

EMPOWERING PEOPLE TO MAKE CHOICES AT THE END OF LIFE.

LESSONS FROM A PILOT PROJECT

INTRODUCTION

Many of us have clear views about what medical treatment we want at the end-of-life. However, all too often people aren't aware of their rights or aren't supported to take the steps needed to make sure their preferences can be respected by formally recording them in an Advance Decision or by appointing a Lasting Power of Attorney (LPA) for Health and Welfare.

Compassion in Dying believes that individuals should be placed at the centre of their end-of-life care and should be aware of their legal rights and choices around decision making. We seek to support individuals to plan what they consider to be a good death by:

- Providing up-to-date information about legal rights and choices, including an Advance Decision form and guidance on making an LPA for Health and Welfare
- Supporting people through our Information Line, one-to-one sessions, CPD training for professionals and volunteers and information materials
- Conducting and reviewing research into rights and choices in end-of-life care

MY LIFE, MY DECISION

In 2012, Compassion in Dying secured funding from the Big Lottery Silver Dreams fund, to pilot a project to engage with older adults, healthcare professionals and community stakeholders around end-of-life rights and choices. The pilot was run in partnership with Age UK East London which incorporates the three boroughs of Hackney, Tower Hamlets and Newham.

The project:

- Gave individuals information about their end-of-life decision-making rights
- Trained Age UK East London volunteers to work with older adults who requested further information and support to formally record their preferences
- Raised awareness amongst professionals and community stakeholders to ensure they were up-to-date with current practice and felt able to have difficult conversations about end-of-life rights with their clients

This report documents the success of the project and key learning which has informed its roll-out across seven Age UKs in England.

“ Some people think these conversations should just pop up when people are ready to have them, but if you leave it like that, it never pops up... it's not something that comes up automatically in conversation. ”

COMMUNITY STAKEHOLDER

“ They are giving you the intellectual help, but they are not taking the thing away from you. It is your decision and you are asked thoroughly 'Do you agree to this?' ”

SERVICE USER

KEY LESSONS FROM THE PILOT PROJECT

- Older people have different information needs. Whilst some wanted basic information about their end-of-life rights and choices, others wanted to engage with the topic in more detail and to be supported to complete an Advance Decision.
- Information spreads through word of mouth. Volunteers not only supported their clients to make Advance Decisions, but also spread the word through their personal networks meaning the project had a wide reach.
- People need to take in information about end-of-life rights and choices in their own time. Whilst we always tried to ensure that the topic was discussed sensitively, over time it became clear that support had to be given at a pace set by the individual. Service users needed time and support to think about what their preferences were, how to word them and then fill in the forms.
- Older people's involvement in the design and delivery of services is critical. An older people's steering committee was crucial in ensuring that we engaged sensitively and that the needs of older people were at the heart of the project.
- Training increases confidence amongst community stakeholders who work with older adults. After training, staff reported they were more likely to raise the topic with clients. As with older people themselves, community stakeholders wanted varying amounts of information. Some wanted an overview of end-of-life rights and somewhere to signpost their users to, others wanted in depth training so that they could support their clients directly.
- Some volunteers and service users were sceptical as to whether health professionals would ultimately respect Advance Decisions, especially when there is no formal system in place to record them. Some volunteers voiced concerns around whether they can act with integrity if the wider systems are not in place to ensure people's wishes can be acted upon.

THE NEED FOR MY LIFE MY DECISION

EVIDENCE FROM OUR END OF LIFE RIGHTS INFORMATION SERVICE

We know that the majority (82%) of us have strong views about end-of-life care and treatment, yet only 4% have made an Advance Decision or appointed an LPA for Health and Welfare. Around half of us (48%) wrongly believe that we have the legal right to make care and treatment decisions on behalf of family members.¹

Review of Compassion in Dying Information Line service shows that around 30% of users indicated that having a trained person to talk to face-to-face would have been helpful when filling in their Advance Decision. We were also aware that a particular type of person currently contacts us; namely information-seekers who are aware they have a right to plan ahead and make decisions about their medical treatment, even if they are not sure on the finer details or how to act on their wishes.

“ I have never done a form in my life. Some people can do it and some people can't, and I am one of the people who can't. ”

SERVICE USER

We also know that there is a lack of awareness and confidence amongst professionals with regard to end of life discussions, with 35% of GPs reporting never having initiated an end-of-life conversation with any of their patients². Furthermore, 9% of our Information Line callers report that their GP had never heard of an Advance Decision.

POLICY CONTEXT

The Mental Capacity Act (MCA) 2005 gave Advance Decisions and Lasting Power of Attorneys statutory force. The Act doesn't detail how these rights might be better known amongst the general public nor how care professionals can engage meaningfully with the subject. A recent House of Lord's Inquiry into its implementation found that *“The Act has suffered from a lack of awareness and a lack of understanding. The empowering ethos has not been delivered.”*³

1. You Gov poll, 2013

2. Dying Matters 2012

3. HM Government (2014) Valuing every voice, respecting every right: Making the case for the Mental Capacity Act. The Government's response to the House of Lords Select Committee Report on the Mental Capacity Act 2005.

The challenge is two-fold: how to ensure that people know what their end-of-life rights are and then empowering them to act on these rights if they wish to.

The Office of Public Guardian is currently working with NHS England on guidance for clinicians explaining the role of LPAs, to encourage them to discuss them more with patients. Similarly, there is ongoing work with local authorities to ensure that information on LPAs is included in guidance on care. However, the Government – prompted by a 2013 House of Lords Select Committee review of the Mental Capacity Act 2005 – has clearly indicated that awareness among the general public of Advance Decisions and a better understanding of the rights created by the MCA among care professionals needs to be addressed.⁴

Using relevant networks to ensure dissemination of information and engagement was highlighted as a key to ensuring people are informed. Future My Life My Decision work will address these concerns head on, working with older people to ensure the project reflects the needs of its users, directly empowering people to make choices and working with stakeholders so they are up-to-date.

“ It’s part of the National Dementia Strategy, dying well, ensuring ‘a good death’. So it’s on the Government’s agenda. We’re well aware that although it’s not a key performance indicator at the moment, our commissioners will be asking for it at some point in the future, so we need to get on with it. ”

COMMUNITY STAKEHOLDER

LEARNING FROM THE PILOT

ENGAGING AND WORKING WITH SERVICE USERS

Engaging older people in the project was sometimes a challenge due to what they perceived as depressing subject matter. Based on feedback and practice, the language, tone and emphasis of training and information sessions we provide and also the name of the project was changed (it was originally called End-of-life Rights Advocacy).

Through a series of mail-outs and events, 2,000 older adults across East London were reached, made aware of the service and introduced to the principles of end-of-life rights. Of these, 100 explored their options further with 1-2-1 or small group discussions on their rights and how to act on them. During the life-span of the 18-month pilot, nine older adults completed an Advance Decision and as the pilot was coming to an end a number were in the process of appointing a Lasting Power of Attorney. Many of these spoke to their friends and family about end-of-life rights – we know that around 75% of callers to our Information Line talk to others about their Advance Decision or wider end-of-life rights and choices – so the likely reach of the project was even wider.

“ When I talk to people about Advance Decisions, often they are unclear about what their wishes are – for most people it’s about having these conversations tentatively over time. ”

COMMUNITY STAKEHOLDER

We have also recognised that whilst callers to our Information Line are ready to discuss the subject matter, for many of the service users with whom Age UK come into contact with it is something they have never thought about or been aware of, and so they need time. From the point of coming into contact with the project it took a year for one service user to decide to complete an Advance Decision. She was very happy with the process, found the support from Age UK East London helpful and would recommend the service to others.

“ ...there’s lots of different scenarios that you have to think about for people to make an Advance Decision, it does take a lot of time. ”

AGE UK VOLUNTEER

It was identified early on by the volunteers that the task of completing an Advance Decision or an LPA for Health and Welfare can be both very complex and emotionally challenging. When a service user wanted to engage with the topic in detail and complete an Advance Decision this often took time and they often saw the service user multiple times. They needed to support the individual to carefully think about their preferences, perhaps discussing what they considered to be a good quality of life, what levels of care they would find acceptable if they lost mental capacity and how this could best be expressed in their Advance Decision.

Our work has also highlighted how important it is for early engagement with older people in order to ensure that when the time comes they, their families and their carers all know and respect what they want.

4. HM Government (2014) Valuing every voice, respecting every right: Making the case for the Mental Capacity Act. The Government’s response to the House of Lords Select Committee Report on the Mental Capacity Act 2005

“ I spoke to a lady the other day and her first response was ‘Oh well it’s all sorted, I did my will a few years back’. So now I’ve been saying ‘This isn’t about when you’re dead, it’s about when you’re alive’. It needs to be delivered in a more humorous way. ”

PROJECT STAFF

BEING GUIDED BY OLDER PEOPLE

The Big Lottery Silver Dreams Fund aims to empower older people, arming them with skills to be in control of decision making. With this in mind, older people were an integral part of the development and delivery of the pilot right from the start. Key to the pilot was setting up the Older People’s Steering Group, made up of representatives from the three boroughs of Age UK East London. The group was invaluable in terms of supporting the project on how to best engage with older people, for example with the language, tone and design of promotional materials and workshops. As a result volunteers and staff were encouraged to use phrases such as ‘what are your rights should you lose the ability to communicate?’ rather than ‘at the end-of-life’ and ‘dying’, which proved less frightening and alienating to people. The group also facilitated

access to numerous older people’s forums across East London and helped shape the evaluation of the service, for example giving advice on approaching and interviewing service users sensitively.

RECRUITING AND TRAINING VOLUNTEERS

Age UK East London volunteers were trained in both the principles and legal side of end-of-life rights, alongside the practicalities of how to support individuals, including having difficult conversations and formally recording treatment preferences.

Initially there was not a steady stream of older people wanting to be volunteers in the pilot. Many of those who are already volunteering with Age UK were unable to commit more time and some older volunteers may have their own health issues or life experiences which discourage them from engaging in discussions about end-of-life choices or make it difficult for them to support others in such discussions. However, there were older people who were interested and we learnt that the key is how they are approached in the first place. When approaching potential older volunteers for the project, we took a similar approach to speaking to people generally about end-of-life rights. It was important to emphasise the benefits of the project and that individuals would be providing peer-to-peer support to other older adults. Ensuring that potential volunteers have a good understanding of the project’s aims avoided individuals turning down the opportunity based on misunderstanding or misinformation.

During the pilot, 45 Age UK volunteers undertook training in end-of-life rights. 26 of these then became actively involved in delivering the project, either taking on the role of giving 1-2-1 support or providing detailed information to service users through events and signposting to further support.

OLDER PEOPLE BECOME EXPERTS IN THEIR COMMUNITIES

The older people involved in our project have been a huge asset to their community, both as volunteers and as members of the steering group. By recruiting a diverse group of local older people, we were able to support them to be ‘champions’ for end-of-life rights. As members of the local Older People’s Reference Group they were able to promote rights to not only their peers but to the wider community. Due to the diversity of the members we were also able to reach individuals in the community we may not have been able to otherwise, for example in local churches, mosques and community centres attended by older people. Many of the people who received training from us would not have done so if it wasn’t for the contacts that the older people we worked had across East London. It is not just service users that they spoke to about this project, but also friends and family.

“ Six of my friends have done it – it’s easy to talk to them about it if you have known them for years... and I have done mine... ”

VOLUNTEER

“ If people come to see you about their gas bill...you can’t say ‘Oh by the way before you go, have you thought about dying. ”

VOLUNTEER

ENGAGING WITH COMMUNITY STAKEHOLDERS

Engaging with stakeholders who deliver care and support to older adults in the community was challenging as end-of-life and decision making rights under the MCA are relatively new areas for many professionals.

Through awareness raising events and training, over 600 community stakeholders were engaged with. These included Subco (who provide day care provision to frail older Asians), a Mental Capacity Act forum, Jewish Care, a Muslim group, various care and sheltered homes, and NHS groups.

It was important to establish the level of knowledge and previous training organisations may have already had. At the beginning of each session the groups were asked to talk about their previous knowledge of the subject matter and their level of comfort with it to ensure we engaged them at the right level. Using case studies that may be particularly relevant to certain groups, providing information for further reading, or referring to relevant radio programmes gave participants a chance to consolidate their knowledge at a later date. Additional top-up training was also offered at a later date informed by feedback from participants.

Some organisations received more training and support than others. For example, some requested short sessions for their staff as part of ongoing development, which took the form of an information session. Others requested a half-day training, which was perhaps integrated into a bigger programme about advance care planning, or to cover a specific issue such as how to have difficult conversations. The pilot project highlighted the need to distinguish between information sessions and more formal training, whilst setting out clear expectations for the attendees.

“ In the seven years I’ve been in post, I think that’s the first time we’ve discussed end of life. I’ve never been to an event, a training session, never had a discussion on end of life...If a client raises the topic and we don’t know about it or we feel uncomfortable talking about it, it will never be addressed – we’ll just carry on with what we are doing. ”

COMMUNITY STAKEHOLDER

“ Until we had the training we couldn’t gauge what people’s knowledge of it was...I had presumed that staff had more knowledge of the difference between an Advance Decision and an LPA, so I had asked for training around ‘starting a difficult conversation’. It then became evident that actually we needed more on what’s the difference, the legalities, and then dispelling the myths, like is an Advance Decision set in stone? ”

COMMUNITY STAKEHOLDER

PLACING INDIVIDUALS AT THE HEART OF END OF LIFE DECISION MAKING:

CASE STUDIES FROM THE PILOT PROJECT

Sarah is in her late fifties, has a number of chronic health problems including mobility problems. She lives alone with support from carers.

Sarah had already heard about Advance Decisions from reading magazine articles and leaflets in hospital waiting rooms. She had read a story about a family who had made decisions about their father's care, only to find out later that it wasn't what he'd wanted. He had wanted to be a donor and they had refused. So Sarah had been thinking for some time that she wanted to write an Advance Decision, *"So that I could make my wishes clear, because I do not want to stay alive if I have lost any more of my bodily functions – and I definitely don't want someone keeping me alive if I am just lying there"*.

When Age UK East London told her they were offering a service to help with Advance Decisions and that it was free, she immediately put her name down. Two volunteers then visited Sarah to help her with the forms. She thought it worked well having them both there because *"They could both give me information and when one was writing things down, then the other one was listening, and I was making interjections in my usual fashion and confusing everybody!"* The whole process took three one-hour sessions.

Completing an Advance Decision reduced some of Sarah's worries. *"It's all going to be in one spot basically, and I don't have to particularly worry about it. And I don't have to worry about being stricken with a stroke and not being able to say anything."*

Sarah felt the process was relatively quick for her, as she had already made up her mind, but she felt other people might need longer. *"Once I make up my mind I head straight for it – I don't get diverted. But if some people still wanted to make up their mind Age UK would be very useful to help define the questions they should be asking."*

Mary is 63 and lives in sheltered housing. She is recovering from a stroke, which has resulted in her having memory problems and difficulties with reading and writing.

Mary heard about Advance Decisions when Age UK East London staff gave a talk at her housing scheme. She decided to complete an Advance Decision because she has no family and thought it the best way to keep a record of her wishes, *"I had been thinking about what to do – you see I don't have any close relatives – so I thought if there was something in writing, then there would be something for doctors to refer to... For someone in my position, it's really good to know I can make my wishes known and hopefully nothing will happen that I don't want to happen"*.

Completing the form gave Mary peace of mind. She was very clear about what she wanted, and she was *"just pleased there was a way for me to let it be known"*.

She was very grateful for the help from Age UK because she thinks she's *"not very good at putting things into words – so they helped me a lot – how to fill it in and how to make it sensible – and yes clarified things"*. She was concerned that if she had done it on her own, *"It wouldn't have got done because my handwriting is terrible. So they filled it in and read the questions and filled in the answers. If I had done it, it would have taken a very long time"*.

CONCLUSIONS AND RECOMMENDATIONS

End-of-life and planning ahead for a time when capacity is lost are not easy topics to discuss. Both the public and professionals want differing amounts of information and support, depending on their circumstances and how they personally feel about engaging with the issues. The East London pilot project demonstrates, however, that getting the information out there, and supporting people to take up their rights, is critical and has a hugely positive impact on individuals and professionals.

Compassion in Dying is honoured to be rolling our project out more widely in partnership with seven local Age UKs, and to give thousands more older people the opportunity to exercise their rights to plan ahead. This work will build on the pilot project, whilst recognising that each area will have its own delivery needs.

The East London pilot of My Life My Decision highlighted that more needs to be done than informing and empowering individuals. One of the most significant concerns of volunteers, and a common concern raised by our Information Line users is that either their Advance Decision will not be available to health professionals at the right time, or that their wishes will be ignored. In order to address this, Advance Decisions or LPAs must be recorded electronically on an individual's records. Compassion in Dying also believes that there needs to be a national register of Advance Decisions, similar to the principles of the Organ Donor Register.

Furthermore, awareness raising of end-of-life rights cannot be left to the voluntary sector alone. As the Government recently commented: *"Raising awareness of the MCA is everyone's responsibility"*⁵. In order to achieve wide awareness, we believe that:

- An explicit mention of the right to refuse treatment in advance and to appoint an LPA for Health and Welfare should be included in the NHS Constitution and all end-of-life care strategies and commissioning plans.
- Information about Advance Decisions and LPAs should be given routinely when planning the care of dying, frail or chronically ill patients.
- There should be a positive duty on healthcare professionals to inform patients of their right to make an Advance Decision or appoint an LPA if there is reason to believe patients may lose capacity – for example, if they are due to undergo general anaesthetic, have a terminal or degenerative diagnosis, or have a diagnosis of dementia.
- There should be mandatory training for professionals on:
 - legal issues surrounding end-of-life decision-making;
 - starting the conversation about end-of-life care preferences;
 - signposting to organisations that can provide information and support around end-of-life decision making.
- Clinical Commissioning Group indicators for end-of-life care must be linked to personalised care outcomes i.e. the number of people who have an Advance Care Plan, Advance Decision, LPA and the proportion of people who have their recorded wishes for end-of-life care respected.

5. HM Government (2014) Valuing every voice, respecting every right: Making the case for the Mental Capacity Act. The Government's response to the House of Lords Select Committee Report on the Mental Capacity Act 2005.

NATIONAL ROLL OUT OF MY LIFE MY DECISION

My Life My Decision will deliver information, training and support services in East London, Hillingdon, Oxfordshire, Lancashire, South Lakeland, South Tyneside and Trafford.



My Life My Decision also has 13 resource partners who will receive training and materials. These are: Age UKs in Brighton & Hove, Camden, Ealing, Kensington & Chelsea, Milton Keynes, Leicester, Surrey, Waltham Forest, Westminster, Lewisham & Southwark and Independent Age, the Beth Johnson Foundation and the National Council for Palliative Care.

The My Life, My Decision project has been received funding from the Big Lottery Fund to run for two years and three months. We aim to achieve the following outcomes during the life of the project:

- 12,000 older people to be made aware of their end-of-life rights and given the opportunity to discuss their end-of-life preferences
- At least 21 volunteers trained to give 1-2-1 support to older people
- 10% more older people to have completed an Advance Decision and/or completed an LPA for Health and Welfare compared to baseline levels before the project started in the delivery areas
- 80% of older people who complete an Advance Decision or LPA for Health and Welfare to report they have discussed their end-of-life wishes with their families and/or health professionals
- 350 community stakeholders to report that they have initiated end-of-life discussions with their service users, having received training from My Life, My Decision

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