

Faith, food and family:

Exploring advance care planning with Portuguese-speaking communities



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Introduction

In April 2018, we began a project in the London borough of Lambeth working with Portuguese-speaking communities. We undertook this work as part of our commitment to empowering diverse ethnic, faith and community groups to communicate their wishes to healthcare professionals and improve their health and wellbeing. We believe that people should be given the opportunity to consider and communicate their end-of-life wishes regardless of culture or religion, and to document the things that they would want those caring for them to know if they were unable to communicate.

External research and learning from Compassion in Dying's services have consistently demonstrated that if people are able to plan ahead for the end of life, and are supported to do so, it can have a positive effect on their end-of-life experience.

We know that 87% of the population want their healthcare team to know their preferences for treatment and care¹. Advance care planning helps this happen. Planning ahead for the end of life also provides peace of mind and reassurance to people in the present, knowing that steps have been taken to ensure their wishes will be respected in the future. Despite this, people's awareness of their rights to plan ahead remains low.

The Care Quality Commission's *A Different Ending*² identifies that minority ethnic groups are more likely to have unmet end-of-life care needs, and experience multiple barriers to accessing good, personalised care. This is especially the case amongst certain communities such as the Portuguese-speaking community in Lambeth. Many of the 35,000 Portuguese speakers living in Lambeth do not speak English, creating significant challenges in accessing health information and services.

1 Polling commissioned by Compassion in Dying - YouGov, 2018

2 A Different Ending: Addressing inequalities in end of life care - CQC, 2016

Partners

The project included four partners:

- **Compassion in Dying** contributed the expertise gained from the Big Lottery-funded *My Life, My Decision* project which supported ethnic minority, faith groups and LGBT communities with advance care planning.
- **The Stockwell Partnership** and **The Latin American Disabled People's Project** brought their in-depth knowledge of the local Portuguese-speaking communities.
- **The Lambeth Portuguese Wellbeing Project** used its community-level relationships to ensure that local people knew about and accessed this project. The Partnership also highlighted the need for bilingual resources.

Compassion in Dying co-hosts the **Lambeth Advance Care Planning Consortium** with Healthwatch Lambeth, an open network of organisations working to make advance care planning accessible for Lambeth's diverse communities and to increase the number of people documenting their wishes, ensuring that what matters to each person is known about when health decisions need to be made. Our project working with Portuguese-speaking communities is part of this larger collaboration to embed advance care planning across the borough of Lambeth.

Aims and strategies

The aim of this project was to support Lambeth's Portuguese-speaking communities to consider, document and share their preferences for care and treatment, thereby facilitating more meaningful discussions between Portuguese-speaking people and health and social care professionals. We hoped that this would in turn enable them to engage more easily with healthcare services, leading to better health outcomes and improved wellbeing.

We also wanted to gain a better understanding of how to support the Portuguese-speaking community in Lambeth to think about and document their preferences, and in turn establish recommendations which we could use to develop this work on a wider scale.

The project ran from April to November 2018 and focused on two areas:

1. **Community-based outreach:** group workshops and one-to-one discussions exploring people's preferences for their healthcare and treatment.
2. **Capability building with local organisations:** tailored training in advance care planning; bilingual resources; and developing delivery partnerships.

As part of this project we:

Trained staff and volunteers in advance care planning so they could support the people that use their services. We trained 38 people from the following organisations:

- The Latin American Disabled People's Project
- Stockwell Partnership
- Respeito
- The Portuguese Speaking Community Centre
- Age UK Lambeth's Safe and Independent Living Service

Held workshops with 19 people to introduce them to advance care planning.

Facilitated one-to-one sessions with four people to develop their own Advance Statement.

Took part in community engagement events to start the conversation about end-of-life choices and to showcase our bilingual resources through which we reached over 400 people. These events included St Martin's Day and Stockwell Festival.

Staff and volunteer training

As advance care planning was a new focus for our partners, we provided training to ensure each organisation felt comfortable engaging in conversations about planning for the end of life. The training also equipped staff with the information and skills needed to continue these conversations after the project had ended.

The focus of the training was on Advance Statements - how they can be used to help people communicate who they are and what is important to them, supporting them to live well until the end of life.

Advance Statement

An Advance Statement is a record 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 make decisions or communicate their wishes in the future. As explained in the Mental Capacity Act 2005, an Advance Statement must be taken into account by health and care professionals making a best interests decision. Free Advance Statement forms are available from Compassion in Dying.

Training objectives:

- Understand what an Advance Statement is and what it can be used for.
- Be able to clearly communicate the benefits of advance care planning.
- Have increased confidence in facilitating conversations about advance care planning.

The training was well received and the staff and volunteers from each partner gained a good understanding of end-of-life rights, and learnt new ways to support the people who use their services.

Group workshops

We held four bespoke workshops for Portuguese-speaking adults who did not read or speak English. The sessions were run by Compassion in Dying with the support of bilingual staff and volunteers from the partners.

One workshop was held for members of the Latin American Disabled People's Project's Wellbeing Group, and a series of workshops based around the Advance Statement was designed for the Stockwell Partnership's Hug group for isolated people.

Workshop objectives:

1. Facilitate discussions about what was important to participants as individuals and as part of their communities.
2. Explore people's preferences for their healthcare and treatment.
3. Discuss the importance of advance care planning.
4. Introduce the bilingual Portuguese and English Advance Statement form.

The community groups we worked with met on a weekly basis, primarily to socialise and take part in activities together. They all knew each other well and gave the impression of being upbeat and positive by laughing, joking and singing. We used these aspects of their identity as a way to engage them in initial conversations around communicating what was important to them.

There was concern that members of the Portuguese-speaking communities would find the subject matter frightening or depressing. During the training a staff member told us:

“There is a deep-seated reluctance, verging on superstition, to talk about poor health and death – just talking about it can lead them to feel they are bringing bad luck down on themselves.”

Understanding this concern in advance enabled us to prepare the workshops accordingly.

The name of our organisation was also suggested as a potential barrier for people engaging with the project - Compassion in Dying is familiar with this concern. However, our branding is intentionally honest to both support those who are ready to engage with advance care planning, and to encourage those who are more hesitant.

The staff and volunteers who acted as interpreters knew the participants well and there was a strong rapport between the groups as a whole which helped the conversations.

Introducing advance care planning

The first workshop was used to raise awareness of the project and allowed Compassion in Dying to get a sense of how much people knew about advance care planning.

We gave a brief introduction to Advance Statements and the reasons why someone may want to make one. Nobody in the groups had heard about Advance Statements or had conversations about their future care and treatment before.



Participants from The Stockwell Partnerships HUG Group.

Understanding the value of Advance Statements

The next workshops focused on our bilingual Advance Statement which enables people to record their wishes in Portuguese and English. Working through the Advance Statement initiated valuable conversations that covered several themes including:

Faith

For those who went on to complete an Advance Statement, it was used as a way of conveying aspects of their faith that were important:

“I pray to the Guardian Angel.”

“I have faith in God. I am Catholic. I pray in the evening and at night. I like to watch masses at Christmas time on TV. I would like someone to read excerpts of the Bible to me if I can no longer read. I respect and celebrate Catholic days. On Sunday it’s a resting day.”

Food and music

We explained that an Advance Statement is a tool people could use to communicate the foods they do and do not eat. The groups discussed the kind of foods that they were intolerant of, and specific foods from their home that they especially liked. There was a general preference in the group for traditional home-cooked Portuguese food.

“She likes homemade Portuguese food. She would like francesinha (traditional dish). And being by the seaside is important too!”

“I like to eat; I like traditional Portuguese food. I love food! I am a chocaholic, if I open a box of chocolates, I can't take one, I have to take them all! But I am restricted because of my health problems. I need to be careful. It's important people know that.”

Linked to the discussions around food was a general discussion around the importance of traditional culture. Fado (Portuguese music originating from Lisbon), and traditional music from Madeira, were mentioned by several participants as something they like to listen to and would want people to know this if they lost capacity.

“I like chicken soup, it's my favourite! I like music from Madeira to remind me of home. With music and soup I am fine!”

Family

Family was discussed as an important part of Portuguese culture and lifestyle. When asked who they would want to be involved with their treatment and care, the majority of participants wanted their family to be able to make decisions on their behalf. There was an incorrect assumption that family members would be able to make decisions on their behalf if they lost capacity.

“I want my children to visit me every day. It’s a cultural thing that we had never really thought about until now. It’s important. Family is important.”

“I am OK now, but I had a heart condition and nearly died. I never lost consciousness but I could not move or communicate. In that moment I wanted to get in touch with my daughter in law but couldn’t.”

“She adopted a child from Angola. He is more supportive than her own child. She wants him to be involved in her care.”

“When I had an operation for cardio failure, I saw a bright light but I could hear voices saying Mummy! That brought me back.”

“On Sunday I like to phone each of my sisters in Madeira, one by one, and then the day is almost over and I am happy.”

Several participants also mentioned it is seen as the family’s responsibility to look after ageing relatives. Those who did not have family to care for them said that they would be happy to be cared for in a UK care home.



Family photos being shown on a necklace.

Lasting Power of Attorney for Health and Welfare

A Lasting Power of Attorney for Health and Welfare allows someone to appoint a trusted person to make decisions about their treatment and care. For more information contact the Office of the Public Guardian on 0300 456 0300.

Isolation

There were several participants who felt like they didn't have anyone to help care for them, or to speak up for them if they lost capacity. For many this was because they did not have family nearby. This left some participants feeling isolated and therefore worried about their future care.

“Some people don't have family here.”

“If I die in my flat it will be my landlord who finds me as he will miss the money. I have no one here.”

“Sometimes people feel alone and shy. They don't want to tell anyone they are alone. They don't want to admit it. Outside happiness, inside sad.”

During this workshop a staff member told us:

“There is a particular fear at the moment about late life care, as apparently there are ‘Parent Orphans’ increasingly in Portugal – elderly parents dropped off and left in hospitals or placed in unregulated cheap care homes, neglected by the rest of their family.”

Refusing treatments

When the groups were given the opportunity to think about life-sustaining treatment, opinions were divided. Some did not want to be kept alive artificially for any length of time.

“She says if something bad happened to her she wants to be left to die in peace, no machines.”

“I am not scared of going into hospital but I would prefer to be cared for at home, I would like my family to look after me. I like to be awake and alert for any care that is given to me. When it is my time to go, I would like to be allowed to die. If I can't think for myself, if I was unconscious and lost ability to communicate, I would not want to be kept alive artificially. This is because I would get no pleasure of being alive. If I was connected to a machine, I wouldn't like that, not even for a month. I feel strongly about this. I know that my sisters would like me to be kept alive but I would like doctors to take this document seriously. I understand that this is not legally binding though.”

However, two participants also had experiences where they had been very unwell but recovered. As a result, they both had strong views about consenting to life-sustaining treatments.

Advance Decision

An Advance Decision allows someone to record any medical treatments that they do not want to be given in the future. Free Advance Decision forms are available from Compassion in Dying.

One-to-one sessions

After the group workshops each participant was offered a one-to-one session facilitated by Compassion in Dying and a bilingual staff member from the partner organisation. The one-to-one sessions were designed to give individual support to the participants to discuss what was important to them, and to record this in the bilingual Advance Statement.

Each one-to-one session lasted for one hour, with some participants needing additional sessions depending on how much information they wanted to include. Once the Advance Statement had been written in English and Portuguese, the information was double checked with the participant to make sure the translation was correct. The participants were then given their bilingual Advance Statement to be shared with health and care professionals and other people involved in their care.

Four participants had one-to-one sessions and completed their own Advance Statement.

Resources

As part of the project, Compassion in Dying produced resources to support the staff and participants, including:

- An information leaflet explaining the benefits of advance care planning and how people can record their preferences for treatment and care in advance. The leaflet was made in English, Portuguese and Spanish.
- A factsheet about Advance Statements in Portuguese and Spanish.
- Two bilingual Advance Statements; English & Portuguese and English & Spanish.
- A bilingual information sheet on advance care planning for health and care professionals.

These resources were used during the workshops and one-to-one sessions, and are now available for any organisation to use through our open-sourcing project.

Open-sourcing

At Compassion in Dying we share our content through an 'open-sourcing' agreement, whereby people can use any of our resources, adjusting them to suit their audience. This may include removing our logo and adding their own, or changing the colourway to suit their branding.

Challenges

This project encountered some challenges and unearthed challenges that some Portuguese-speaking people themselves are facing within the current health and care system.

Reluctance to talk about ill health and the end of life

The groups were extremely welcoming and were keen to support our work. However, there was an unspoken sense that they were uncomfortable with the subject matter. Many of the participants struggled with talking about death. This made us examine how and why culture, belief, traditions and expectations affect how an individual may or may not engage in the subject of ill health, death and dying.

Being aware of the community-level relationships and power dynamics was also important in ensuring that people joined the group with genuine willingness. For example, when asked if anyone had discussed the project outside of the group, one member stated “people have two faces, they say in front of me – ‘yes I’m interested’ but behind me, no!”

“Some of the questions made me feel scared. They make me seem I am close to needing to go into a care home. I think you were very brave to talk about this!”

“There is a lot of denial and fear at the root of the discussions. People want to keep these feelings private.”

One participant who was initially engaged did not return to the sessions as she felt the topic was too sad. However, another participant considered talking about their future care as an opportunity to express important aspects of themselves. They told us:

“I don’t want to be dressed in black. I have had my fun. I want to wear a red jumper when I die to make my sisters laugh! My sense of humour is important to me.”

Mistrust of health and care professionals

Some people did not trust health and care professionals in the UK and preferred to see family doctors in Portugal who knew them, who had more time for appointments, and with whom they felt more comfortable having these important conversations.

“At home they have what’s called a family doctor. We do have more time in Portugal. She says, in Portugal, if you have a headache they want to find out where it comes from.”

Even those who completed the Advance Statement expressed doubts about whether it would be taken into account when decisions were being made. One participant who completed an Advance Statement said she felt she needed to have access to an interpreter and support to speak to her GP about it in order for it to be taken seriously.

“There is also a worry that without anyone legally responsible for the Advance Statement, their hopes that it will change things are likely only to be dashed. They are mistrustful of health practitioners and also worry about their family seeing things through.”

“She is worried that no-one will care, that no-one will look at it.”

Accessing interpreters

Having access to interpreters was cited as one reason that people found it difficult to engage with healthcare professionals and others involved in their care.

“It’s difficult to access interpreters when we need them at the GPs. My daughter normally comes with me, but what about people who don’t have family? People use different methods, some people use friends, others have to pay someone. I don’t have enough time to explain my problems. It takes time.”

Lack of understanding of the benefits of advance care planning

Some participants said they enjoyed the workshops but didn't need a one-to-one session because they didn't see themselves spending the rest of their lives in the UK, and therefore didn't think it was relevant for them.

“I want to go back to Portugal.”

“Because I am going home. This is not for my country.”

“In the future I want to go home. Next year that is my plan. I have more support and friends at home. They speak the same language.”

A staff member expanded on this stating:

“Portuguese speakers feel the family should care for them and a lot of people want to go home because of this.”

Competing priorities

For many people, current support needs around healthcare, finance and employment make it extremely difficult to contemplate future care. During the workshops, participants shared diverse experiences they are managing on a day to day basis including caring responsibilities, living with multiple health conditions and difficulties around benefits and housing.

Staff and volunteer turnover

The staff and volunteers from the partner organisations were enthusiastic and committed during their involvement in the project. Unfortunately, an important staff member from one of the organisations left during the project and was not replaced due to funding issues. With this lead role left unfilled, the work did not continue as planned after the initial project period came to an end.

Recommendations

The purpose of this project was to talk to and work alongside Portuguese-speaking communities, and to understand how best to do so. We hoped this learning would allow us to develop this work on a wider scale and make recommendations for others hoping to engage Portuguese-speaking communities in their health and care. Although each community is different, learning from this project highlights several elements to consider when working alongside non-English-speaking communities.

1. Be aware of the importance of language

Some members found the subject matter difficult to engage with initially. The terms ‘death’ ‘dying’ and ‘end-of-life’ were frightening to some. Being guided by community level organisations and community members themselves helps to ensure that a culturally appropriate tone is adopted. Focusing on what makes people’s lives worth living and phrases such as ‘living well until the end’ seemed to engage people more.

2. Focus on people as individuals, not just as members of a particular community

It is important to remember that people are individuals as well as members of a community. Although many members shared similar interests as part of the Portuguese community, individual variation of opinions, needs, tastes and interests were demonstrated through the workshops and one-to-one sessions. Highlighting individual differences and explaining that people should not assume that others will know their preferences helps to demonstrate the value of writing an advance care plan.

It’s also important to remember that people have competing priorities, such as caring responsibilities or financial concerns, and so advance care planning may be a low priority for some. Allowing time to discuss the reality of these priorities is important when initiating conversations about advance care planning.

3. Consider involving support systems (family, carers or younger people)

Many of the participants talked about the importance of involving family, where possible. We are aware of the value of intergenerational approaches which ensure older people are supported by trusted younger generations to consider their wishes for the end of life. Unfortunately, we were unable to develop this strategy in this project as the majority of participants were isolated older people.

4. Use examples to help people consider what is important to them

We found that when we gave examples of other people's experiences this helped the participants to think about their own, and opened up discussion. Having staff members involved who knew the participants well meant they were able to provide prompts about things that might be important to them which also helped people to open up.

5. Advance care planning is a process

This project demonstrated that some people find it easier to think about and discuss the things they do want regarding their health and care, rather than things they do not want. By starting the conversation based on an Advance Statement, which records what is important to people and their way of life, you can engage people with advance care planning without bringing up death from the outset. Once people have been given time to think about their priorities for the future, and process this, they are more likely to engage with conversations about death and dying.

6. Take a flexible approach

Keeping the structure, timings and content of the project flexible means that it can be adapted to meet the needs and priorities of the participants involved. The groups in this project were relaxed and so we tried to avoid having anything too structured, allowing the group to be more open when sharing their thoughts and experiences. It also meant that participants were able to direct the project, making sure that it covered the topics that were most important to them.

Partners

The Latin American Disabled People's Project

Latin American Disabled People's Project is the only organisation in London devoted to serving disabled people from Latin America, Europe and Africa, whose first language is Spanish or Portuguese, as well as their carers, families, and communities.

They provide a range of services, projects, information, English classes, training, advice, advocacy, volunteering opportunities, and social and cultural events, to improve the quality of life for their service users. All activities are based on equal opportunities, confidentiality, empathy, and a non-judgemental approach dedicated to helping the members of their community succeed in every aspect of their lives.

The Stockwell Partnership

The Stockwell Partnership is a charity run by local people for local people. They aim to improve the quality of life in the local neighbourhood by undertaking projects, building partnerships, and supporting residents to take action on issues they care about. They work with residents to create a neighbourhood where people feel happy and safe, and where they have a sense of pride and ownership.

The Lambeth Portuguese Wellbeing Project

The Lambeth Portuguese Wellbeing Project is a grassroots network made up of over 40 local groups and community members. They combine their knowledge, passion, resources and skills to improve the health and wellbeing of the Portuguese-speaking communities in Lambeth.

Together they share a vision of a thriving community in Lambeth where anyone interested in any aspect of their health and wellbeing feels free and confident to get what they need from people they trust.

About us

Compassion in Dying is a national charity that helps people to prepare for the end of life - how to talk about it, plan for it, and record their wishes.

We can support you to plan for your treatment and care, in case a time comes when you can't make decisions. This helps you get the support that's right for you, when you need it. When what matters most to you is known and recorded, it makes it easier for your family, friends and healthcare professionals to follow your wishes, giving everyone peace of mind.

We help people through our free information line, publications and resources and through our work with diverse communities. We specialise in supporting people to make Advance Decisions ('Living Wills') and to talk about their goals and priorities when living with a life-changing illness. Our free MyDecisions website helps people to record their wishes for care in a legally binding way.

Have any questions? Talk to us.

Contact us

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