeded the number of training sessions we had originally planned to deliver.

Training Sessions:

Having the people with dementia present and involved during the training meant additional consideration and planning for the trainers and staff. The language and visual materials used by the trainers needed to be sensitive to the situation and the people present which meant every session was adapted in some way and needed extra preparation time.

As we anticipated, the Talking Mat did not work with everyone, especially those with later stage dementia. Some carers however, thought that their relative's dementia was not far enough advanced to need to use a Talking Mat. People coming to terms with the diagnosis of dementia find it difficult. The timing of offering support is crucial and perhaps some of the families we met found it hard to accept that communication support might be needed. On reflection we were perhaps not clear enough about how Talking Mats can be used at different stages of dementia even when there are no obvious communication difficulties.

It became very clear that using Talking Mats with a close relative can be a challenge as negative issues, as well as positive, can be revealed. As well as finding out enlightening things about their family member, they may also discover things about their relative that may be difficult or they don't necessarily agree with and therefore avoid using the mat.

Some, but not all, families found some of the topics difficult to explore and would have preferred more concrete topics like 'where to go on trips out' rather than exploring bigger issues such as how the person with dementia felt about themselves or where they live.

At the first session all the staff were very enthusiastic about Talking Mats and could see how useful it could be for them. However, some staff reported difficulties in getting time to practise the mats, confidence also appeared to be an issue. Interestingly, all the staff said they felt they wanted further training.

We had originally planned to visit families between sessions to provide support where necessary, but we requested that staff on the course provide this support instead.

Learning for the future

Unexpected outcomes:

There were several unexpected outcomes, firstly for the families.

1. Some couples swapped roles and the person with dementia became the 'interviewer' finding out the views of their spouse. This led to a deeper understanding between them and also considerable humour.
2. Talking Mats frequently sparked unpredicted discussions and memories. E.g. one lady, M, with fairly advanced dementia was usually distracted and very confused. However, when she attended the training sessions and her relative asked her what she thought about **music**, she told the group quite coherently that she had played the piano, had been in the church choir and had been to operas at Covent Garden (all confirmed by her relative).
3. Talking Mats was used as a family activity to include different generations. One family included teenage children and another showed it to their 5 year old granddaughter who then did it with her grandad. A third family saw Talking Mats as a 'bridge' between generations.
4. Several spouses felt they knew their partner too well to use Talking Mats and were not learning anything new. However, one wife was very surprised to learn that her husband had issues with her having the light on to read in bed. We used this story at subsequent training sessions to try and highlight that we don't always know everything about those we live with. In addition staff told us that interests and views might change as the dementia progresses.
5. Four families have requested the digital version of Talking Mats to use at home.

Unexpected outcomes for staff

- 1 Staff commented that they felt that using Talking Mats gave them better quality of information in a shorter time than by using speech – they said it was a more efficient way of getting the views of people with dementia.
- 2 One family member, whose relative died during the project, came back to the follow up session and said that she really saw the potential in Talking Mats and was looking at ways of using it with others, perhaps in the centre.
- 3 Centres came up with several ideas for making Talking Mats sustainable. These included having regular 'Talking Mats surgeries'; using Talking Mats with carers to find out what they are needing to provide them with relevant support; using it in the dementia cafes;

having a regular follow up meeting for staff to share Talking Mats stories and ideas.

Key learning points:

There are several key learning points which have implications for the future.

1. We must bear in mind that, even if families are initially enthusiastic, for some, the practicalities of living with someone with dementia can make it difficult to use Talking Mats successfully.
2. Some family members thought that they should only use a Talking Mats topic once to get the person's views. In future we should emphasise that some topics can be used regularly with people with dementia to see how they feel at different points in time because their views about their health or their mood can change daily.
3. All participants were given three symbols topics as a starter pack. Many indicated that they wanted more topic sets and ones that were more concrete that could be used for conversations. These are highlighted on page 6. We will make these available to the Centres which took part.
4. Although including people with dementia was a good decision ethically and helpful to the family members who often had no one to look after their relative. In retrospect this made the training more complex and probably less effective. However having people with dementia present was helpful for us as we could see some of the difficulties facing family members.
5. We suggested that the people with dementia who attended should be at the early stage of dementia, but this should have been explicit in the information sheet. Having people with different stages of dementia taught us two things: that Talking Mats can be used with people at early stage dementia to get their views on quite complex and abstract issues whereas for people with late stage dementia it is most helpful as a conversation tool.
6. In the proposal we hoped that there would be peer support for each other at the training. This did not happen as much as we expected, although there was some support from families to each other-e.g. how to adapt their gardens to make them more dementia friendly, how to help the person with dementia find his way to the bathroom at night easier. In future we could gather suggestions from people and make them available to other groups.
7. Although staff were keen to use Talking Mats at the first session, some staff who came to the follow-up session had not used it. For some this

- was due to time pressures and holidays - others appeared to lack confidence and the general feeling was that they needed to practise using Talking Mats straight after the training. This was not the case with family members. Every family member who came to the follow up session had tried Talking Mats at home. With hindsight we could have encouraged staff more to bring back at least one case study to the follow up session as we do at our fuller training. This would have helped their learning.
8. Having managers present at the training is important as they can encourage and involve staff and make decisions about future training and resources.
 9. We had assumed that offering free training might result in it being valued less. However, 83% of staff and 62% of family members and 54% of people with dementia came back for the second session and legitimate reasons were given for people not being able to attend.
 10. As highlighted by managers, staff would benefit from their own, full training to help them embed Talking Mats in practice.
 11. We had planned to run focus groups with staff following completion of all the training but in practice there was no time for this. This was partly because staff changes caused delays; partly because organising the sessions took longer than expected and partly because including people with dementia in the training, which we had not originally planned for, meant the training took longer than expected
 12. The information sheets could have been more explicit for family members and staff.

The final learning point is that we should never make assumptions. This is best illustrated in a story from one of the managers.

13. The manager was using Talking Mats with D, a man with moderate dementia, about **Leisure Activities**. She had a symbol for **sewing** and assumed that, being a man, he probably had no interest in sewing. She was about to miss it out but then decided to include it anyway and maybe have a joke about it. But **sewing** triggered something in D's memory and he told her all about his work during the war when he sewed parachutes for the Airforce.

What we would do differently

There are three key things we would do differently in future

- 1 We would run separate training courses for staff and families. We would run staff training first and then run workshops for families where the staff would already be trained and on hand to provide additional support.

- 2 To support staff learning and to make the training more embedded in practice we would encourage staff to bring back at least one case study to the follow up session.
- 3 To ensure full understanding of the potential of Talking Mats we would have managers present at the training

How we collected the information

We gathered evidence anecdotally by listening to all participants and wrote up summaries immediately after each training session. We used a Talking Mat at the second session to find out about families and staff experiences of using the tool at home and in the Centres. This provided valuable feedback about their views on issues including their confidence, the symbols, engagement, information obtained and future use.



Figure 3 Talking Mats feedback mat

Feedback forms were sent to families and staff who were unable to attend the second session and some staff shared their experiences via email – (See Appendix).

Mind maps were used to gather information about what topic sets families and staff felt would be helpful for using Talking Mats in the future.

The future

We will produce additional symbol sets for the Centres involved to share with staff and families.

We wish to give feedback to the families and staff on the project. Once the final report has been accepted by the ALLIANCE we will produce a summary report and make the summary, as well as the full report, available to all those involved.

Throughout the project, we have had very helpful discussions with Maxine Dinnes, Head of Training & Development | Quality and Workforce Development with Alzheimer Scotland. She has also made useful comments and suggestions on the final report which we have included. We are planning to meet with her to discuss the recommendations in the report and to plan for how we take Talking Mats training forward for Alzheimer Scotland.

We are also discussing family and staff training with other organisations, including the Alzheimer's Society, Advocacy centres, Care homes, Social Work Departments.

We are also looking at providing similar training for other groups such as people with learning disability,

Acknowledgements

Thanks to all the families living with dementia who volunteered to take part in this project. We are very privileged to have worked with them and to have heard their stories. We have learned huge amounts from them and are encouraged that for many, Talking Mats has helped them manage their lives better.

We are also indebted to the staff in the Dementia Centres who organised the groups, provided their premises for the training sessions and shared their experiences of using Talking Mats with us. We are encouraged that many of them want to extend their use of Talking Mats.

Thanks also to Alzheimer Scotland who helped us find Centres to take part and who provided us with invaluable advice.

Finally we are very grateful to the ALLIANCE who funded this project.

Appendices

1. Information sheet for Centres

TalkingMats



Training for Family Members of People with Dementia

Talking Mats is a social enterprise whose vision is to improve the lives of people with communication difficulties by increasing their capacity to communicate effectively about things that matter to them.

Talking Mats uses a mat with symbols attached as the basis for communication. It is designed to help people with communication difficulties to think about issues discussed with them, and provide them with a way to effectively express themselves in a visual way that can be easily recorded.

Talking Mats is an established communication tool, underpinned by robust research evidence. Two major research projects in the area of dementia found that:

- (i) Talking Mats was effective for people at early and middle stage dementia and also improved the quality of interaction for people at late stage dementia (Murphy et al 2010);
- (ii) Talking Mats helped people with dementia and their family members to feel more involved in discussions about managing their lives and that family carers in particular felt more 'listened to' by the person with dementia. This is because Talking Mats provides a visual framework which supports conversation and helps people to stay on track, remember and review what they are talking about (Murphy and Oliver 2013).

In this project, we want to build on previous work done in collaboration with Alzheimer Scotland where we trained family members of people with dementia and some staff to use Talking Mats to find out the views of their relatives. From this initial project, we learned three things:

1. Talking Mats can help many families to communicate and share their views more effectively. It provides a tangible framework for structuring conversation which helps the person with dementia to understand the topic being discussed and stay on track.
2. Some families need additional support to be able to use Talking Mats effectively. Although some of the carers who attended the training felt that Talking Mats would be a useful tool, in practice, some found it difficult to introduce and use with their relative.
3. People felt that Talking Mats could be used to help them manage and cope with everyday life. For example, helping carers to plan activities with their relative; levels of support needed for carrying out activities of daily living or discussing health issues prior to GP or hospital appointments.

Building on what we have learned, we wish to work with family members, people with dementia and staff in dementia resource centres to develop a model of training and support which can be implemented across dementia services in Scotland.

2. Information sheet for families

TalkingMats



Training for Family Members of People with Dementia

Talking Mats is a social enterprise whose vision is to improve the lives of people with communication difficulties by increasing their capacity to communicate effectively about things that matter to them.

Talking Mats uses a mat with symbols attached as the basis for communication. It is designed to help people with communication difficulties to think about issues discussed with them, and provide them with a way to effectively express themselves in a visual way that can be easily recorded.

A key aspect of the work done by Talking Mats is to find ways to improve the lives of families living with dementia and to help them find positive aspects of living with this long term condition.

In this project for family members of people with dementia, we want to build on previous work done in collaboration with Alzheimer Scotland which sought to empower unpaid carers and provide them with an effective method of communication to use on a day to day basis.

We wish to work with family members, people with dementia and staff in a dementia resource centre to develop a model of training and support which can be implemented across dementia services in Scotland. This will provide carers with a practical tool which they can use in everyday life with the person with dementia to help them express their views and thereby improve everyday communication.

Previous carers who have completed the training said:

- *"Small changes made a big difference"*
- *"It gives me time to sit down and listen to him"*
- *"It slows you down which is needed with someone with dementia"*
- *"It helps me know where he is at the moment"*
- *"It showed my husband the things he CAN do rather than what he CAN'T do"*

This project will give families living with dementia the opportunity to listen to and share their views with each other. It will also enable them to plan and manage their lives together. In addition, because we have designed the training model to be self-sustaining, families will be involved in empowering and supporting others living with dementia.

3. Family feedback form



Talking Mats Feedback form

Did you use Talking Mats? If yes please answer the questions below:



- **What do you think worked well?**

I used the talking mats to find out what activities our people with dementia like to do. I got some really interesting feedback and used the exercise to inform the reviews of service we provided. This information was then included in the Personal Outcomes Plan/Support Plan.



- **What do you think could have been better?**

For some activities I felt I needed more activity cards in order to gain more information e.g. the 'games and puzzle card'. We will make up our own cards to expand on this subject.



- **Do you think you will use Talking Mats again?**

Absolutely. It is a great tool for using to inform reviews

- **If you did not manage to use Talking Mats please tell us what made it difficult**

Thank you for your comments