



Making end of life planning accessible – evaluating Talking Mats (TM)

Project aims:

We aimed to find out to what extent the 'Thinking Ahead' TM resource could be used to support people with neurological conditions to have conversations about their preferences for the future.

What we have done:

We have delivered training to 19 participants who were keen to use the TM Thinking Ahead resource to support people living with neurological conditions to have conversations around Advance Care Planning (ACP). TM is an evidence based visual communication framework developed at the University of Stirling. The Thinking Ahead resource was developed in partnership with Strathcarron Hospice but had never been tested with people with neurological conditions. The training provided a space for participants to think about how they approach these discussions. It was devised in partnership with the Scottish Simulation Centre and was shaped by conversations we had with people living with neurological conditions.

In addition to this, we have mapped the TM resource against other toolkits and consulted with people living with neurological conditions to find out if any topics were missing from the resource. As a result of this mapping exercise and our analysis of returned summaries, we have been able to further develop the TM resource and make additions and adjustments to the symbol sets and options.

Two people who undertook the initial training have been put forward to become licenced trainers. This means that they will be able to train others within their organisations in the use of TM, thus ensuring sustainability. There are plans to add a Thinking Ahead module to the suite of on line courses TM offers on its learning platform.

Evaluation approach:

Over the course of the project, we have gathered stories and experiences from people living with neurological conditions and those who work with them. We have collected and analysed data from the returned TM reflections – this includes information about actions from the conversations as well as the extent to which people felt involved and listened to, using the Care Measure¹. As well as collecting individual feedback from TM sessions, we also conducted a focus group with practitioners to find out about their experiences of using the resource. This data has been analysed thematically and is reported in the findings section of this report.

Findings:

Nineteen practitioners attended training in use of the TM Thinking Ahead resource. Their roles are summarised below:

Job role	Numbers	Sector
Nurse	1	Third sector (Hospice)
Occupational Therapist	1	NHS
Support worker	2	Third sector (Hospice)
Activity coordinator	4	Care home/third sector
Volunteer	2	Neurological support group
Speech & Language Therapist (SLT)	5	NHS
Advocacy worker	2	Third sector
Practice Educator	1	Third sector (Hospice)
Creative arts facilitator	1	Third sector (Hospice)

Experiences and reflections from the training:

The one-day training, using four simulation scenarios to support people to experience and engage in sensitive conversations with people around thinking ahead prompted much reflection and learning. The physical act of using the TM resource in a safe space enabled people to test out how they might introduce use of the resource as well as explore how to respond to distress and provide space for reflection when needed. Crucially, the scenarios helped people explore how they might support people with severe communication difficulties, revealing how use of TM can give people the opportunity to get into a conversational rhythm, without the need for lots of words and explanation.

The sessions allowed practitioners to focus on listening to people's views, while not pre-judging or jumping to 'fix' mode when a person became upset. One of the scenarios powerfully explored the impact of holding emotion and giving a person space to figure out their own solutions to an issue. The mats create a safe space that enables courageous conversations to occur. The group really valued the practice experience of creating that space and observing what worked and what did not.

Uptake of use of the TM resource:

Since the training, 26 completed summaries have been returned to us. Participants were given the option of using the card or digital resource, but the majority (n = 23) used the card format. Of the 19 people who attended the training, 10 people used the resource. Reasons for not using the resource are outlined below:

Role	Reasons for not using the resource
Practice educator	Not in a role working with people directly – therefore little opportunity to use it
Support workers	Did not engage in the project after the training
Advocacy workers	Others in organisation blocked use of the resource due to an apparent culture where only professionals in nursing or allied health roles were deemed able to have these conversations
Activity coordinators (care home)	One member of staff left role. The other was unable to engage due to time constraints
Nurse	Did not engage in the project after the training

This project took place while Covid was still disrupting health and social care delivery. Several of the people involved got Covid during the project and services were under significant pressure because of this. Participants told us that this was a reason why they had not used the resource as much as they had committed to. From the 26 returned, the majority were from Speech and Language Therapists (SLTs). We explored this in some detail at the focus group, who felt that SLTs were in a unique position to be able to build a relationship with the person over time, particularly as their communication deteriorates:

"I think you do have to do a bit of a bit of groundwork first and then a bit of relationship building"

There were also comments about building confidence in using TM, and having a chance to practice:

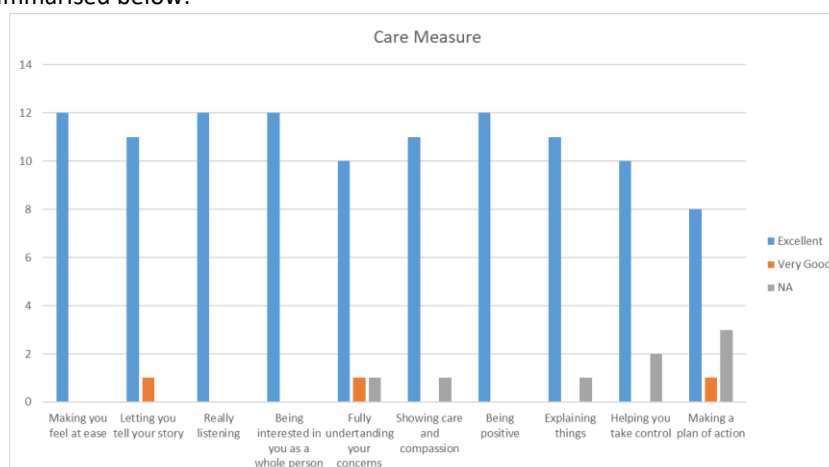
"I think probably there has to be that bit of confidence in the person using it. So I think if that's not there you know that that could definitely be a barrier".

The SLTs in the group were clear that their role was about supporting a person's communication, rather than acting on decisions on behalf of the person:

"So then I think our role becomes clearer around where the facilitators of the communication rather than necessarily the person who's going to kind of take on some of the issues"

Care Measure:

The Care Measure was used to provide feedback about the extent to which people felt listened to, in control and involved in action planning. Twelve Care Measures were completed and returned to us. Results from these measures are summarised below:



The Care Measure scores suggest that participants felt high levels of involvement, empathy and control during the sessions. The majority, but not all, felt that some form of action planning had happened as a result of the session. This will be reported on in more detail in the next section.

Use of Talking Mats – feedback from reflection sheets:

Feedback from the TM reflection sheets has been analysed thematically.

Process:

Participants told us that some of the cards needed further explanation (for example, the term ‘advance directive’ was not familiar to everyone). Another told us the definition of the cards ‘acute hospital’ and ‘day care’ were not clear.

Several participants talked about the difficulties of finding appropriate space with privacy to have the conversation. Others talked about how they worked round difficulties with physical access creatively (e.g. using a pin board so the person could eye point to symbols). One person who used the digital TM was able to use eye gaze technology to enable the person to access the symbols directly.

Emotion:

Participants found that often the discussions were emotional but that use of TM helped to create a space for people to think through important issues. This was beneficial both for the thinker and the listener:

“This was a positive but emotional conversation. My thinker shared a lot of her plans for leaving memories I was a bit anxious about raising some of the topics with her as she has always been very reserved and hasn’t wanted to talk very much about the future, however following the mat she opened up in a way that she hasn’t before” (participant 8)

Another participant reflected on the fact that the topic of thinking ahead is an emotional one, and it would be important to ensure the listener knew how to provide support during and after the conversation. This had been addressed to some extent in the simulation scenarios but experience of use in practice and reflection will build confidence in this.

Information gained:

Participants told us that they found the conversation using TM provided them with new information and insights from the listeners. For some, the process of thinking through the issues highlighted that they had most things in order. For others, it prompted them to think about things they needed to do:

“Person reported feeling that he was more organised than he thought, and that he now knows what else he needs to sort out” (participant 5)

“They originally thought they had everything planned for the future but there were a few areas they had not considered and said they found it very helpful and plan to talk to their son” (participant 1)

For some, their health was changing and this meant that having a conversation to review ACP discussions was really important. The Thinking Ahead resource allowed people to review how they were feeling about issues in relation to their deteriorating health:

“the family have had previous ACP conversations however with his decline in health there are now further complexities to future planning. For example, end of life hospice care was not seen [in the past] to be appropriate, he now believes that this may be the right decision”.

Inclusive communication:

Use of TM helped people to participate in conversations that they would have struggled to do had they been reliant on speech alone. Those who used TM had a range of neurological conditions, including MND and MS, and some used alternative and augmentative communication systems accessed through different methods,

including eye gaze. These methods can be tiring to use, but use of TM created a space for people to consider and think about issues one at a time, and later reflect on each issue in relation to others. TM could be used alongside the person's normal method of communication, which was helpful:

"It was helpful to do this short mat after an SLT session when we had been discussing optimising communication and making use of modalities other than speech – hopefully the mat illustrated that conversations can be enhanced with symbols and emphasised the importance of continuing to have important conversations, in spite of communication difficulties" (participant 9).

Action:

Most of the TM conversations resulted in actions, either from the point of view of the listener or the thinker. These included contacting a GP to discuss an advance directive, another to opt out of the organ donation scheme. Others were going to speak to family members to further discuss funeral arrangements or put things in place around giving away possessions after their death. Other actions included going home for Christmas, planning for discharge from hospital or directing future team input (e.g. physio).

Focus group with practitioners:

Much of the discussions in the focus group mirrored the themes from the TM reflections. In addition, there was discussion about how the sessions were helpful in stimulating interest from other professions in the team:

"They now want to be trained in Talking Mats and that they really see like such a huge value, particularly for that patient group." (participant 8)

Participants talked about the power of using symbols to communicate about this emotive topic and how the mat created a space and a distance, enabling people to really think about the topic without having to put everything into words:

"You know he, he got so much out of it. But he had such a recent diagnosis of a very short prognosis. So there's a lot of emotion that there's a lot of turmoil going on with them. And he in fact enjoyed the cards being held up. So they didn't have to be in much communication at all." (participant 4)

Members of a third sector support group were initially not keen to use TM, and suspicious of motives. However, once they engaged in the conversations, they found it helpful and someone even wrote an article for the group's newsletter:

"Those who took part really enjoyed the experience of talking about their chosen topic, benefitting from new insights. Some felt it confirmed what they already knew. Some also welcomed the opportunity to talk openly about certain areas of their life with someone who was supportive and provided a listening ear. They felt they were then able to take their issues back to those who are involved in their life to plan further."

Other issues discussed at the focus group included how to manage when different members of a family had opposing views and how having other people present might change the dynamics and influence the thinker. Others found it helpful to have a member of the family available to help interpret what was said.

The group reflected on the impact that the pandemic was still having on people's ability to engage with healthcare professionals, with some still being wary of people visiting them at home. Although it was acknowledged that sessions could be done remotely using the digital version, relationship building was seen as crucial to being able to start such a sensitive and potentially emotional conversation.

Some practitioners worried that starting a conversation would open up issues they might not be equipped to deal with:

"And I think sometimes the barrier of having these conversations is the worry that you open up a can of worms and you don't know, like, you don't know how to deal with that information". (Participant 8)

We had some discussion about the digital version of the TM, which very few people had used in practice. Some reflected that it was easier to use in places such as a ward setting, where space could be tight. Others felt that use of the digital created an additional barrier as more work was needed to set it up prior to the conversation. However, those who had used the digital version felt it was easier afterwards as the report was easy to find, save and share others (with permission).

What would we do differently?

This project has enabled us to train a range of professionals to use TM to support people to have conversations around ACP. In partnership with the Scottish Simulation Centre, we developed four scenarios which gave practitioners the chance to rehearse use of the thinking ahead TM in a safe space. Not everyone who attended the training went on to use TM, and the majority of those who did were Speech and Language Therapists. To address this, we would spend more time in the training exploring values around communication difficulties and the right for people to be involved in shared decision making, as well as building confidence in explaining and introducing the framework and topics. We would also consider the role of post-training mentoring and ensuring people have support in the workplace so they can put their learning into practice. Given that very few people went on to use the digital TM version, we would also build more active use of that version into the training and use the digital platform in the simulation. We would also create a simulation to explore the advantages and disadvantages of others being in the room and where there are differences of opinion, encourage the use of two mats to enable different perspective to be openly shared.

People told us that at times they were worried they were 'opening a can of worms'. This is again something we would address in future training – building in time to explore how to manage uncertainty, hold emotions and acknowledge that the 'can of worms' will be there already and explore the risks of not addressing or talking about this. We would discuss how to ensure the right support is available to sign post people on or deal with issues as they come up. One organisation that had agreed to take part later restricted use of TM, saying it was not within the remit of the workers' practice. Next time, we would check that participants had a sphere of influence in an organisation and explore the barriers with potential professional groups.

People's experience of using the Thinking Ahead resource has shown us that we need to provide more information to explain different symbols and what they mean. The next version of the resource will include notes for the practitioner. We will also include additional symbols such as respite, being physically active, being mentally active and connected to the wider world. We will also include an explanation about adding blanks, with information about why specific options (such as NG and PEG feeding, antibiotics and DNACPR) aren't included, but can be added as additional symbols if appropriate to the individual.

Next steps, sustainability and dissemination:

Two people have been put forward to become licenced trainers, which means they will be able to train others to use TM within their organisation. We are planning to further develop and complete an on-line training module so it will be available for people to access. Our learning from this project will inform the content of this module.

We have submitted an abstract to Hospice UK conference where we hope to present our work to a national audience. We also plan to submit an article to the International Journal of Palliative Nursing. In addition to this, we will arrange a webinar to disseminate our findings. This will reach an international audience as both the TM team and Strathcarron Hospice have strong international links. We are very grateful to the Scottish Government Neurological Framework fund who have funded this project, and to all those who took part in this project and gave their time and expertise to share their stories and help us further explore this important topic.

¹ https://www.gla.ac.uk/media/Media_65352_smxx.pdf