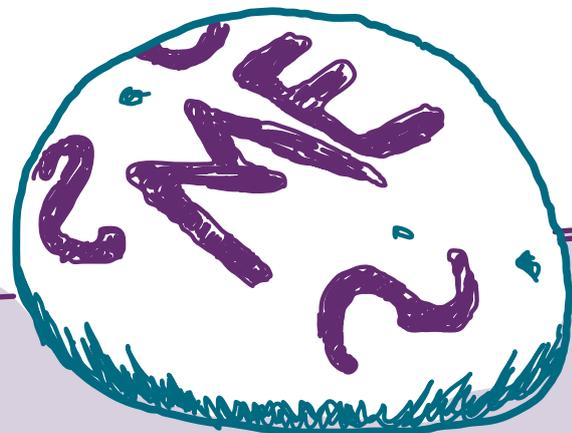


Tea, Talk and Samosas:

Planning ahead for the end of
life with the South Asian community



October 2016

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Executive summary

Every individual deserves to get the care and treatment that is right for them, particularly at the end of life. Recently, increasing consideration has been given to improving end-of-life care in the UK. Despite this, there still remains inequality in the level of understanding and access that people from particular groups have in relation to their care.¹ This is especially true in the context of how they can communicate and record their preferences and wishes for the end of life, or for a time when they may not be able to express what they want.

Learning from Compassion in Dying's services and external research has consistently demonstrated that when people understand their rights to plan ahead and are supported to do so, it can have a positive effect on their end-of-life experience.² A YouGov poll we commissioned in 2015 showed that where a person's wishes were recorded, they were 41% more likely to be judged by loved ones to have died well.³ Planning ahead also provides peace of mind and reassurance to people that steps have been taken to ensure their wishes will be respected in the future.⁴ However, the level of awareness of these rights is limited.⁵

To address this, we developed the *My Life, My Decision* (MLMD) programme. This provides one-to-one support to people aged over 50 to record their wishes for treatment and care and also raises awareness amongst the public, professionals and other organisations.

As part of this programme, we partnered with Age UK Lancashire to run a project with a group of older South Asian women living in Great Harwood, Lancashire. The project ran for six weeks between December 2015 and February 2016.

The project had two aims:

- To develop an effective and accessible service approach to raising awareness and discussing the importance of planning ahead and end-of-life rights.
- To develop new culturally appropriate materials.

Consultation was the focus of the sessions and the group provided invaluable insight into how to appropriately and sensitively raise awareness of end-of-life rights throughout the wider Muslim communities in Lancashire.

At the same time, we were working with a group of Somali women living in Tower Hamlets, London in partnership with Women's Health and Family Services. Feedback and learning from this project was used to guide and prompt discussion in Lancashire.

Based on learning from the project, this report provides a series of recommendations for health and care providers to ensure they can provide culturally appropriate care covering practical, system-level and cultural changes. It also includes recommendations for other charities and organisations that want to engage in this type of work, which broadly focus on working collaboratively and flexibly with people from Black, Asian and Minority Ethnic (BAME) groups, and exploring different methods of supporting communication to meet the needs of the group.

We hope that these recommendations go some way to demonstrating what needs to be done to ensure that people from BAME groups are able to engage in and receive high quality, person-centred care at the end of life.

Project structure

A series of workshop sessions were held with the group. They were attended by between six and thirteen South Asian women aged over 50, a member of Compassion in Dying staff, a facilitator from Age UK Lancashire and an interpreter. The facilitator had experience of working within the NHS and was also familiar with the subject matter through their work with local BAME communities at Age UK Lancashire.

The group was first introduced to the MLMD project at an event in summer 2015. The group had been established as an exercise class as part of another project funded by the Big Lottery Reaching Communities Fund. Although this project was coming to an end, it meant that the group had already been meeting for several years by the time Tea, Talk and Samosas began. Holding the workshops in a familiar environment with people the women already knew helped provide a space where they felt comfortable talking about the subject.

The sessions began with a lunch of tea and samosas followed by an hour of group discussion.

The first session provided an overview of the subject. The three main tools for planning ahead were introduced and there was discussion around the rights of family members to make decisions about a relative's medical treatment and care, using a recent Court of Protection case as a discussion point.

The following four sessions included discussion of a key question, relevant to an Advance Statement, where each woman was able to contribute a response. Two sessions were also used for watching and then discussing "I didn't know that", a film produced by Dying Matters, which documents the end-of-life experience of a Muslim family.

The final two sessions focussed on developing a document that the women could use to record the things that were important to them. This broadly drew on the content and structure of our Advance Statement form, but was adapted in partnership with the women and the facilitators to make sure that it was in a format that the women would feel comfortable using.

Introducing the project

In the first session, the three legal tools for planning ahead – Advance Decision to Refuse Treatment (ADRT), Advance Statement and Lasting Power of Attorney for Health and Welfare (LPA) - were introduced to the group.

At the preliminary meeting in the summer, the Compassion in Dying staff member used a jar with pieces of paper inside that had things that were important to her written down. These were things that she would want to be known by people looking after her, if she was ever unable to communicate. Examples included ‘tea in a china mug’ and ‘no male carers.’ The women remembered the jar and this helped them to understand the relevance of the three tools to them. It also provided a connection between Compassion in Dying and the women.



In the first session, the group discussed experiences of dying relatives and everyone believed that family members were able to make decisions:

“When my husband died he told us what he wanted. My daughter put his words into action and he passed away at home.”

“Mothers tell their daughters what they want.”

“We sit down and tell them this is what I want. Children are obliged to do your wishes.”

The Compassion in Dying staff member explained the Mental Capacity Act 2005, including how a family member cannot make a decision on behalf of their relative unless they have been given the legal power to do so in an LPA for Health and Welfare.

The group also discussed the recent Court of Protection case of *M v Mrs N*⁶. In this case, a woman was in a minimally conscious state as a result of multiple sclerosis and lacked capacity to make a decision about her medical treatment. Her daughter argued that she had no quality of life and would not want to be given clinically assisted nutrition and hydration which was sustaining her life. However, her doctor refused to withdraw the treatment. After learning about this case, the women agreed it was important for them to know more about their rights.

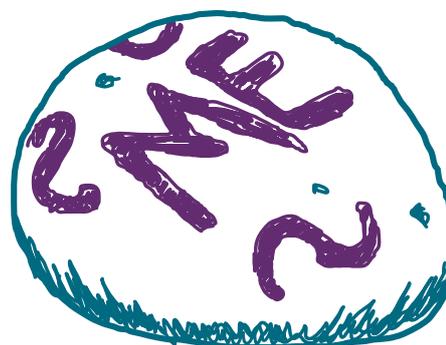
At the close of the first session, the structure of the remaining five sessions was agreed. The group knew other women who might want to join and also said they would like to share a lunch together.

While reflecting on the first session the facilitator said:

“The women seemed very positive and would consider end-of-life planning for the future. They feel the documents you highlighted are very important. However, they are not familiar with their legal rights and expressed concern regarding the future as they feel intergenerational work needs to be carried out and the younger generation need to be informed of such decisions. One woman did emphasise that generally within the Asian culture important decisions which involve all the family are made collectively and there is a general consensus that the eldest son or male member within the family takes the lead on such matters.”

The workshops

The following sessions began with lunch and were followed by a discussion which focussed on a different question each week. Each group member was acknowledged by holding and passing around the ‘me stone’ where they shared their name and response to the week’s question. This activity allowed everyone to contribute their opinion. The discussions provided the basis for what would be included in the document that the women later developed to record their wishes.



What did you do before 9am this morning?

All of the women shared that they prayed between 6am and 6.30am and then each described their morning routine. This included looking after others, cleaning and how they liked their morning tea.

What is your favourite food?

Each of the women shared their favourite things to eat. These included mango, banana, carrot halva, tea first thing in the morning, profiteroles, pasta, grapes, tangerine and watermelon.

What is your favourite thing to do?

Each of the women shared their favourite things to do. These included praying, looking after family and grandchildren, helping children, family gatherings where everyone eats together, faith, religion and cooking.

What do you do to make yourself feel better when you are sad?

The women all had different things that they did to make themselves feel better when they were sad. These included praying, spending time with their children, going out for a change of scene, gardening and cooking. Some people preferred to be alone while others liked talking to their family.

What does privacy mean to you?

Each of the women shared what privacy meant to them:

“Privacy means respect.”

“If I can’t look after myself, like go to the toilet and change my clothes, I would want my daughter or a female carer to do this for me.”

“I need privacy when I’m angry, I need to stay alone.”

“I’m a private person, I hold things inside.”

“I want my husband with me at the end and my sister, I wouldn’t like to hear famil discussing my business in another room if I could hear.”

“The prophet said, if you want to be respected in the community, you must keep yourself to yourself and you will be respected.”

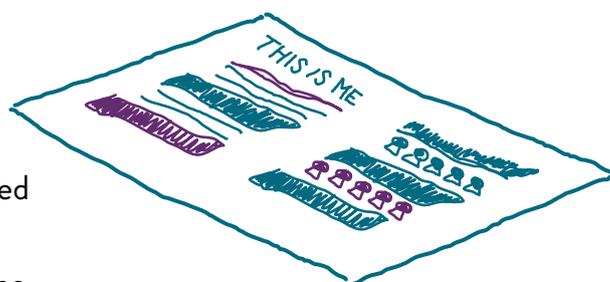
“When you’re ill, in hospital or at home, there should be a close family member to cover you and give you water at all times.”

'This is me'

Some of the women in the group were keen to express their preferences by creating their own jars and some brought them in to start work on them. Others felt that their family would think the jars were silly. As part of the Somali women's project delivered at the same time in East London, a visual Advance Statement booklet had been developed and this was shared with the group in Lancashire. Although the women liked the booklet, they found it too big and too daunting a task to complete. As a group, the women began to think about ideas for how to record the things that they shared as important to them in the earlier sessions.

Development

Following the discussion in the first four sessions, the Compassion in Dying staff member developed an Advance Statement document that the women could use to record their preferences called 'This is me.' This was a two-sided template form based on what the women said they would find useful and after the fifth session, nine women took a copy home to complete. Each woman was given a folder to keep the document in, which was labelled with their name.



Following discussion, it was agreed that if the form was in Urdu all present could read enough to be able to complete it themselves. However, because it was in English they needed support. Those present were happy to have the support of their daughters. One of the women (who is an NHS interpreter), said that if the form went to hospital, there would be staff who would be able to read Urdu.

Content

The first page of the 'This is me' sheet provided a space for the women to record their preferences around the topics of daily routine, favourite foods and things to do, things they do when sad, and privacy.

The second page of the 'This is me' sheet provided a space for considering the legal tools for planning ahead, as introduced in the first session and discussed in each subsequent one. Significantly, it also allowed the women to think about the role of family members in decision-making and how to formalise this if they wished. Including the names of family members helped the women to more clearly understand the role of family members under the Mental

Capacity Act. By the end of the session everyone appreciated that they had clarified their wishes regarding who should be consulted in decisions about their care, but also appreciated that this was not legally binding.

The women who completed forms all made it clear who they would like to make decisions about their care but none wrote down particular medical treatments they would wish to refuse. All members of the group (including the facilitator and the interpreter) were clear that in the future they would consider making an LPA for Health and Welfare because they wanted their family members to have the legal authority to make decisions. However, none of the group members were interested in making an Advance Decision.

Discussing and sharing

The women who completed a sheet were asked if they had discussed it with their husbands or sons. Only two had discussed it with their husbands but they had all spoken to their children. One husband was interested and said: “It sounds good.” Another said: “You always get things your way so you don’t need to worry about this.” Everyone laughed at this. One woman said that her son was also interested to know what was discussed in the sessions. Completing the sheets also helped the women think about how they could be important for their community:

“We know each other in our community so well that we don’t need this form to tell our close families what we want but it is useful for the wider circle of people or for the medical professionals.”

“We still need this form to talk about diet and clothes and medication.”

“We need to be thinking about these things because times are changing. In the past people would chip in and support you and then later you’d pay them back in some way, but now there’s a gap growing. People in our communities are becoming more and more selfish.”

“I didn’t know that” film

During some of the sessions the group watched the film “I didn’t know that”, which was developed by Dying Matters to raise awareness of the needs of the Muslim community at the end of life. The group watched the film over the course of two weeks so that there was enough time for translation and thorough discussion of the issues that were raised.

During the discussion one woman was reminded of a time when she visited her son in hospital who had asthma. In the bed next to her son was an elderly man who was not a Muslim. He was very close to the end of life and his elderly wife was with him. She was very distressed and there were no other family members around. The woman told the group:

“This should never have been allowed to happen. Every human being should be respected and should have privacy when they take their last breath. They should have had a room on their own. This should not just be for Muslims. It isn’t about religion. Everyone should be treated with respect.”

The woman made further comments about the importance of a dying person having the right people around them at the end of life:

“Mostly in our culture they will have someone, some family member they can talk to after a death, but not everyone has that, not in all cultures. The lady I saw grieving over her husband was just crying out loud and she was in her eighties and didn’t have anyone. I’m pretty sure she didn’t have anybody to support her.”

Other participants commented:

“Some people don’t want anyone around them, they want to be left on their own with their dying relative.”

“Everybody is different. Some people don’t want to share with others, but want to be on their own.”

After watching the next part of the film, in which the doctor is called away from the family, the group reflected on the role of healthcare professionals at the end of life:

“The doctors shouldn’t have been called away from the family. There should be somebody there who can talk to the couple for five or ten minutes to speak to them. To say do you need any help? It doesn’t need to be a doctor but somebody should support the family.”

“It’s inappropriate to take the doctor away in any culture, not just ours.”

The group felt that most of the film accurately highlighted what is important to Muslims at the end of life:

“When they’ve taken their last breath, their face should be turned to the right side and their hands and legs should be straight with the body, not facing upwards.”

“It doesn’t have to be family - if they’re not present then it’s okay for a male nurse, it doesn’t matter if they’re Muslim as long as it’s done in a respectful way. It’s not important that gloves are worn. It’s not a faith issue.”

“Back in Pakistan they take money but at least they can look after you better there.”

“Islamic tradition requires that eyes are closed and facing Mecca, everyone agrees with that.”

“There should be a male for a male, or female for female if it’s a nurse, but if it’s a family member it doesn’t matter.”

“If there’s Muslim staff available then it’s better, but it doesn’t matter. Different faith doesn’t matter but opposite sex does.”

While watching the second part of the film, the reaction focussed predominantly on the part of the film in which the son’s body is taken to the morgue. For Muslims, it is very important that the body is intact when it is buried and that it is buried quickly. The need for a post-mortem examination in certain cases means that this is not always done and is often distressing for the families who must wash the body and prepare it for burial. Post-mortems can also lead to delays in the body being buried.

“It [the body] shouldn’t have been put in the freezer at the hospital... If a Muslim passes away then the paperwork should be made ready because it is in our religion to deal with the body as soon as possible.”

The group found the film very informative as they hadn’t thought through a lot of the issues that the film raised.

“People who work in the hospitals should be watching this film in their training. That would help them to understand what’s important.”

“Everyone should be treated with respect and have a private room when they take their last breath whether they are Muslim or not. The best thing that I’ve got out of this is that I would like a separate room in hospital for my family.”

“This is important because I need to know what happens so that I can make sure things happen according to my faith. I don’t have anyone that has passed away recently. But if I watch this I can tell my children what is important to me according to my faith.”

Learning

Talking about the end of life

A theme that was consistent throughout the sessions was talking about the end of life. This was important for the women to be able to engage with the workshops.

“In our culture, we are good at talking about death. People are clear in their wishes for after death. Death is openly talked about.”

“For Muslims, life and death go together. Death is just after the life.”

Raising awareness

It took several weeks for the women to understand and trust that the three tools for planning ahead could be significant in their lives and they reiterated that family can make decisions. It took a long time to find ways of presenting the information in ways that would resonate with the members in the group.

The Compassion in Dying staff member revisited the tools at the start of each session. Although the women appreciated the need to make sure they were all able to make an informed choice and that it was good to know their rights, they concluded that it didn't apply to them because their family would deal with these sorts of issues. Finding a way to address this in a respectful way was the key challenge throughout the sessions. Gradually over time, stories were shared that highlighted times when families were unsure of what a person's wishes were. These were generally about wishes for after death, rather than wishes after a loss of capacity.

Interpreters

The group also shared their experiences of interpreter services in the NHS. Many would take their husbands or daughters with them if they needed to visit their GP.

“One of my GPs speaks Punjabi but it's a different dialect so I don't understand him.”

“I can talk to the doctor in Punjabi, but if the doctor is different then I take my daughter with me.”

“There should be more Urdu speaking doctors, everyone understands Urdu the same.”

The facilitator also reflected on the difficulty of using interpreters with healthcare professionals:

“It’s difficult using an interpreter because sometimes interpreters will leak out personal information. A social worker in an Asian community leaked it out. Just saying small things to others that should have been kept private, talking personal things to other people. It’s difficult in a small community.”

Linking with the Somali women

Each week selected feedback from the Somali women’s project was shared with the group. As a result, the group heard about what was going on in that project and enjoyed learning about what the Somali women had shared was important to them at the end of life and their experiences of death and dying.

Sharing feedback from the Somali women’s project also prompted discussion within this group. For example, one of the Somali women had shared the following:

“Back home they tell the family that the loved one will die soon but never tell a dying person. It’s been difficult that the doctors have a duty to tell the dying person that they are dying.”

The women in Lancashire felt strongly that you shouldn’t tell a dying person that they are dying but did not feel that this was a religious issue.

“You wouldn’t tell that person, the person who is dying will die sooner, you want them to stay positive.”

“That person will probably die far quicker if you tell them. I had a cousin who said that you should always say the positives to a dying person because it helps them keep going.”

Linking with the Somali group gave the women a sense of belonging to a broader project and that they were contributing to a national debate about the experiences of BAME people in the UK at the end of life.⁷

Feedback and looking forward

The feedback on the workshop series was very positive:

“We thought we had to obey orders, whatever has been said... Now we are more confident. We know our rights. First we didn’t know we had any options – now we know we have got a say.”

“We have learnt good things from here – that puts our mind at rest.”

“It has been a joyful session giving us lots of knowledge.”

In the final session the women discussed and prioritised the ideas that had been shared throughout the previous sessions of how the *My Life, My Decision* project could help other older people from South Asian communities in East Lancashire to be aware and feel more confident about their end-of-life rights and care. Voting cards were used to allow the women to express which option they preferred.



The idea that received the most overwhelming support was to run the Tea, Talk and Samosas six week workshop series with other groups from the community. It was felt that it was necessary to be able to discuss the issues to fully understand them and make choices.

“Explaining about this subject is best done in groups, it’s an opportunity to express your feelings. And different groups may say different things, you should do more groups and see.”

“Talks are the best way to communicate things.”

The group also suggested that we work with younger people. They felt that if we introduced younger people to the online tools they would be able to assist family members. One woman brought her niece to a session, she said she found it very helpful and would like more information so she could support her family more when completing the documents.

The group also discussed the possibility of using local radio and the Asian Image newspaper and The Local Herald magazine to raise awareness.

Recommendations

These are the key recommendations that we will take forward in any further work with this community, and which we believe will be useful for other organisations and healthcare providers.

Provide written information in English and Urdu

- The women stated throughout the sessions that leaflets were not important. However, when leaflets about organ donation written in Urdu were provided, the women took them.
- When talking about ways forward all of the women agreed that leaflets and publications in Urdu would be beneficial and that the 'This is me' sheet should be in English and Urdu.

Share learning from other communities and groups

- The link with the Somali women's project not only prompted interesting discussion but also meant the women felt they were part of a project that was contributing to a national debate about improving end-of-life care for their faith community. As women from a small Northern town, the group enjoyed having a connection with another group of Muslim women in London and learning about their experiences.
- Building up a body of work through stories and shared experiences would support inter-community work, trust and relationship building, and would stimulate discussions between different groups.

Be aware of what language the group prefer to communicate in

- At the start of the project the group clarified that the majority could speak Punjabi and some English, but could not write Punjabi. Two of the women who spoke Punjabi were fairly nervous speaking in front of the group but their confidence improved as the project progressed. One woman surprised the group by responding to a question in English even though they knew each other well, it was the first time any of them had heard her speak English.
- The group were also asked in the first session if they would like written information in Urdu. They said no and that they would be able to read English with the support of their family. As the discussions progressed however, the women all agreed that having written information in Urdu would be helpful.
- It is important that the group are supported to communicate in the way they feel most comfortable with.

Build a social media strategy into the workshops

- In this project, the Compassion in Dying staff member informed Dying Matters via Twitter that the group were watching the awareness film, “I didn’t know that” and as a result of this exchange, the group’s feedback on the film was requested.
- Using social media – specifically Twitter – helps to raise awareness of the work with different stakeholders and can also lead to collaborative work across different communities. As well as this, it helped the women to feel part of a broader discussion, and that their views were being taken into account to improve care within the Muslim community.

Focus on building trust and a safe space for people to talk

- Building relationships is crucial when dealing with such personal and emotive subject matters. It means that the participants feel comfortable sharing potentially difficult experiences and feel able to engage in the project because they trust that what they are saying is being addressed throughout. As the women had the opportunity to provide feedback at every stage, they had ownership of the structure and direction of the sessions and influenced all of the activities.
- Whilst the women were broadly comfortable with talking about death, many of them had not had an opportunity to talk about decision-making at the end of life before. Sharing experiences not only allows us to use the information to influence policy and practice, but also allows the women to share experiences with each other.

Provide written information on the legal position around post-mortem examinations and organ donation

- Discussion of the Dying Matters film in particular stimulated a lot of views about what happens to the body after death. The group felt that they were ill-informed about what happens after someone dies in hospital and also that there was a lack of awareness of Muslim practices such as the importance of washing the body.
- Clear information about the reasons why post-mortems are carried out in certain cases and the procedures involved is needed including how people can make their wishes around post-mortems known. As post-mortems have religious implications, it is important that these religious beliefs are taken into account as far as possible when post-mortems are carried out. This is also applicable to the system around organ donation.

Common terms

Advance Statement

An Advance Statement (also called a Statement of Wishes) is a general statement of what is important to a person regarding their future care. It is usually written down and can contain any information they feel is important for others to know if they become unable to communicate their wishes in the future. It must be taken into account by healthcare professionals making a decision on their behalf if they lack capacity.

Advance Decision to Refuse Treatment (Advance Decision)

An Advance Decision allows a person to record any medical treatments they do not want to be given in the future, in case they later lack capacity and cannot make or communicate a decision for themselves. It was previously known as a Living Will. Advance Decisions are legally binding in England and Wales as long as they meet certain requirements.

Capacity

Capacity is the ability to make a decision. It is time and decision-specific. The law says that a person must be assumed to have capacity unless it is proven otherwise.

Advance Care Planning

Advance Care Planning is a process of discussing and/or formally documenting a person's wishes for their future care. It allows healthcare professionals to understand how they want to be cared for in case they become too ill to make decisions or speak for themselves.

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Compassion in Dying

Compassion in Dying is a national charity working to inform and empower people to exercise their rights and choices around end-of-life care. Our vision is of a world in which individuals are placed at the centre of their end-of-life care. We believe everyone should be given the information and support needed to make decisions about their treatment and be helped to plan ahead to ensure that their wishes are known and followed.

My Life, My Decision

My Life, My Decision is a two-year project funded by the Big Lottery Silver Dreams fund which supports people aged over 50 to plan ahead for their future treatment and care. It is delivered in partnership between Compassion in Dying and seven local Age UKs across England. The project covers three main areas:

1. Providing one-to-one support to people aged over 50 to plan ahead by making an Advance Decision, Advance Statement or Lasting Power of Attorney for Health and Welfare.
2. Raising awareness of end-of-life rights and the importance of planning ahead including by providing Continuing Professional Development (CPD) accredited training to healthcare professionals and other organisations.
3. Developing tailored projects and materials to support hard to reach groups including BAME and Lesbian, Gay, Bisexual and Trans* (LGBT) communities.

Age UK Lancashire

Age UK Lancashire is a county-wide charity working with and for older people. They believe that later life should be valued and fulfilling. Through their services and support they aim to promote independence, enhance health and well-being and enable older people to access the information they need to make informed decisions about their lives.

Acknowledgements

With thanks to the women, staff and volunteers at Age UK Lancashire for their continued involvement and support.

The film used in the workshops, “I didn’t know that” was developed by Dying Matters, in partnership with the Heart of England NHS Foundation Trust. For more information visit: www.dyingmatters.org/page/dying-matters-films.

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