

Solihull Action Through Advocacy and Marie Curie Midlands Pilot: End-of-life Planning for people with Learning Disabilities and/or Autism

Dr Susannah Baines

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1. Background

The extent and impact of inequalities on the health of people with learning disabilities have been well-documented. Research indicates that people with learning disabilities are three times as likely to die early than the general population. They are also more likely to experience poor general health, and to have high levels of unmet physical and mental health needs ¹

These inequalities also extend into palliative and end of life care, with studies showing that people living with learning disabilities and autism are less likely to have access to good and timely pain relief, care, and support. In 2021/2022 less than 4% of people with a learning disability or autism that died in Birmingham & Solihull accessed hospice services.²

2. The pilot

In recognition of this gap, Marie Curie Midlands and Solihull Action Through Advocacy partnered to run a pilot to start supportive conversations about death, dying and bereavement. They opted to hold the sessions at the Marie Curie West Midlands hospice on a weekly basis across 7 weeks. The first session was a Marie Curie Life Café session, and the following 6 sessions used resources from the Victoria and Stuart toolkit.

¹ [LeDeR-Annual-Report-2022-23-FINAL-PUBLICATION.pdf](#)

² [LeDeR Annual Report 2021-22.pdf](#)

A Marie Curie Life café is designed to start conversations about what matters to people at the end of life and has been successfully used with a wide range of communities across Marie Curie since 2019. The Victoria and Stuart project toolkit was developed by Kingston University through a multi-disciplinary team that included researchers with lived experience of learning disabilities. The toolkit is designed to find the best ways to help people with learning disabilities plan for the end of their life, ensuring that people with learning disabilities get the right care and support when they are ill and going to die. For more information see [End Of Life Care Planning | The Victoria And Stuart Project](#)

2.1 Aim of pilot

The aim was to work collaboratively to:

1. Increase the awareness and understanding of palliative care including hospice care and how people can access these services
2. Promote supportive conversations about death, dying and bereavement with people with learning disabilities and/or autism
3. Support the initiation of conversations around Advance Care Planning
4. Provide a safe and supportive environment for people to explore their own personal losses

2.2 Expected outcomes for the pilot

1. People with learning disabilities and/or autism will feel more knowledgeable about their wishes should they become ill and their wishes for their funeral
2. People with a learning disability and/or autism will have plans in place for how they wish to be cared for should they become ill and a plan for their funeral. They will know who to share these plans with
3. Attendees will feel more comfortable to talk openly about death, dying and bereavement

3. The evaluation

At the initial stages of developing the pilot, the impact and evaluation team was approached by the service team to help evaluate the project. The evaluation was designed to promote the full inclusion of people with learning disabilities and/or autism using accessible methods. During planning discussions with Solihull Action through Advocacy (SA^tA), the team decided to use red/green/amber cards to provide instant feedback for evaluation purposes. The benefit of this method is that it is straightforward to understand and can aid the session facilitator as well as providing data for evaluation.

3.1 Methodology

- 1 or 2 confidence questions were asked at the beginning of each session with red/amber/green response cards
- At the end of each session, attendees were asked two questions and used with red/amber/green response cards
- A short survey was sent to family members/and/or paid carers about their perception of the sessions after the final session
- A focus group for Marie Curie and SAtA staff was held after the sessions were complete
- The Impact and Evaluation manager attended a session to speak to participants in a group setting

NB Evaluation session

The Impact and Evaluation manager attended session four. The aim of attending in person was both to see the sessions in action and to capture additional data by asking focus group questions to participants. It was felt by Solihull Action through Advocacy and Marie Curie that participants would be more receptive to answering questions in person than attempting to do this over Teams.

4. The sessions

The sessions were run in the Rehab room at the West Midlands hospice. The attendees were invited to attend by SAtA as they had previously expressed an interest in wanting to start planning for their future but were unsure of where to start. One member of the group attended due to a recent palliative diagnosis and the support workers around him felt it was important to introduce conversations about planning.

The community engagement manager was the primary facilitator alongside a Marie Curie bereavement counsellor and social worker. Two facilitators attended from SAtA.

Table 1: The session format and resources

	Format	Resources
Session 1	Life Café introductory session Activity – pick a picture that makes you feel happy Discussion - The people in my life, who knows me best, who is important to me	Pictures from Life Café kit Whiteboard people – Life Café kit
Session 2	Who supports me to make decisions? Introducing the sessions	Picture cards

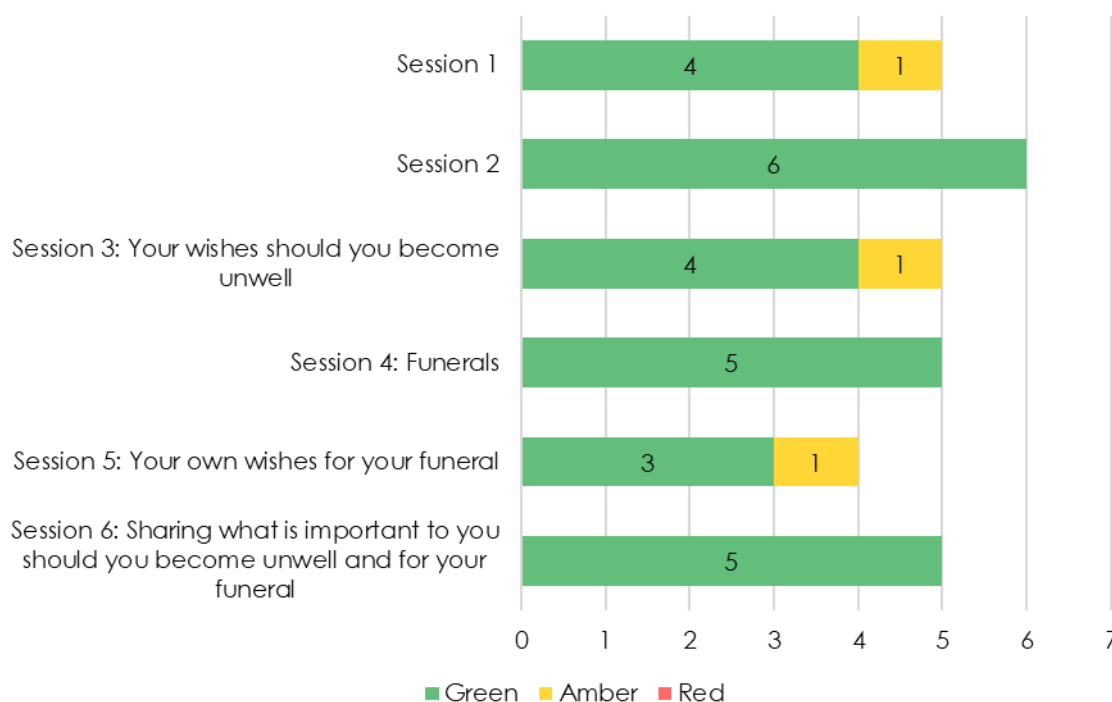
	Introducing the subject themes for the future workshops. Understand what current knowledge and awareness	Decision making profile sheets Subject cards
Session 3	Hospice tour When I'm ill planning Discuss with participants what is important to them should they become unwell.	Victoria and Stuart Toolkit – When I'm ill cards
Session 4	Funerals Using the funerals picture cards - group discussion about what funerals are, why we have them and what is involved	Victoria and Stuart Toolkit – Funeral cards
Session 5	My funeral cards - discuss with participants what is important to them for their funerals	Victoria and Stuart Toolkit – My funeral cards
Session 6	Putting plans in place - bring all that has been discussed and recorded into a final plan	Victoria and Stuart Toolkit – recording sheets
Session 7	Checking plans – make sure that what has been captured for each member is accurate and their own wishes Therapy dog visit	Victoria and Stuart Toolkit – recording sheets

5. Results

The feedback at the session, survey responses, in person evaluation and focus group transcription were collated and coded for common themes. Results are provided under the themes of sessions and content, set-up, and administration of the pilot.

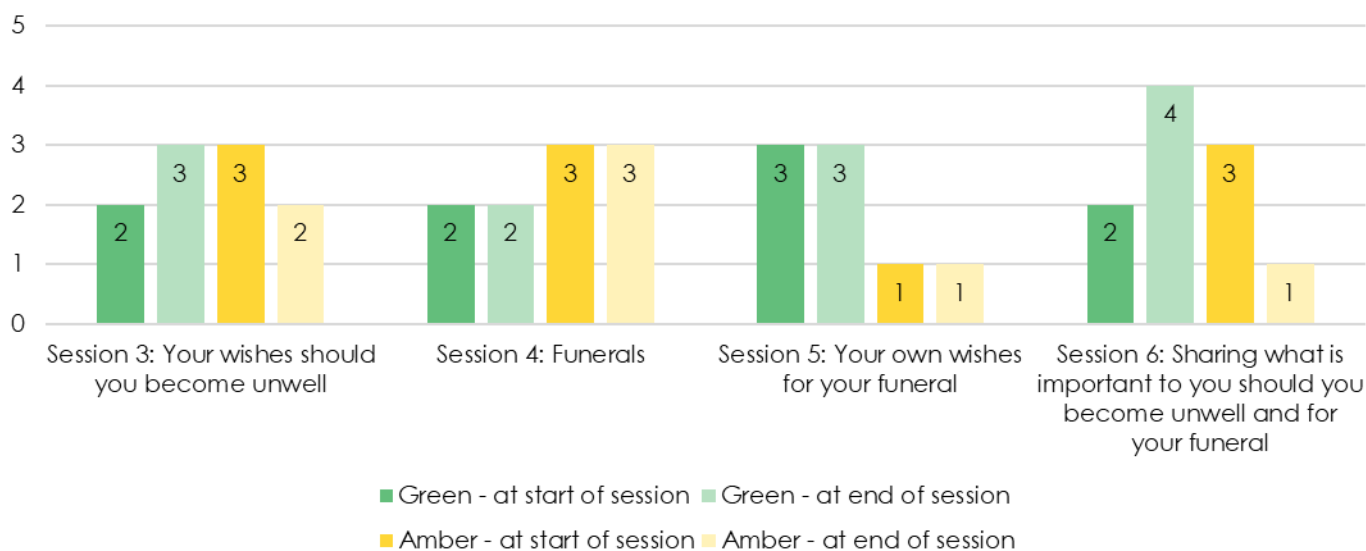
The red/amber/green card responses, along with the questions are presented in the graphs below.

Responses to "I have been able to share what is important to me", by session



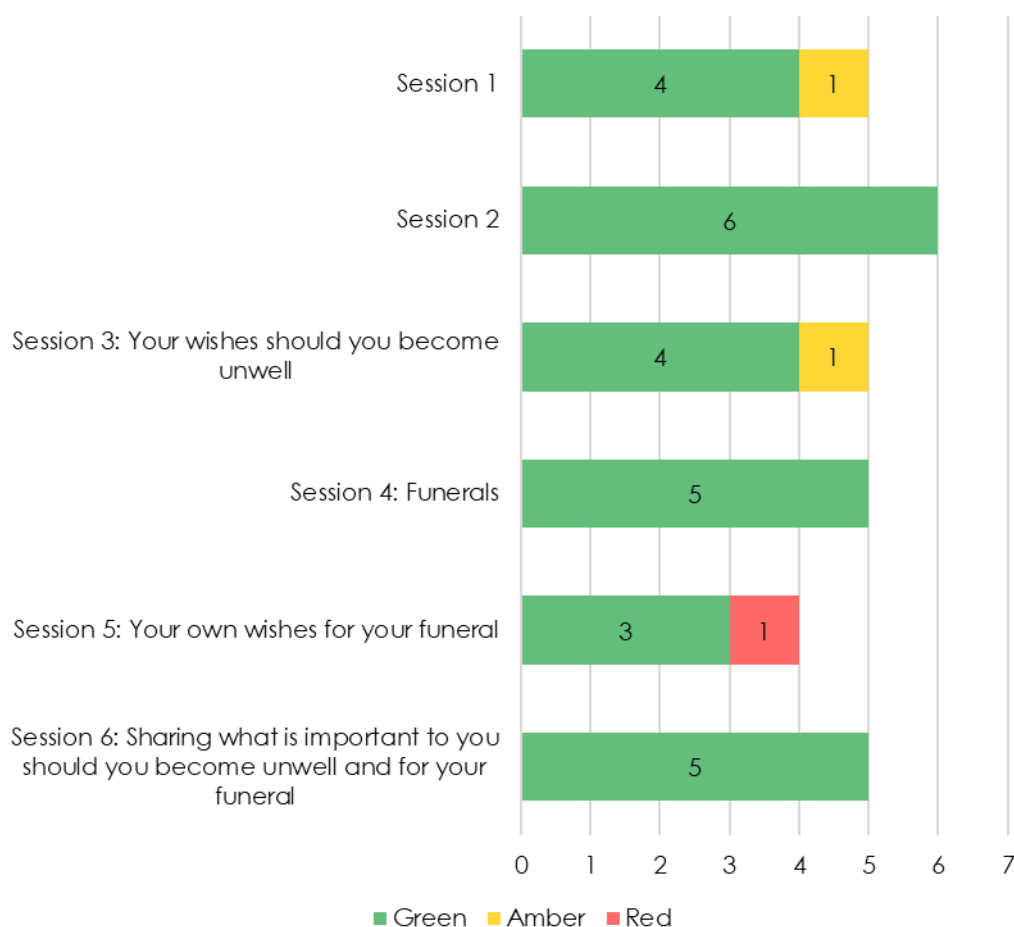
Participants were very positive that they had been able to share what was important to them during the sessions with predominately green responses.

Responses to "how comfortable/ confident do you feel talking about..." at the start and end of each session



The responses to this question stayed the same for sessions 3,4 and 5. For session 6, participants indicated that they felt more confident about sharing what is important to them if they were unwell or wishes for their funeral. This session focussed on recording their wishes and this increased their confidence.

Responses to "I am glad I came to the session", by session*



*In week 5 one participant initially showed a red card and said that was because she had felt emotional during the session. However, she very quickly changed it and expressed that although she had felt emotional she was glad to have had the chance to share so was pleased that she came to the session.

The responses were positive with a majority of participants at each session showing a green card.

5.1 Sessions and content

Attendees reported that the sessions were accessible, jargon free and not 'scary'

The resources and the sessions used language that is easier to understand and without too many difficult words. The facilitators also used shorter sentences, and explained any difficult concepts. This meant that the attendees were able to follow the sessions and engage fully.

“[Sessions were] very accessible for [name] to get to and also very well adapted for people with learning disabilities, having someone support with writing down important information and reading/explaining and discussing concept”

Survey response paid staff 2

The topic of death, dying and bereavement was felt by others outside the group to be intimidating, whereas the participants felt that approach meant that it wasn't scary or difficult to talk about.

"I had someone ask me if coming to these sessions is scary. I said considering the topic, you are made to feel comfortable so it's not"

Weekly session feedback

Attendees were able to talk about end of life and share what is important to them, which is something they don't often get the opportunity to do

It is recognised that people with learning disabilities and/or autism are not always included in discussions about the end of life. One of the motivations for the Victoria and Stuart project is to enable people to be able to live and die how they want.

"People with Learning Disabilities and / or Autism don't always get the opportunity to be involved in the planning for the end of their life. It is important that people have the opportunity to have their wishes known"

Survey response paid staff 1

"I think this course is excellent. It covers topics and planning regarding illness/end of life which can be very difficult to think about and navigate but the course helped people with a learning disability do this in a very sensitive and adaptable way."

Survey response paid staff 2

The participants and staff praised the sessions as allowing them to express and share what was important to them. It was expressed that it felt like a safe space for people to talk about difficult issues such as the funerals of family members.

"All the sessions I attended were individualised for [Name] and she was able to discuss openly her wishes"

Survey response paid staff 1

"The space and group felt very safe enabling those attending to share what they felt comfortable with"

Survey response paid staff 2

One of the aims of the sessions was to help participants feel more comfortable with talking about death, dying and bereavement.

"Felt good to talk about it. Today I talked about my dad – feels like a weight has lifted. I feel comfortable talking about it with this group"

In person feedback to the evaluator

"Working in a group you realise everyone feels like this, it's a lot less lonely and normal"

Weekly session feedback

Having wishes written down and recorded made participants feel more confident

The feedback from participants was that they liked having their wishes written down to refer back to and to share with others. Most of the participants needed some help with writing down their wishes and therefore had not been able to do this before.

"I can't plan my funeral before now as I can't write"

Weekly session feedback

"Enjoyed being able to get some of my wishes written down it felt great"

Feedback to evaluator

"I feel more confident about discussing with family"

Feedback to evaluator

Touring the hospice was a highlight of the sessions for all the participants and enabled them to feel more comfortable in this setting

At the in person evaluation, all participants were asked for their highlights of the sessions to date and they all mentioned that they had really enjoyed the tour of the hospice. The tour included the complimentary therapy rooms, café, gardens, hospice rooms and the quiet room. One of the participants, James (not his real name), who has limited verbal communication, engaged with this space, enjoying touching the pebbles and looking at the stained glass window.

"the tour of the Hospice, which was really important because we discussed right at the start that... doing it in the Hospice every week allowed people like James to feel more comfortable. [The other attendees] may have been OK to do a group elsewhere and just come in for the day, whereas actually for James, that would have been really distressing. There's no way he would have come in, for just one session or one day"

Facilitator focus group

The toolkit resources were helpful for prompting conversation, however, the 'when I'm ill' section felt less useful for this type of session

The resources were praised by the group for being clear and thought provoking. For example, the funeral cards had illustrated pictures of various situations that could be relevant to a funeral including people at a graveside, a coffin being cremated, a headstone etc. One picture was of an open casket and one of the facilitators said afterwards that she felt like turning that one over before the session started as it felt 'too much'. However, that picture card promoted a discussion amongst the group and afterwards the facilitator recognised that she was more uncomfortable with it than the participants.

"So she didn't turn [the open casket picture] over, but it was actually [Marie Curie staff member] that picked it up and it had, like, an instant reaction, you know, for some people, really interested. It enabled a conversation that probably would never have been had for some people because [support workers] would have shielded away from it and they would have censored themselves from it."

Facilitator focus group

Another benefit expressed by participants about the toolkit is that the resources helped them normalise grieving.

"learning that it doesn't make you weak to be grieving. You open yourself up to feel better"

Weekly session feedback

The 'when I'm ill' cards were felt to be less useful for the group because participants felt it was difficult to answer questions about a hypothetical illness. The level of detail included on those cards e.g. would you have a stoma, would you want a syringe driver etc, was felt to be too overwhelming.

"if someone had bowel cancer, then I think the cards would be very useful. But for me, sitting with someone who's not got that condition, and then talking about [stomas], they automatically just kind of reeled from it like, 'oh, no, I wouldn't like that, I wouldn't be able to get my head around that'. But actually that's not a true representative of if they were in that situation, what they would pick"

Facilitator focus group

5.2 Pilot set-up and administration themes

Having sessions over a period of time allowed attendees time to consider and to get to know their group members which meant they felt comfortable sharing what is important to them

The first session was based on the Marie Curie Life Café format which are designed as an informal session to start conversations about death, dying and bereavement. The feedback from the attendees immediately after the session was that it had helped the participants become more familiar with one another.

"This session was good for getting to know each other."

Participant feedback at session

The importance of this initial session was also highlighted at the facilitator focus group where it was felt that this first session was integral to participants being able to go on to talk about more difficult topics in later sessions.

"the first one was quite a gentle one in a way and getting to know people and I think that got people more secure as a group"

Facilitator focus group

"I think it was quite necessary as well for people to get to know each other, to then have them deeper conversations. I think it really helped people sort of feel like comfortable with one another to then start the other conversations and almost like an introduction to sharing things"

Facilitator focus group

"Having the course run over a number of weeks I think is beneficial so that it does not feel rushed and the attendees have time to think about ideas in depth and build rapport with other group members and facilitators"

Survey response paid staff 2

Most but not all participants had a written record to take away with them

Most participants finished the session with some written plans for what they wanted in the future. They were able to articulate what they wanted although some needed help with writing it down. One participant was less able to express his own wishes and the staff member who supported him felt that in order to complete a written plan, there would need to be more input from others in his circle of support.

"[The support worker] felt that it needed to be done with a much wider team and that he didn't feel like he, that he could necessarily be the one speaking for everybody and that actually he felt that it needed to be done with [Name] and him, possibly some of the other support workers. And the other team around them"

Facilitator focus group

The sessions required a high level of staff support from both Marie Curie and Solihull Action through Advocacy

There were different levels of ability and skills within the group of attendees. As would be expected working with this population group, they all needed one to one support at some points during the sessions to varying degrees and the sessions needed to be carefully facilitated so everyone was able to contribute. Some of the sessions required more hands on support particularly when completing the workbooks. At the facilitator focus group it was discussed that for those able to write they needed help with some of the concepts and to keep things on topic.

"[Name] filled it out herself [including off topic information], if you wanted to then use this as a document to then go and take to, say, a healthcare professional, there's no way a GP would sit and read through this and read all of this detail"

Facilitator focus group

Through attending the sessions, support staff for a participant who had a palliative diagnosis reached out for further support from Marie Curie

One of the attendees with a terminal diagnosis came to the sessions along with his support workers. The support workers felt that they needed more support regarding what to expect, progression of illness, how to offer emotional support to the individual and also emotional support for them as staff. None of the workers had been in the position of supporting a service user through a terminal illness and they were wary about what to expect. The sessions helped the support workers to understand more about end of life planning with people with learning disabilities and also what support can be offered

through Marie Curie. The Community Development Manager has organised a follow up session with a clinician for support workers to attend.

6. Conclusion

The pilot of using the Victoria and Stuart toolkit in partnership between Marie Curie and Solihull Action through Advocacy to promote conversation about death, dying and bereavement has met its aims and objectives. The sessions were felt to be engaging and supportive and provoked conversations around people's own losses, and their future wishes. Holding the sessions within the hospice and holding a tour of the hospice allowed the attendees to feel comfortable in this environment and illustrated the scope of what hospices can offer. The participants expressed that they had increased confidence in being able to talk about their own wishes and most but not all participants had written plans in place.

7. Learnings

Working with this population group requires a high staff to participant ratio

At the sessions there were at least three facilitators, a mix of Marie Curie and Solihull Action through Advocacy staff. This level of staffing was needed, particularly during the sessions that involved completing the workbooks. There was a mix of reading and writing abilities within the group, but all needed an element of help and supervision, and some needed a scribe to write for them.

Holding the sessions at the hospice helped participants feel comfortable in a new environment

The hospice setting meant that the participants became familiar with the layout of the hospice, and felt comfortable enough to visit the café either before or after the session. This felt particularly useful for one member of the group who had a terminal diagnosis to be able to become familiar with the environment and for his support workers to make links into the hospice.

The Victoria and Stuart toolkit promoted relevant and helpful conversation although the specificity of some of the hypothetical discussions were challenging for participants

The toolkit was a useful resource and some of the most successful sessions were prompted by the discussions from the cards. The 'when I'm ill' cards were less suited to general conversations about death, dying and bereavement and for future sessions facilitators felt that any cards which involved hypothetical situations, for example, would the participants want a stoma bag, were best avoided.

For those less able to express their own wishes, having more members of their circle of support present may help complete the workbook

For those less able to express their own wishes and needs, inviting along to the sessions those who know the person well, for example, family, friends or paid staff could help record wishes for the future.