

Tie your camel first:

Planning ahead for the end of
life with the Somali community



October 2016

Contents

Executive summary	2
Project structure	4
The workshops	7
The one-to-one sessions	17
Conclusions	19
Looking forward	20
Common terms	24

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

Learning from Compassion in Dying's services and external research has consistently demonstrated that where 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 But, the level of awareness of these rights is limited.⁵

To address this, we developed the *My Life, My Decision* 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 Women's Health and Family Services to run a project with a group of older Somali women living in Tower Hamlets. The project ran between October 2015 and March 2016 and had three key aims:

1. Inform the women and the Women's Health and Family Services staff about the importance of planning ahead including how they can communicate and record their preferences.
2. Learn from the group about what is important to them when thinking about culturally appropriate care at the end of life.
3. Develop a culturally appropriate information resource that could be used within the group and to inform future work with other Black, Asian and Minority Ethnic (BAME) groups where English is not a first language. We had already developed a template Advance Statement form and we wanted to adapt this to create a Visual Advance Statement, which would use images to help the women think about, communicate and record their wishes.

The first half of the project consisted of a series of workshops which focussed on what is important to the women when thinking about their treatment and care and their experience of end-of-life care in the UK. It became clear early on that there were related issues that would also need to be addressed if we were to gain insights into the women's experiences of healthcare in the UK. We therefore decided to spend less time on the Advance Statements and allow the women to have a space to talk about some of the difficult experiences of end-of-life care they have had. We kept the content and structure of the project flexible to accommodate this.

The second half of the project provided one-to-one support to the women in the group who wanted to record their preferences for future care and treatment in an adapted Visual Advance Statement form we had developed. In these sessions, 14 women completed an Advance Statement that they could share with the people close to them and with healthcare professionals.

This project demonstrated how valuable it can be for people from BAME groups to engage in discussions about their preferences for care. It shows what is necessary to improve the provision of culturally appropriate care for their community. It has also shown how important it is for every individual to engage in discussions about their preferences for future care to make sure that they can be supported to record these, enabling them to have the care and treatment that they would want. However, fundamental improvements need to be made across all levels of healthcare to make sure that people are supported to understand their rights to make decisions and record their preferences in a robust way. This will help to make sure that they get the care and treatment that is right for them at the end of life.

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. This report also outlines 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 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

Workshops

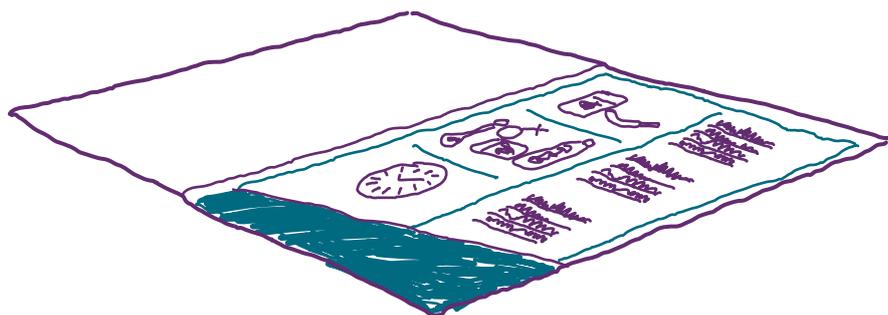
We held eight workshops which were attended by between eight and eighteen Somali women between the ages of 50 and 91, two interpreters and two Compassion in Dying staff members. For cultural reasons, female facilitators were present at the sessions. Both interpreters worked in healthcare and were familiar with the subject matter. They also already knew some of the women in the group and had a good rapport with them.

The group had been meeting regularly in the same place for a number of years. Holding the workshops in a familiar environment with people they knew helped provide a space where the women felt comfortable talking about the subject with each other and with us.

The workshops were held between 11am and midday on Friday mornings. This allowed the women to attend prayers at 12.30. The Compassion in Dying staff had time with the interpreters before and after each session to clarify any issues that had arisen and to ensure the subsequent sessions were tailored to the women's needs and priorities.

The first half of the workshops covered things that were important or common to the group (particularly at the end of life). The second half was dedicated to taking the group through our Advance Statement. This meant that the project moved from a focus on the women as part of the Somali community, to a focus on the women as individuals.

We produced a visual record of what had been discussed in the sessions, as well as written notes. This was to support the women who could not read or write in English. We found pictures to illustrate the things that the women had told us in response to each question and discussion topic. These minutes were then used in the one-to-one sessions to help the women remember what had been discussed.



How we used interpreters

All of the quotes in this report were spoken by the participants in the group to an interpreter. Where possible, the quotes are direct translations from what the women said but in some cases the interpreter elaborated further on what the women said in order to explain cultural terminology, phrases and context.

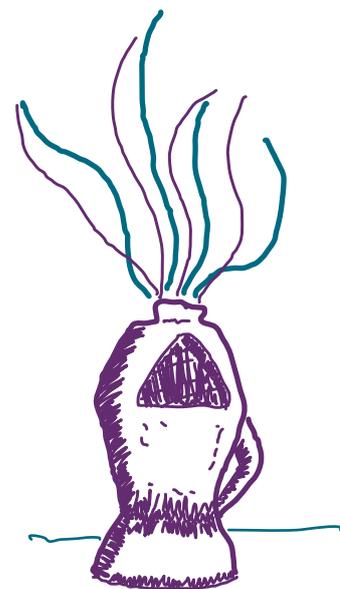
One-to-one sessions

After the workshops, one-to-one sessions were used for the women who wanted to complete an Advance Statement. Fourteen women took part in these sessions, which were attended by a member of Compassion in Dying staff and an interpreter.

Each woman had two sessions. The first was for talking through the Visual Advance Statement. We used the visual minutes to help the women remember what had been discussed in the workshops and to help them communicate their wishes. These sessions took approximately one hour depending on how much information each woman wanted to include. After this, the staff member typed up the notes and put them into the Visual Advance Statement, along with images to illustrate what was written. The second session was for checking what we had done to make sure that we had recorded the woman's wishes accurately, and to see if there was anything else they wanted to add.

Celebration event

Midway through the series of one-to-one sessions we held a celebration event, which the women attended along with representatives from Compassion in Dying and Women's Health and Family Services. The event was a celebration of the project and the women brought along some of the things that they had talked about during the sessions, including Somali pancakes, Unsi (Somali incense) and there was Somali drumming and dancing.



The event was also a way to celebrate the relationships that we had formed with the women and the interpreters.



“We may not share being Muslim, but we share so many other things.”

The workshops

Early concerns

At the start of the project, both Compassion in Dying and Women's Health and Family Services had concerns that the women would find the subject too emotional and as a result find it difficult to engage with the project. However, initial discussions with the interpreters suggested that Somali people view death as a natural part of life and are generally comfortable talking about it. For example, one interpreter talked about how nomads from her grandparents' generation would carry a white shroud around with them in preparation for their burial.

We realised from the first group session that the women had a lot of concerns about healthcare that might affect their willingness to engage in the project because of its focus on planning for the future. This was reiterated by the frustrations they were already facing when they had to engage in the healthcare system:

“Why would a GP listen to an Advance Statement when they don't listen to me now?”

To address this, we used this Hadith to contextualise the topic; “Tie your camel first then put your trust in Allah.” A Hadith is a collection of reports that describe what the prophet Mohammed said or did on a particular matter. They are regarded as important tools for understanding the Quran and daily life.

“Tie your camel first then put your trust in Allah.”

This is understood to mean that people should take responsibility for achieving a good outcome and then put their faith in Allah that this will happen. We interpreted this as conveying the importance of planning ahead, and used it to introduce the project and to make it specific to the women's community. The group appreciated the use of this analogy and it helped them to understand the significance of the topic in the context of their own lives. Using the Hadith also helped the women to appreciate that we had an understanding of their beliefs and this contributed to building a relationship of trust between us and the group.

What is important to you?

“Peace and milk.”

– a Somali saying (nabad iyo caano)

In the first workshop we asked the women to introduce themselves and share two things that are important in their lives. Every participant stated that Allah was the most important thing. Other things mentioned included family, being kind to others, having access to an interpreter, being able to say prayers, being able to read the Quran, being warm and having a female carer.

Barriers in healthcare

The second workshop focused on the barriers that the women faced when accessing and using healthcare services in the UK. Difficulty with communication was a significant and a common concern, which had a big impact on the care the women were receiving. This was often due to a limited availability of interpreters.

“The most difficult thing is we don’t speak the language.”

“The GPs always say that you have to have an interpreter to see them.”

“Before we reach the end of life we feel neglected because we are not getting what we want now.”

At times, the women struggled to understand how putting plans in place would be useful in the future.

“We are already at the stage where we cannot communicate our wishes.”

A good death in Somalia

After this, we moved the focus on to end of life and what would be necessary for a ‘good death in Somalia.’ This would help us understand what things were important for the women and to develop a way to raise awareness of these within healthcare. Three key things were reiterated in this session – the Shahada, zam zam and the role of family and friends.

The Shahada

The Shahada is the first and most important pillar of Islam. It is an Islamic creed that declares belief in the oneness of God and in Mohammed as the messenger of God. The Shahada is whispered into the ear of a newborn baby and is also said by a dying person. If they are unable to communicate they can say it in their head or if they are unable to say it, their family can say it for them.

The women in the group all shared the wish to say the Shahada at the end of life. This was also linked to the provision of pain relief and many of the women went on to express in their Advance Statement that they did not want any medication that would mean they would be unable to say the Shahada.

“When people are dying it is sometimes a painful process. Sometimes the doctors give them an injection that does not just take away the pain but makes them unconscious. It stops them being able to communicate and they are unable to say the Shahada, which is a problem.”

Zam zam

The women also stated the importance of zam zam water:

“In our community the special water we give people is called zam zam. We give people that are dying this holy water that is from a well in Mecca.”

Family and friends

The role of family and friends is very important at the end of life.

“In the Muslim faith if you have lost capacity the chapter has closed. You no longer worry about whether your actions are good or bad. Instead it becomes a duty of those around you and your family.”

These duties include supporting the dying person to say the Shahada by keeping the mouth moist or saying it if the person is not able to say it themselves. Other things that are important are turning the person towards Mecca and closing their eyes and mouth when they are approaching death. If it is not possible to move the body, a person's face can be turned towards Mecca. If there are no close family or friends available, there is an obligation for others in the community to perform the duties.

“We are all brothers and sisters in the community.”

More importantly, it must be the family (and if there is no family available then someone else in the community) that perform these actions, rather than a healthcare professional.

“They [the healthcare professionals here] are able to look after the person but are not familiar with the responsibilities of the family – or example, it is important for the next of kin to close the person’s eyes and mouth just before they die. This is something that the next of kin need to do. If the next of kin do not manage to do this, then it is a defect in their morals and leaves them depressed.”

The duties would be done even for a stranger – this means that nobody is alone because everyone is part of a shared community and religion. This has an impact on the traditional understanding of next of kin, which is much broader for Somali people and can include family and friends.

“Everyone is your next of kin.”

Visiting someone who is dying is also very important to Somali people but this can have an impact on the person’s (and their family’s) end-of-life experience. This is particularly so if they are in hospital as having large groups of visitors often goes against hospital procedure.

“Why go to their funeral if you haven’t visited them when they are dying?”

Sharing experiences of end-of-life care

After the first two workshops we asked the women to share their experiences of a ‘good death’ and afterwards, experiences where things could have been improved.

Positive experiences

“From diagnosis, treatment and death, it was straightforward. My husband played a central role in decision-making. The nurses bathed him regularly, cleaned sheets, turned him towards Mecca and helped with the Shahada. He was able to communicate and ask for what he needed.”

“My husband had throat cancer and reached the stage where he couldn’t feed himself so he had a tube fitted. His care was good, maybe because he was able to speak English and speak for himself.”

“The hospitals never found it difficult to allow them to have friends and family near them throughout the illness.”

Negative experiences

“Two weeks ago a family member was in hospital with no capacity. Her son had looked after her for a long time and used to feed and wash her. The night she died he was asked to leave the room at 1am while they examined her. They wouldn’t let him stay. They called security and asked him to leave. She then died without him, without the Shahada and zam zam. He was informed by telephone that she had died.”

“A lady had died and they [her family] were not allowed to stay over. She was given an injection that meant she couldn’t do Shahada and there was nobody with her that could do it so she died alone.”

“Facilities in hospitals are very good – the person is kept clean, the bed is kept clean. Doctors and nurses can do all the responsibilities to the dying person but are not good with the family.”

This was an emotionally demanding session particularly because some of the experiences were very recent. One woman left the session midway through, although she returned later. We thanked her for being able to share her story and this reinforced how important it was for us to hear about these experiences in order that work can be done to address them in the future.

There were three issues in this session that prompted particular discussion. These were informing someone they are dying, hospice care, and post-mortem examinations.

Informing someone they are dying

When discussing negative experiences of end-of-life care one woman shared the following:

“My husband was told that he only had a few months to live. This is not accepted in Islam. It is an insult – the same as someone saying they are going to cut off your head. Only Allah knows when someone is going to die. The person is already burdened with illness and pain and to tell them they are dying makes it worse.”

However, whilst many of them women felt it would not be appropriate for a doctor to tell someone their prognosis, this did not mean they rejected planning ahead – although they did not want detailed information on prognosis, they still wanted to take the opportunity to set out their preferences in an Advance Statement.

Hospice care

During discussion of preferred place of care, we highlighted the possibility of a person going in to a hospice towards the end of life. The response to this was generally very critical:

“I don’t want to go in to a hospice. It’s where people go to die. If I’m waiting for death, I’d rather wait for it at home.”

“When someone is referred to a hospice, they are on the list of the dying.”

“It’s like being rubbish thrown out. There is no difference between chucking someone in a bin, than taking them to a hospice.”

For the group, hospice care was also linked to a family abrogating their duties to a dying person, which was unacceptable. They felt that people can have what they need at home:

“The family are happy to give help and the individual is happy to receive.”

Although the general consensus towards hospice care was negative, some members of the group did acknowledge that care in a hospice is preferable to care in a hospital. This was because hospices are more easily able to facilitate culturally appropriate and personalised care. For example, some members of the group said that hospices have Imams who can help a person who does not have any family, but hospitals do not.

Post-mortem examinations

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.

The group shared some very emotional experiences of post-mortem examinations and of negative experiences happening to others. The women had heard of bodies arriving at the morgue that had been “sliced” and tampered with, including children’s bodies. There was a fear that this was a problem that disproportionately affected the Somali community.

“We would like to know why autopsy is done so much in the Somali community. When washing the body you can see that it’s been cut up, it’s empty inside. They took everything, even in young people.”

Making it personal

The second half of the workshops focussed on what was important to the women as individuals. We used the structure of our Advance Statement form to guide the sessions, but some of the sections and prompts were adapted to make sure that they were appropriate for the women.

Hobbies

The concept of hobbies was not something that the group recognised so we rephrased the question to ask about what they enjoy doing outside of their daily religious obligations. Some of the things the women shared included reading the Quran, watching Somali television including Somali soap operas and dramas, watching Islamic TV, watching the news, burning Unsi (Somali incense), using Henna in their hair and on their hands, listening to Somali music, looking at pictures of the Somali countryside including the camels and sheep, visiting family and friends, cooking and sewing.



Religious and spiritual beliefs

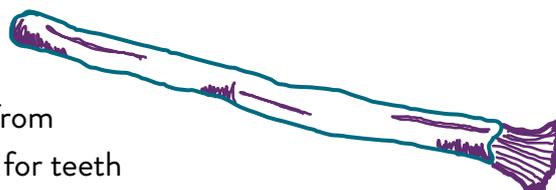
Although the women all shared being Muslim they had different rituals and practices that they followed around this. Some of the women prayed five times a day (which is the obligatory amount) but others did additional prayers and supplications too. Their routines also differed after prayers. In winter, the women wake up between 6am and 6.30am to pray. Some go back to sleep afterwards while others stay awake and read the Quran.

Care preferences

The majority of the group expressed a preference for having a female carer. Some of the women were adamant that they did not want to be touched or cared for by a man who was not a blood relative. Others acknowledged that there would be circumstances where this might not always be possible. A similar sentiment was expressed regarding hospital gowns, which many of the women had strong dislike for – “it’s like being half naked” - but accepted it would be necessary to wear one in certain situations.

The importance of being clean was also something that was common to the group. Washing with water after going to the toilet is a requirement for all Muslims. This was linked to the need to perform obligatory ablutions before praying. It is often facilitated by the presence of an ablutions jug in a bathroom. Although this facility is present in Muslim countries, it is not always so in the UK. Because of this, many of the women carry bottles of water around with them to make sure they would be able to wash regardless of where they were. When this was raised in the group everyone reiterated how important it is. One of the interpreters said she had forgotten to mention it before because it is such an intrinsic part of her daily routine.

Similarly, when one woman mentioned how she liked to have clean teeth, it prompted the rest of the women to pull out a root known as miswak from their bags. The miswak is used throughout the day for teeth cleaning and people will often bring miswak from Somalia as a gift when visiting people in the UK.



Although some preferences such as having a female carer, being covered up and being clean were common to the whole group, there were differences of opinion. Some of the women would prefer to have a private room if they went into hospital so that they could spend time with their family and have space to pray. Others wanted to be on a ward so that they could be around people, be sociable and engage in conversation.

Diet

The group shared many preferences around diet including wanting halal food and not wanting cold food, such as sandwiches, or frozen meals. This was because in Somalia many of the women did not have fridges and were used to buying fresh food every day. They also shared a dislike of very spicy food, which they said was often given to them at events or in hospitals because they asked for halal food and there was an assumption that this needed to be spicy. They said that there are many Bengali people living in Tower Hamlets and because Bengali cuisine is spicy there is an assumption that Somali people also like spicy food.

Other preferences included Somali tea (tea with added spices such as cinnamon and cardamom), Somali pancakes, lamb and rice, warm water and no pork. Many of the women also ate an odd (uneven) number of dates each morning. They explained that this was because the Prophet would eat dates in odd numbers.



Medical conditions

This discussion focussed more generally on preferences for certain types of medication, allergies and alternative medicine rather than specific issues around conditions. This meant it was not too personal or intrusive.

Many of the women used herbal medicine including honey, lemon and aloe vera. Nigella seeds are also commonly used and are known as ‘habasoda’, which means ‘one black.’ There is a Hadith that states:

“Use the Black Seed for indeed, it is a cure for all diseases except death.”

The women also had conditions including arthritis, high blood pressure and diabetes, which they took prescribed medication for. Some, but not all of the women mentioned that they or a loved one had discussed prescribed medical treatment with their Imam.

We also wanted to use this session to find out if there were any medical treatments that the women did not want to have, either for conditions they had currently or in the future. We briefly discussed Advance Decisions because we wanted to make sure that the women were made aware of the different ways they could record their wishes.

It was however difficult to convey the purpose of an Advance Decision and therefore why it might be appropriate for the women in the group. One woman said that “you might get a condition and want to try everything to get better.” Another said that they would not feel they knew enough about the condition or treatment to refuse medication for it. This was linked to a general sentiment that came up at other times in the sessions which was quite deferential to doctors and their knowledge.

As a result of this conversation, we continued to focus on the Advance Statement with the group, but emphasised that we could look at Advance Decisions in more depth with any of the women who said they wanted to make one. Ultimately, none of the women expressed a wish to make an Advance Decision.

The one-to-one sessions

Outcomes

14 women completed a Visual Advance Statement. They were each given their own durable plastic binder to keep it in and a spare copy to give to somebody else. The folder also contained a note to healthcare professionals that gave a brief introduction to the project and explained how the statement was completed. The folder also included a glossary of relevant cultural terms and a factsheet we have produced about Advance Statements.

Example Advance Statement

“I like being around my family. I like to stay close to the people that know me.

I like to wear Somali clothes, the dira. There are two types, cotton for every day and a transparent one for special occasions. I like to wear the cotton one on a daily basis for covering up and the other one for special occasions. I wear the jilbab.



I’m a Muslim. I pray five times a day and then I read the Quran. I want people to understand how important prayers are to me. I want to be dressed modestly and covered at all times if possible. Only my hands and face should be bare.

In the morning I have brown cornflakes with hot milk. At the weekend, I like Somali pancakes. I have seven dates in the morning. I don’t like the taste of lemon. I don’t eat cold food – if it’s summer it’s okay, but not in the winter. I don’t want very hot or spicy food, just normal.

I don’t want a room on my own – I want to be with the people. If I can’t talk I’ll look. I’d feel lonely, they shut the door. I like to be with the people. I have asthma and I have an inhaler. I take it regularly and if there’s smoke, or it’s cold and if I have hay fever. I always have it with me.”

Challenges

The number of women who expressed an interest in completing an Advance Statement was encouraging and we wanted to make sure that everyone who wanted to had the opportunity to do so. However, this meant that we needed to extend the project beyond the celebration event, which was originally intended to take place at the end of the project. As a result, some of the women thought the project had finished with the celebration event and they needed to be reminded to attend the subsequent sessions for their one-to-one.

There were times when the women did not mention things that we felt they would want to include, probably because they were so routine to them such as the preference for halal food. It was in these situations that the visual minutes became useful as they reminded them of some of the things we had discussed that were common to the group, which they might want to include in their Visual Advance Statement.

However, we also had to make sure that the women did not solely rely on the minutes or use them as a checklist. We had to balance the need for the women to share the information that was important to them, with the need to make sure that they dictated the amount of information they were comfortable about sharing and recording.

Conclusions

The project provided the women with a space to share the things that were important to them and to talk about difficult experiences with each other. This helped them appreciate the value of recording their wishes. It showed they had a right to express these preferences and that this would improve their own experiences and the experience of the wider community in the future.

“We feel included, we feel listened to, we feel wanted.”

“You knocked on our door. If you hadn’t asked, we wouldn’t have answered and told you this information.”

“You are informing the mainstream of what is ours.”

They were especially appreciative of the visual minutes that we produced following the workshops. The visual minutes demonstrated that we had listened to what the women had said and were acting on it.

“You put the spotlight on us, our religion and culture and what’s important to us, and put it all in one place.”

The use of these minutes when creating the Visual Advance Statement also helped to address the women’s fears and frustrations at not being able to communicate with healthcare professionals. It gave them a way to express the things they want.

“She is saying that it is important for her because if she goes to hospital and is unable to speak, instead of the doctors saying ‘who is she, where is she from’, she now has a book which describes everything about her. For her she has made that easy and easier for the clinicians as well.”

- Somali woman (spoken via interpreter)

The interpreters talked about how the workshops also gave the women the confidence to engage in the process by putting a focus on their culture and community and by showing them that they have a voice:

“They feel that they have joined an existing club, what could they do about it?”

“They think that English people have a choice and they don’t – this dents their confidence.”

“When you have not had a formal education, you don’t know about influencing policy and what grassroots campaigning is. They have done it, they just don’t realise they have done it.”

Looking forward

The project provided excellent insight into the Somali community and what is needed to ensure culturally appropriate end-of-life care. It also empowered the women to plan ahead and record their wishes. However, many things still need to be done to improve the experience of the Somali community within healthcare in the UK.

Recommendations for health and care

Awareness of religious and cultural beliefs

- Making sure that healthcare professionals are aware of a person’s religious and cultural beliefs, particularly at the end of life, is vital to them being able to provide person-centred care.

Organ donation and post-mortem examinations

- Clear communication of 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. Post-mortems have religious implications and it is important that these religious beliefs are taken into account as far as possible. This is also applicable to the system around organ donation.
- Improved information and awareness-raising within the community would also help to address the fear that many of the women had that this was a problem that disproportionately affects the Somali community.

Hospices

- Hospices need to consider how they can engage with different communities.
- A good starting point for engaging the Somali community in hospice care could be to make sure that they are given information and support to understand the benefits of hospice care. This includes how a hospice can support and enhance the role of the family, rather than diminish it, as well as the benefits they can provide for people with a life-limiting condition but who are not necessarily nearing the end of life.

Interpreters

- Providing an interpreter for people who do not speak English is an essential part of empowering individuals to feel confident enough to engage in decisions about their healthcare. The current lack of interpreters is a barrier to people accessing healthcare and must be addressed.

Practical adjustments

- Care settings need to be aware of the practicalities involved in facilitating culturally appropriate care. For the Somali community, this could include making sure there is space to pray, facilities for washing and space for visitors and families.

People should be encouraged to record their wishes regardless of culture or religion

- Every individual should have the opportunity to engage in planning ahead in order to document the things that they would want those caring for them to know if they were unable to communicate.
- An awareness of preferences such as washing and dental hygiene in this context is not only vital for facilitating culturally appropriate care for the Somali community as a whole but also for illustrating the importance of planning ahead on an individual level.

The problems of communication and how to achieve person-centred care need to be addressed across all levels of healthcare

- Many of the barriers the women highlighted can apply to all groups and individuals. Projects such as these are vital for learning about the Somali community, but also contribute to a broader discussion around improving person-centred healthcare in the UK.

Recommendations to other organisations working with BAME groups

The project was invaluable for us in developing our learning around how to engage with BAME groups on the topic of end-of-life care. Although each group is different, learning from the project demonstrated that the following points would be helpful for future work and to other organisations who want to engage with BAME groups.

Focus on visual methods of communicating and recording information

- Visual information and tools can support people who do not speak, read or write English, as well as people who do not read or write in their first language. Using images to record information gave the women a way to express their wishes and communicate with healthcare professionals, which they did not feel they had before. In the context of this project it also helped them to understand that their voices had been heard.

Focus on people as individuals and not just as members of a particular community

- It is important to remember that people are individuals as well as members of a community. A key example of this from this project was the divergence of opinion on preferences for having a private room or being on a ward. This demonstrated the importance of asking what the women wanted as individuals.

Space to talk about experiences and fears is valuable in itself

- Many of the women had not had an opportunity to talk about this subject before. Sharing experiences not only allows us to use the information to influence policy and practice, but also allows the women to share difficult experiences with each other, which can help with the grieving process.
- Having conversations is the first step to improving care for the community. This is because, unless people express what's important to them, their preferences cannot be facilitated.

Different Advance Care Planning tools will be appropriate for different people

- Not every individual or group will feel that a particular tool is right for them. The Advance Statement can be a good place to start because it can be adapted to the individual or group and provides a place for a person to record their wishes and make their voice heard. It can also provide a starting point for difficult conversations about end of life.

Be clear about the limits of the project

- We wanted to make sure that the women were able to use the sessions in a way that would be beneficial for them and would help them feel empowered about their rights but we also needed to be mindful of managing their expectations. When discussing hospital gowns it was necessary to remind them that sometimes these instructions could not be followed because there may be medical reasons why a gown needed to be worn. As we continued with the sessions, the women appreciated that just expressing these preferences was helpful.

- Be clear that having these conversations is necessary to make sure that things can be addressed in the future, even if there was a limited amount that could be done about what had happened in the past.

Make the process collaborative

- The focus should be on sharing experiences and creating a dialogue rather than just asking questions. It was important for the person presenting the sessions to begin by asking the questions and to then give personal examples. The women were also interested in knowing what things were important to the Compassion in Dying staff facilitating the sessions.
- The women were also interested in knowing what things were important to each other and appreciated the opportunity to share their own examples, and see how these differed from the other people in the group. Giving each person a chance to contribute helped them to feel acknowledged, involved and listened to.

Allow time to build relationships

- Building relationships is crucial when dealing with such a personal and emotive subject matter. It means that the participants feel comfortable about sharing potentially difficult experiences and feel able to engage in the project because they trust that what they are saying is being acted on and addressed throughout.

Take a flexible approach

- Keeping the structure and content of the project flexible means that it can be adapted to meet the needs and priorities of the people involved. This means that the participants are able to direct the project and make sure that it covers the things that they feel are most important. It is also important to be flexible around the time and duration of meetings to make sure that people are able to participate when it is best for them.

Be conscious of terminology

- At first, we used the phrase ‘a good death’. However, this concept was unusual to the women as they struggled to understand how death could ever be seen as ‘good’ because someone has died and this is inherently a sad thing. To make sure they could relate to it, we went into more detail about how the focus was on whether the person had received appropriate care and treatment which allowed for them to die the way they would have wanted.

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.

A person lacks capacity to make a decision if:

- they have an impairment or disturbance of the mind or brain (for example, because they are unconscious, have dementia, a mental health condition, a brain injury or a stroke)

and because of that impairment, they cannot do one of these things:

- understand information relating to the decision
- retain that information for long enough to make the decision
- take that information into account when making the decision
- communicate the decision

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.

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.

For more information on planning ahead contact our Information Line on 0800 999 2434 or info@compassionindying.org.uk

My Life, My Decision

My Life, My Decision is a two-year project funded by the UK 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 CPD accredited training to healthcare professionals and other organisations.
3. Developing tailored projects and materials to support hard to reach groups including BAME and LGBT communities.

Women's Health and Family Services

Women's Health and Family Services is a multi-cultural community health charity focused on health and empowerment issues for disadvantaged women and their families.

Based in Tower Hamlets, they have been working and campaigning since 1981 to promote health education and equal access to healthcare for local communities, through a model that recruits and trains local women as advocates and volunteers to deliver health services.

For more information visit <http://whfs.org.uk/> or call 020 7377 8725.

Acknowledgements

With thanks to the women, staff and volunteers at Women's Health and Family Services for their continued involvement and support.

References

- ¹ A different ending: Addressing inequalities in end of life care, Care Quality Commission, May 2016
- ² Plan Well, Die Well 2015, Compassion in Dying, available at <http://compassionindying.org.uk/library/plan-well-die-well/>
- ³ YouGov, 2015
- ⁴ Plan Well, Die Well 2015, Compassion in Dying, available at <http://compassionindying.org.uk/library/plan-well-die-well/>
- ⁵ YouGov, 2011

Contact us

181 Oxford Street, London, W1D 2JT

-  0800 999 2434
-  info@compassionindying.org.uk
-  www.compassionindying.org.uk
-  www.facebook.com/compassionindying
-  [@agooddeath](https://twitter.com/agooddeath)

Funded by



LOTTERY FUNDED

In association with

Daily Mail

Compassion in Dying is a registered charity in England and Wales 1120203 and a company limited by guarantee 05856324

**COMPASSION
IN DYING.**
SUPPORTING YOUR CHOICES

