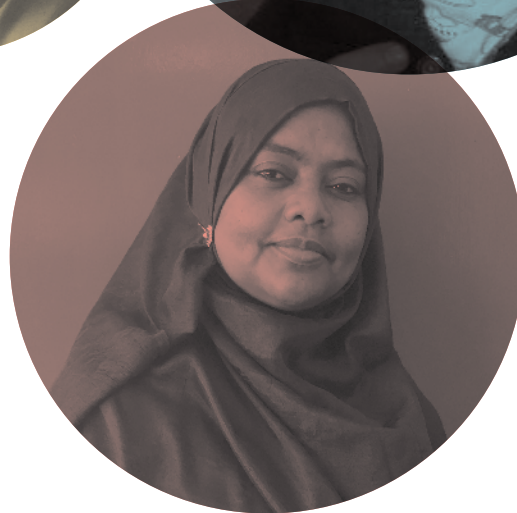


My Life, My Decision: Planning for the end of life

A new approach to engaging
people and communities

**COMPASSION
IN DYING.**
SUPPORTING YOUR CHOICES



October 2016

Contents

Part 1: Summary learning from the <i>My Life, My Decision</i> programme	2
Part 2: Programme evaluation	18
An ambitious programme	18
Need: why plan ahead?	20
A multi-layered programme	21
One-to-one support	25
Raising awareness	41
New approaches to engaging diverse and minority communities	45
Training	59
Research and policy	67
Conclusions and recommendations	76

The quotes used throughout this report are from our service users and others who accessed the programme. This report covers activities delivered in the first 24 months of the programme, from July 2014 to July 2016.

Part 1: Summary learning from the *My Life, My Decision* programme

Introduction

***My Life, My Decision* was an ambitious, multifaceted programme of work delivered by Compassion in Dying and its partners, and funded by the Big Lottery's Silver Dreams Fund to run from July 2014 until October 2016. Its aim was to support people aged over 50 to think about and plan their care in advance, helping to ensure they have the death that is right for them.**

The programme tried and tested new ways of engaging people and communities in planning for the end of life. It developed a service that placed the individual at the centre of their care decisions and supported them to express and record their wishes in a legally binding way. It also developed effective models of partnership between health services and voluntary organisations, enabling healthcare professionals to refer patients to trusted community partners who could support those patients to plan their care.

Key learning and recommendations

The My Life, My Decision service developed a multi-layered approach to enable people to plan for their end-of-life care encompassing:

- Raising public awareness, including engaging with minority groups
- Providing one-to-one support to individuals to plan ahead for their future care by making an Advance Decision to Refuse Treatment, an Advance Statement or a Lasting Power of Attorney for Health and Welfare
- Providing training and awareness-raising for professionals



Each of these activities reinforced the others.

For example, professionals who received the training were more likely to refer patients into the one-to-one service. Individuals who received one-to-one support to plan ahead often raised awareness by introducing friends and family into the service, and by taking their completed Advance Decision (or other care planning document) to their GP to be placed on their medical record.

Learning from the service demonstrates that this multi-layered approach:

- gives people who use the service peace of mind about their future care
- saves time for healthcare professionals by enabling them to refer patients who want to plan ahead to a trusted community partner for support
- will save money in the long-term by ensuring people do not receive treatment they do not want
- helps to deliver the Government's vision for person-centred end-of-life care by raising awareness, training professionals, and engaging communities¹

Our recommendations are set out in more detail in part 2 of this report, but in summary the experience of *My Life, My Decision* shows a need for:

- commissioning local support services for individuals alongside training on Advance Care Planning for professionals
- tailoring services that meet the needs of different groups who face challenges when accessing services
- educating the public on the benefits of planning ahead and the reasons why someone might do so
- developing and testing different approaches of raising awareness and providing support

Context

We launched *My Life, My Decision* in 2014 in the context of a (then) ongoing review into choice in end-of-life care and a recently completed review of the Mental Capacity Act in practice,² with the aspiration that the programme would test new approaches to engaging members of the public and professionals with early Advance Care Planning.

Numerous reports on end of life and mental capacity in the last three years have reiterated similar findings, particularly on the barriers there are to people effectively planning ahead, and what is needed to tackle these barriers:

- Better training for healthcare professionals on having difficult conversations
- Significant improvements in public awareness about their rights to plan ahead
- Development of new partnerships and approaches to improve care for minority communities which at present is often poor
- Greater focus on understanding and respecting people's wishes, with personalised care plans for all

This report takes these as given. Indeed in practically supporting, informing, listening to and working with our partners, the *My Life, My Decision* programme has sought to address these barriers and implement many of the recommended changes on the ground in real time and with limited resources.

Need: why plan ahead?

The need for the *My Life, My Decision* service is clear. When people are supported to plan their care and record their wishes and goals for treatment it can have a hugely positive impact on their end-of-life experience.

Research³ shows that Advance Care Planning (the process of thinking about and recording one's treatment and care wishes) results in:

- Better person-centred care. People who have completed an Advance Care Plan have earlier access to palliative care, receive care and treatment that is more closely aligned with their preferences and are more likely to die in the place of their choice.
- Improved relationships and communication between families and healthcare professionals. Having early conversations about preferences and creating an Advance Care Plan helps build relationships and reduces conflict within families and between families and staff. Family members of people with an Advance Care Plan also have a more positive bereavement process.

There is also a clear need for the awareness-raising element of programmes like *My Life, My Decision*. 82% of people say they have strong views about what treatment they would want to refuse or accept at the end of life. However, despite the evident benefits to planning ahead we know that only 4% of adults have made an Advance Decision or a Lasting Power of Attorney for Health and Welfare.⁴

Activity and impact: summary

We worked across England: East London, Hillingdon, Oxfordshire, Lancashire, South Lakeland, South Tyneside and Trafford

Supported 1,068 people

Reached 6,824 older people in their communities through 554 talks and awareness-raising events

Delivered 1,505 one-to-one sessions

Provided accredited training to 117 health and social care professionals, 145 Age UK staff and volunteers and 156 community stakeholders

Helped to complete 577 Advance Decisions, Advance Statements and Lasting Powers of Attorney for Health and Welfare

We developed three in depth CPD-accredited training modules for professionals on the Mental Capacity Act and Advance Care Planning

Raised awareness among a further 3,790 health and social care professionals and charity staff through briefings and awareness-raising events

Raising awareness

6,824 older people in their communities were reached through 554 talks and awareness-raising events.

“ I have always felt I would not want my life extended if I had dementia or was in a coma. But I didn’t know I could put that in writing in a document that doctors would have to follow until I went to an event at Age UK.”

Supporting individuals with Advance Care Planning

My Life, My Decision supported 1,068 people to think about their wishes for end-of-life care. We delivered 1,505 one-to-one sessions and 577 Advance Decisions to Refuse Treatment, Advance Statements and/or Lasting Powers of Attorney for Health and Welfare have been completed with support from project staff and volunteers.

The value placed on the service by the individuals involved was clear – it gave people peace of mind and a strong sense of empowerment. For many people, the process of thinking through their wishes, discussing these with their family, and then recording them, is not easy.

“ ...I really wanted to make the Advance Decision. Sometimes it was hard, thinking it all through, or talking to my children about it. But I am so glad that I got it done. I can stop worrying about the future now, and just get on and enjoy the here and now... ”

The service was largely used by people who needed support and could not have completed a planning tool without it.

Reaching and engaging with diverse and minority communities

We have developed new approaches to working with minority communities, working closely with three Black, Asian and Minority Ethnic (BAME) groups in London and Lancashire, and developing new, tailored publications for Lesbian, Gay, Bisexual and Trans* (LGBT*) and for Jewish communities.

Learning from the service shows that for some of the most isolated groups there is huge value in reaching out and enabling them to have a conversation and record their wishes for end of life. This applies both to their understanding of their rights to make decisions about their health and their confidence to put this into practice.

“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? and Where is she from? She now has a book which describes everything about her and what care and treatment she wants... For her she has made that easy and easier for the clinicians as well.”

Somali service user (spoken via an interpreter)

*The asterisk following the word trans in the LGBT acronym has been introduced by the community to indicate the most inclusive method of including the full spectrum of non-binary and gender nonconforming individuals who identify under the very diverse umbrella term of trans.

Training and engaging with professionals

We have provided Continuing Professional Development (CPD) accredited training to 117 health and social care professionals, 145 Age UK staff and volunteers and 156 community stakeholders.

A further 3,790 health and social care professionals and charity staff have attended *My Life, My Decision* briefings and events.

Learning from *My Life, My Decision* shows that professionals who received the training valued it highly and felt more confident in talking to patients about the issues as a result.

Professionals who engaged with the wider *My Life, My Decision* service recognised that the ability to refer patients to a community service that could support them with Advance Care Planning was hugely beneficial, both in terms of helping limit the many demands on their time and ensuring patients received high quality support from a trusted local service.

Cost savings

The return on investment (ROI) of this programme was 1:2.24. That is, for every £1 spent on this programme, £2.24 will be saved on unnecessary hospital admissions or treatment. That is a significant saving in itself but, taking into account cost savings that could be made were the learning from this programme to be replicated elsewhere in a publicly funded programme, we anticipate the return on investment to the public purse would be in the tens of millions.

The primary benefit of Advance Care Planning is that it results in people having better deaths by ensuring they do not receive unwanted treatment and by facilitating communication between the individual and their healthcare professionals and their loved ones. Nevertheless the cost savings associated with people being more likely to die at home if they have an Advance Care Plan are a welcome side effect of the process.



Case Study:

Phyllis, East London

“My name is Phyllis. I was born in 1931 in the house that I live in now and I hope to die here too. I’ve had a full and active life and I still keep myself occupied with lots of different activities.

It’s been my dancing that’s kept me going. That and a long marriage with Ted – we were married fifty-eight years. He had not long come out of the merchant navy when we met.

We had a good life together. Nothing too flash, but we were comfortable and happy. There was always something going on, family-wise, and we had great times together with my extended family, whether bowling,

or, in the latter days, sequence dancing. Ted and I both worked hard and he retired a while before I did. I had a series of good jobs in a number of industries and I always seemed to be able to form and lead my own teams.

When I wasn’t working I was able to indulge my passion for sequence dancing.

I taught Ted many of the moves that we would use when we danced together. We would go to clubs and meet loads of other people, some of whom would become our closest friends.

Sadly, Ted passed away in 2009 and I miss him a lot. You see, life is a bit like sequence

dancing. You have to have a partner. You can do things on your own or in a group, but it's never the same without a partner.

I retired in 1990, so I've had a lot of time since then to do things that I wanted to do. My elder sister lives quite close, she is 99, and I go to see her as often as I can. As well as dancing, which I do when I can, I go to exercise and computer classes.

I know that when my time comes I am ready for it. I don't wish to be kept alive artificially. I don't wish to be in a situation where my basic needs can only be met by carers.

Nor do I want any of my close family to be put in a situation where they have to make decisions about me. At present I am capable of making my own decisions and I want to be responsible for my care and treatment in the future. No one else.

That's why I approached *My Life, My Decision* to help me complete an Advance Decision. I heard about the project through my girls group.

I was very clear with the project co-ordinator that I wanted life-sustaining treatment stopped almost immediately if there was little or no prospect of recovery from a severe condition that would permanently and seriously affect my quality of life. We discussed this issue at length and I was able to write down my wishes, as the project is all about my rights and choices.

I have also just registered as a donor with the NHS Organ Donation scheme.

With all of this done, I have greater peace of mind and I can keep myself focussed on the things in life that I enjoy.”

What can be done?

Raising awareness

It is clear from the *My Life, My Decision* programme, Compassion in Dying research and other sources⁵ that public awareness of the ability to plan ahead is lacking. Similarly, in absolute terms, the number of people who have made an Advance Decision or Lasting Power of Attorney for Health and Welfare is very low at just 4% of the population.

Clearly, further research is needed into people's assumed reluctance to plan and how we can communicate the good reasons to do so in a way that does not imply the need for lengthy and complex methods to prepare for something that may feel very distant. However the experience of *My Life, My Decision* suggests some groups are more likely than others to want to make some form of Advance Care Plan. For example, 20% of our service users in the second year of the programme were in the early stages of dementia. For these people there was an urgent need to plan ahead, as they were facing the prospect of losing capacity to make decisions in the relatively near future.

Compassion in Dying will build on learning from the *My Life, My Decision* programme to research these issues and launch a public campaign to raise awareness of how to plan ahead for future care, the reasons why you might want to plan ahead and the benefits of doing so. We will also seek to raise awareness among groups facing a likely loss of capacity (such as people with dementia) of the benefits of engaging with Advance Care Planning before the need to do so becomes urgent.

Supporting individuals with Advance Care Planning

It has long been established that different people have different needs. That is why there continues to be a strong push for care to be personalised. Advance Care Planning is no different.

The *My Life, My Decision* programme has confirmed this and established that using one single method (such as free online tools) to encourage people to plan ahead is insufficient. One-to-one support has a significant benefit and is vital for people who need support to think through, communicate and record their wishes, as this service has clearly demonstrated, but it needs to be delivered alongside other online, offline and face-to-face strategies.

Compassion in Dying will seek to continue working with local partners to provide face-to-face support to plan ahead for those that need it. Although this approach requires funding, as shown above, there is a clear return on investment in taking this approach.

In addition we will continue to provide our free information service, planning ahead packs and online planning resource MyDecisions.org.uk.

Reaching and engaging with minority communities

Through the programme's innovative work with diverse and minority communities we have learned that Advance Care Planning largely remains geared to those already able to engage effectively with the healthcare system.

- **BAME and faith communities**

There are significant additional barriers to encouraging those from some BAME groups to plan ahead. Firstly, language barriers make it difficult to communicate wishes for current treatment, let alone future treatment. Furthermore, there are different views across communities and cultures about what is seen to be a 'good death' which can compound communication difficulties.

Through our programme we worked collaboratively with groups and individuals from different BAME and faith communities directly. This is a model to be replicated. Providing group-based and one-to-one support to specific communities to inform them of their rights to plan ahead is vital. Through this work we have developed alternative ways to enable people to express their wishes despite communication barriers, such as providing people with a way to visually express their views and wishes so that they can be translated into written format.

- **LGBT* communities**

Research has identified that for older generations of LGBT* people, traditional family structures may not apply. During the project, we heard many examples where LGBT* people had specific significant others who they wanted to make decisions. However, in the absence of a Lasting Power of Attorney or Advance Decision setting out wishes for treatment, when the individual lost capacity, their family members, who often hadn't been in the person's life for several decades, were consulted. Many felt that an aspect of that person's identity was lost as a result.

Compassion in Dying will continue to seek to work with minority groups who are at present, less likely than the wider population to receive good end-of-life care, and less likely to engage with Advance Care Planning.⁶ These groups are likely to benefit from the opportunity to plan ahead and to express preferences for their end-of-life care that may be different to the mainstream, such as wanting a friend rather than estranged family members to be consulted about their care, or wanting medical professionals to be aware of religious and cultural beliefs around what makes a good death.

It is clear that efforts to raise awareness in BAME and LGBT* communities on the benefits of Advance Care Planning will be more successful if they go hand in hand in with work to address the existing barriers that they face in accessing health and social care and in expressing their wishes. This requires both community engagement and better training of healthcare professionals.

Training and engaging with professionals

What is clear from this programme is that healthcare professionals have limited time to be directly involved in supporting individuals to plan ahead. Whilst they play an important role in helping people understand their rights and in understanding the medical implications of any conditions they have currently or may have in the future, any system of Advance Care Planning reliant on healthcare professionals being the lead provider of support is set for failure (unless there are radical increases in staffing, which seems highly unlikely).

This programme demonstrated that partnerships between community organisations and clinicians can work effectively on the ground. Such an approach, where the skills and resources of clinicians and community organisations are put to best use, will increase the numbers planning ahead whilst reducing the strain placed on healthcare professionals' time.

Community organisations should be commissioned across the country to lead on the delivery of one-to-one support, with clinicians signposting and referring patients who want support to plan for future care to them.

Compassion in Dying will seek to continue working with local partners and healthcare professionals to provide face-to-face support to plan ahead for those that need it. Again, this approach requires funding, but as shown above, there is a clear return on investment to taking this approach and demonstrable benefits both for patients and professionals.

Part 2: Programme evaluation

An ambitious programme

My Life, My Decision was an ambitious, multifaceted programme of work delivered by Compassion in Dying and funded by the Big Lottery's Silver Dreams Fund to run from July 2014 until October 2016. Its aim was to support people aged over 50 to think about and plan their care in advance, helping to ensure they get the care and treatment that is right for them at the end of life, or if they were to lose mental capacity.

The programme tried and tested new ways of engaging people and communities in planning for the end of life. It developed a service that placed the individual at the centre of their care and supported them to express and record their wishes in a legally binding way. It also developed effective models of partnership working between health services and voluntary organisations, maximising the capacity of healthcare professionals by enabling them to refer patients to trusted community partners who could support those patients to plan their care.

***My Life, My Decision* set out to:**

- **provide one-to-one support** to people to discuss their wishes for treatment and care, and to complete Advance Care Planning documents, namely an Advance Decision to Refuse Treatment (Advance Decision), Advance Statement and/or Lasting Power of Attorney for Health and Welfare
- **raise awareness** of people's right to plan their treatment and care in advance
- **develop new approaches to engaging with diverse and minority communities** on planning for their future care

- **develop new resources** that are accessible and meet the needs of diverse and minority communities
- **deliver accredited training** on Advance Care Planning and the Mental Capacity Act to professionals, volunteers and community groups and **explore new approaches** to working with health and social care professionals on these issues
- **commission research** looking at the benefits of Advance Care Planning and at how to engage diverse and minority communities, and ensure learning from the project is shared and incorporated into national **policy work**

Our partners

We delivered the programme in partnership with seven local Age UKs in areas across England: East London, Hillingdon, Oxfordshire, Lancashire, South Lakeland, South Tyneside* and Trafford.

In addition, for some parts of the programme we partnered with Women's Health and Family Services, Jewish Care, SubCo Trust, Opening Doors London and Stonewall. We also commissioned research by the Woolf Institute and a literature review by the International Longevity Centre-UK.

*Age UK South Tyneside became Age Concern Tyneside South on 1st September 2016.

Need: why plan ahead?

The need for the programme is clear. When people are supported to plan their care and record their wishes and goals for treatment it can have a hugely positive impact on their end-of-life experience.

Research⁷ shows that Advance Care Planning (the process of thinking about and recording one's treatment and care wishes) results in:

- **Better person-centred care.** People who have completed an Advance Care Plan have earlier access to palliative care, receive care and treatment that is more closely aligned with their preferences and are more likely to die in the place of their choice.
- **Improved relationships and communication between families and healthcare professionals.** Having early conversations about preferences and creating an Advance Care Plan helps build relationships and reduces conflict within families and between families and staff. Family members of people with an Advance Care Plan also have a more positive bereavement process.

Polling commissioned by Compassion in Dying in 2015⁸ also found:

- when a person's end-of-life wishes were not recorded, they were 53% more likely to receive treatment that they did not want
- those who did have their end-of-life wishes formally recorded were 41% more likely to be judged by their loved ones to have died well.

Recording preferences for treatment and care in advance also gives people peace of mind – our service users felt better informed about their rights and more confident that their wishes would be respected after using the service.

“The support from *My Life, My Decision* to formally record what I want to happen if I become more ill in the future has allowed me to get on with living now.”

A multi-layered programme

- We worked across England in East London, Hillingdon, Oxfordshire, Lancashire, South Lakeland, South Tyneside and Trafford.
- We supported 1,068 people through 1,505 one-to-one sessions. As a result we helped to complete 577 Advance Decisions, Advance Statements and Lasting Powers of Attorney for Health and Welfare.
- We reached 6,824 older people in their communities through 554 talks and awareness-raising events.
- We provided accredited training to 117 health and social care professionals, 145 Age UK staff and volunteers and 156 community stakeholders.
- We raised awareness among a further 3,790 health and social care professionals and charity staff through *My Life, My Decision* briefings and awareness-raising events.

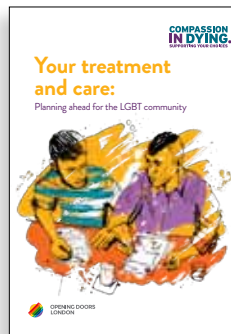
We developed:

- a new approach to engaging diverse and minority communities in planning for their future care
- a new approach to working with GP practices to train staff and raise awareness among patients
- three accredited training modules: An Introduction to the Three Tools for Talking and Planning; Advance Decisions in Depth; and Lasting Powers of Attorney for Health and Welfare in Depth

We have produced new resources:



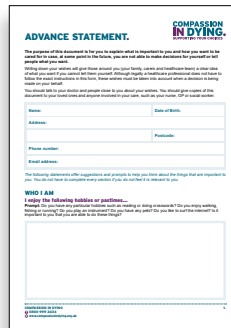
An introductory planning ahead leaflet in six Asian community languages.



A booklet on planning ahead for the end of life for LGBT* people.



A booklet on planning ahead for the end of life for Jewish people.



A new Advance Statement form.



Case Study:

Glenda, South Tyneside

“My name is Glenda. I am 85 years old and live alone in the same bungalow I’ve lived in for the past 28 years. My only family is a nephew and great-nephew, but we’re not in touch. I spend my days knitting, baking and early morning shopping. And, although these things fill my day I do worry that there may be a time I can’t do them anymore and that I will lose my independence. My independence is very important to me.

My quality of life would be no good without independence. I am a bit jealous of the 17 people in my street who have died because I am frightened of losing control.

I was put in touch with the *My Life, My Decision* project by the Information and Advice Service team at Age UK South Tyneside. They had helped me in the past with accessing benefits and support with my garden. I have a good relationship with them and I told them that I am worried that when the time comes I will not be allowed to die. So they referred me to *My Life, My Decision*.

The *My Life, My Decision* project coordinator came out to see me and explained about Lasting Power of Attorney for Health and Welfare and Advance Decision. I don’t have anyone that I would feel comfortable

“With the support of *My Life, My Decision*, I was able to put these wishes on paper... I feel confident that my wishes will be respected.”

assigning as my Attorney, but I did like the Advance Decision. I liked that it would allow me to put my wishes into a legally binding document.

I was very clear about my wishes – I do not want to be resuscitated or have any interventions to prolong my life. I want to be able to go when the time comes.

With the support of *My Life, My Decision*, I was able to put these wishes on paper, know that they are legally binding and that the professionals have to listen to them. I found the whole process very easy and the balance

of my mind wasn't disturbed at all. I felt like I knew what I was doing.

I know that if I am unconscious I am going to die in comfort. I will not be resuscitated or given any treatment to prolong my life.

I have also been to see my GP and she is in agreement with my wishes. It is wonderful!

My GP has a copy of my Advance Decision and I have the original copy in plain sight in case there is an emergency. I have even discussed it with my taxi driver who I have known for ten years and trust. I feel confident that my wishes will be respected.”

One-to-one support

Need

We know that 82% of people say they have strong views about what treatment they would want to refuse or accept at the end of life.⁹ However, despite the evident benefits to planning ahead only 4% of adults have made an Advance Decision or Lasting Power of Attorney for Health and Welfare.¹⁰ A review of Compassion in Dying's Information Line service users in 2011 showed that 31% of people said that having a trained person to talk to face-to-face would have been helpful when filling in their Advance Decision.¹¹ *My Life, My Decision* sought to address this need.

What we did

Working with our local Age UK partners we established a planning ahead outreach service in seven areas across England. In each locality an expert project coordinator and volunteers delivered one-to-one sessions to people aged over 50 in their communities.

Through these sessions we supported people to explore what is important to them. They did so over a period of time allowing them to build rapport and trust with the project staff, thus enabling them to feel comfortable thinking about and discussing their wishes for the end of life. Depending on their wishes we supported many people to complete an Advance Decision, Advance Statement or a Lasting Power of Attorney for Health and Welfare.

“...my daughter-in-law’s mother, has Parkinson’s and she has no quality of life, I would hate to not be able to do the things I love so I do not want to end up like that.”

“I really appreciated the home visits as I live rurally and can’t get into town. The coordinator visited at the times that were best for me. She provided good, clear information and handled the discussions sensitively.”

After the first six months of delivering the one-to-one outreach service, it became clear that some people did not want to refuse specific treatment in an Advance Decision, but did have other preferences for their future care. In response to this we developed a new template Advance Statement form. To support people to consider their wishes, the form includes prompts and questions on themes around quality of life that have recurred frequently in our one-to-one sessions, such as place of care and spiritual or religious beliefs.

Motivations

People accessed the one-to-one service for a range of reasons. Some people had been given a diagnosis of a condition such as Alzheimer’s or Parkinson’s and they wanted to control their treatment and care once they lost capacity to make decisions. Others had personal experience of seeing people living in a situation that to them would not be a meaningful quality of life. There were also some people who had strong views about their future care and treatment and wanted a way to formalise their wishes.

“...if I did lose my marbles for want of a better phrase I didn’t want my family to try and look after me, I wanted to go in a home”

“I wanted to get things in order - I feel as though I want to live forever, but it’s not going to be the case, is it? ...[the service] helped me get my thoughts on paper and I’ve given the documents to my daughters and my doctor so they know what I want now if anything happens and I can’t speak for myself”

Who we supported

Many of the people we supported had dementia and other health conditions. Project staff would explore with them the things most important to their quality of life and support them to express their end-of-life goals. This would naturally lead to conversations about priorities for treatment and care, and in some cases, refusing treatment in advance in the event of them lacking capacity to make decisions.

Many people who accessed *My Life, My Decision* lived alone and did not have family, friends or a network to support them make decisions about their care. Our one-to-one support was therefore essential to them being able to express their wishes and understand their rights to plan their treatment and care in advance.

The level of support given varied depending on people’s needs. Often multiple sessions were needed to enable service users to fully understand their options to plan ahead, and then to complete an Advance Decision, Advance Statement or Lasting Power of Attorney for Health and Welfare if they wanted to do so. For those that did complete one of these documents an average of two one-to-one sessions were needed, though some people with higher support needs required several more. People were most likely to need several face-to-face sessions if they had multiple long-term conditions, fluctuating capacity, for example due to dementia, and higher support needs around communication, for example if they did not speak English and needed an interpreter.

“I could ask as many questions as I needed and I was given as many one-to-one sessions as I needed support with.”

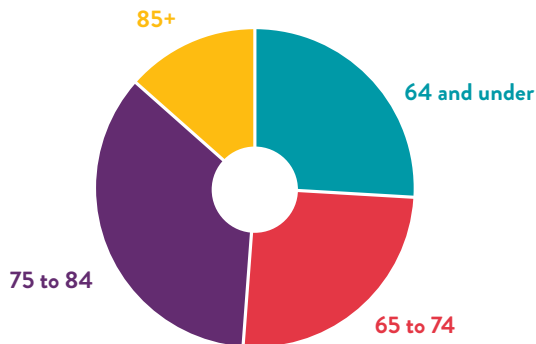
“The coordinator visited at the best times of the day for me, when I would be most alert. She explained everything, was patient, and made the signing easy using coloured paper as guidance because my sight is not good.”

Demographically, people who used *My Life, My Decision* were broadly reflective of the service users of the Age UKs we worked with. 25.8% of those who used the service were aged 64 and under, 25.4% were aged 65 to 74, with 48.8% aged 75 and over. Women made up 68% of the service users.

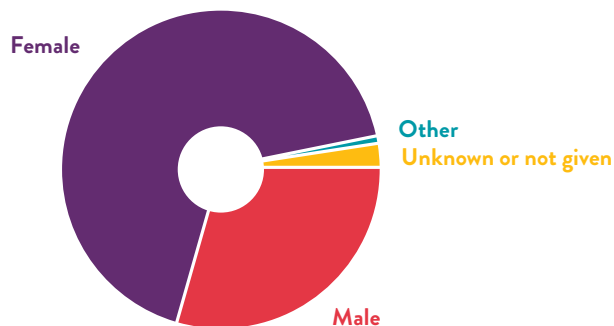
Over 81.1% of those who accessed the service described themselves as white British. 60.7% described themselves as heterosexual/straight and 1.5% as lesbian, gay or bisexual (a large number of service users either were not asked, or chose not to answer this question; this is reflective of wider experience in the charity sector,¹² though we developed new training on monitoring for project staff in the second year of the programme to address this issue).

Who we supported: demographic data

Age	%
64 and under	25.8
65 to 74	25.4
75 to 84	35.3
85+	13.5



Gender	%
Male	29.3
Female	68.0
Other	0.1
Unknown or not given	2.6



Sexual orientation	%
Heterosexual	60.70
Lesbian/gay/bisexual	1.50
Unknown or not given	37.80

Ethnicity	%
White (English/Scottish/Welsh/Northern Irish/UK)	81.1%
White (Irish)	1.3%
Any other White background	2.5%
Mixed ethnic background	0.8%
Asian (Indian)	1.5%
Asian (Pakistani)	0.9%
Asian (Bangladeshi)	0.3%
Asian (Chinese)	0.2%
Any other Asian background	0.5%
Black (African)	0.6%
Black (Caribbean)	2.7%
Any other Black/African/Caribbean background	0.5%
Any other ethnic background	0.4%
Unknown or not given	6.6%

Age

The age ranges of people who used *My Life, My Decision* were broadly reflective of those who use Compassion in Dying's Information Line - 90% of the people who contact us by phone are aged 65 and over, compared to 74.2% of *My Life, My Decision* service users. For both services approximately 50% of service users are aged 75 and above.

However, perhaps unsurprisingly people who use our digital services reflect a younger age range. Almost 50% of people who use our website are under 65 but that age range accounts for only 10% of callers to the Information Line and 25.8% of *My Life, My Decision* service users. Only 17% of those who use the website are aged 75 and above.

Gender

Women tend to have higher engagement levels in services aimed at older people (this was established by our local Age UK partners through baseline service use mapping in advance of the programme starting), and have a higher life expectancy than men¹³ so our experience may simply reflect these facts.

Research by Independent Age¹⁴ also found that women were more likely to consider conversations about care as important:

- 84% of women see discussing preferences for end of life as important compared to 74% of men.
- 26% of men said they have not discussed end of life preferences with a relative compared to 19% of women.

Given these figures and our experience on *My Life, My Decision*, there is potential for further work to be done to engage men in planning ahead.



Case Study:

Sharon, Project Coordinator at South Tyneside. A family perspective of planning ahead

“My Mom became aware of her right to complete an Advance Decision to Refuse Treatment through my work as a coordinator of the *My Life, My Decision* service. Although her path to planning ahead came from my professional involvement with the project, the outcome of this knowledge for us as a family, and for me on a personal level, has allowed us to navigate a particularly difficult time with some direction and certainty.

Mom was a Registered Nurse when the NHS was in its infancy. She was a strong and resourceful person, creative and caring. She was not afraid to look life straight in the eye

and deal with whatever came her way, grasping opportunities and chances when they presented themselves. She lived her life and showed her children the importance of living every Moment, of being true to oneself, of coping with the lows and relishing the highs. Poise, strength and independence are the three words I would use to sum her up.

The past few years had taken their toll on my Mom. She suffered with Meniere Syndrome for a long time but lately her Osteoporosis and chronic obstructive pulmonary disease (COPD) created new challenges that she

didn't like. Suddenly her world became smaller, limited to the flat she shared with my step-dad. Her energy levels inhibited her ability to paint, a pastime and talent that gave her solace and an outlet for expressing herself. Her world, once so vast and unlimited, was becoming four walls, reliant on her family to bring as much of the world to her as we could. Being dependent on others and restricted in her movement was like a prison for my Mom.

Last summer, Mom decided that she needed to take control of her future. She did not want to leave it to chance so she completed her Advance Decision. She refused all life sustaining treatment. In December, she was admitted to hospital with a suspected chest infection. She made sure the staff knew about her Advance Decision. One medic said to her that she was brave to have committed her wishes to paper. She said it wasn't brave, "it's brave not to have one."

Over the next few months, Mom was in and out of hospital, receiving blood transfusions, antibiotics and oxygen therapy. She still had capacity and knew that there was something more serious than an infection, something that she would not overcome this time. Finally a definitive diagnosis was given – myeloid leukaemia.

On Friday 4th March, Mom and I trekked up to the hospital for her to have another blood transfusion. On Saturday, at home, she was finding it increasingly difficult to breath; she could feel the use of her muscles diminishing and was quite anxious. She knew that she was going to become more reliant

“I can say that she followed the path in her own way, in control of it and with dignity.”

on carers and didn't like the thought of strangers having to go through her drawers and of not having control over herself. I asked if she wanted to ring an ambulance or go to the hospital but she didn't reply. So I didn't. Because we had had the conversation, I knew she didn't want that.

I sat with Mom that night. She ate a bit of fish and chips and had some lemon pudding – more for my benefit than hers I'm sure. I helped her get ready for bed, held her hand and read to her. She was a lot calmer and seemed more settled than when I first arrived.

My Mom died in her sleep that night, the Eve of Mothering Sunday. Although I grieve the loss of my Mom I can say that she followed the path in her own way, in control of it and with dignity. She was in her own room with familiar surroundings and the man she loved close to her. Because we had had the discussions and she had made her wishes quite clear, it was easier for us as her family to support her through it.

“Because we had had the discussions and she had made her wishes quite clear, it was easier for us as her family to support her through it.”

It is never easy to lose the people we care about and talking about it can be distressing. But I can't imagine having to make those difficult decisions without having had the discussions before. I knew what Mom's wishes were and her thoughts on quality of life. She directed her own path, just the way she had done all her life.”

Dementia

20.41% of service users had a diagnosis of dementia. We began recording this information one year into the programme after realising that many people accessing the service were doing so because of their diagnosis or were signposted from local memory services.

The high representation of people with dementia is significant. It is important that people with dementia are given the opportunity to talk about their preferences for the end of life at a time and in a way that is right for them. This has been recognised by the Care Quality Commission (CQC) in their recent report into inequalities in end of life care, which showed that people with dementia received worse end-of-life care than people with other conditions.¹⁵ The report acknowledged that there are particular challenges around planning ahead for people with dementia but that these can be addressed through early, supported ongoing conversations:

“Identifying dementia early, so that people have the opportunity to consider Advance Care Planning and make meaningful choices at an appropriate time, is particularly important as the person will progressively lose the mental capacity to make decisions about their end of life care.”¹⁶

“Talking to people and families about Advance Care Planning can be challenging and sensitive. However, people who have dementia have a greater need for early and ongoing conversations about end of life care in the last phase of life as part of their wider treatment and care planning. This is supported by conversations with family as well as health and care staff, and can start when people are well and able to make decisions.”¹⁷

My Life, My Decision addressed this by providing a service through which people could think about and document their wishes at a time and in a space which was comfortable for them.

Some service users' capacity fluctuated. Staff therefore encouraged them to take notes over time of their thoughts and beliefs so that they could revisit this with them and use these thoughts as a prompt to frame their conversations.

Impact

My Life, My Decision supported 1,068 people. We delivered 1,505 one-to-one sessions and 577 Advance Decisions, Advance Statements and/or Lasting Powers of Attorney for Health have been completed with support from project staff and volunteers.

Support for healthcare professionals

Healthcare professionals and staff at other community organisations who engaged with *My Life, My Decision* reinforced the need for the service. Critically, from healthcare professionals' perspective, a dedicated service such as *My Life, My Decision* can invest time that they do not have in supporting patients to think through their preferences and complete an Advance Care Plan.

“We’d welcome a closer working relationship with the service - we don’t have time to support with planning ahead.”

“I signpost people to *My Life, My Decision* a lot – it’s not a conversation that can be rushed and the staff give patients the time they need.”



Case Study:

David, Lancashire

A volunteer's perspective

“My name is David Perry and I am sixty-two years old. I live in Burnley where I have lived all my life apart from three years when I attended Sheffield University to study for a Chemistry degree. I retired from being a teacher two years ago after a career lasting thirty-eight years.

Throughout my career I taught science and chemistry to pupils aged eleven to sixteen. In the latter part of my career I was Deputy Head Teacher and even Acting Head Teacher.

I have been married to Maureen for nearly forty-one years and it is indirectly through

her that I became involved with Age UK Lancashire. Maureen has worked for the organisation since 2000 and with older people since 1987. We have two sons and three grandchildren.

A few years ago, Maureen introduced me to Heather Johnson and between us we organised some of the students to assist in activities such as computer classes for older people. It was through this that I decided I wanted to volunteer for Age UK Lancashire when I retired.

In Autumn 2014 Heather contacted me to see if I would be interested in assisting her on the *My Life, My Decision* service.

I immediately realised what a worthwhile project this was and I was only too willing to assist. This was something to get my teeth into along with my other interests like Burnley Football Club, golf, cricket and of course, more importantly, my family.

After a short period of training from Heather and Esther from Compassion in Dying, I was ready to put my newly learnt skills into action. The confidence I had built up during my teaching career and my people skills together with the excellent information and support I was given helped me to settle into my volunteering role very quickly. By December 2014, I was assisting Heather in one-to-one discussions with service users. We were there to support people complete their own Advance Decision, Advance Statement or Lasting Power of Attorney for Health and Welfare.

Shortly after this I was confident enough to go out on my own and carry out discussions. With the assistance of Heather and Esther,

things blossomed. I regularly carried out discussions with service users either by telephone or face-to-face. After a while I became confident enough to go and give talks to a few other local groups and I assisted at some awareness-raising events.

Initially I was disappointed with the lack of knowledge that people had about the possibilities they had on offer to them, but over the 18 months of my volunteering work I have been pleased to see a massive rise in what people know. It has been an eye-opener for me and a very humbling experience. I have met some incredible people who never cease to amaze me by how they cope with adversity. I am hopeful that a lot of people have found my assistance beneficial. It has been challenging at times, though I feel that my previous experiences of dealing with the wider community had me well prepared for what I have faced.

Overall I have thoroughly enjoyed what I have done and hope to continue my volunteering work for some time yet.”

Peace of mind for individuals

An independent evaluation of *My Life, My Decision* found that service users consistently report “knowing their preferences have been recorded and are legally binding consistently brings people peace of mind and reduces their worries about the future.”¹⁸

Of clients who completed an Advance Decision, Advance Statement or Lasting Power of Attorney for Health and Welfare, 82.8% said it had reduced their worries and given them greater peace of mind.

“...now everyone definitely knows what my wishes are rather than thinking they know what my wishes are.”

“I know what’s going to happen if anything should happen. I’m glad I did it.”

Peace of mind for carers

Those caring for people who had used the *My Life, My Decision* service reported that this, and the conversations about care preferences it had facilitated, gave them peace of mind.

“... it’s not a nice subject to talk about but having discussed it with Mum makes me feel a lot better, that I know what her wishes are, and puts my mind at ease as well...My mother appointed me her Attorney because she wanted me to make those decisions. When she had her stroke I had to make decisions for her. It is very important to me, yes that we had the conversations and did it all properly.”

“My husband had dementia. When he gave me Lasting Powers of Attorney we had no idea how quickly his health would decline. I’m so glad we did it though. I wouldn’t have been without it. It was just... I felt in control on his behalf. All these doctors - well, I’ve been dealing with hospitals for years with my husband and they’re not always right. So, as difficult as the whole situation was, I was reassured that I knew what he wanted and I could make sure the doctors understood his wishes.”

Raising awareness

Need

It was clear from the start of the programme that the low numbers of people who make an Advance Decision, Advance Statement or Lasting Power of Attorney for Health and Welfare meant that significant efforts were needed to raise awareness of people's rights to plan ahead. This was also important for generating interest in the one-to-one support service.

What we did

We adopted a community based approach to awareness-raising by holding talks and events in local areas. We developed relationships with local organisations, healthcare professionals and other support services to highlight the work of *My Life, My Decision* and we also publicised the service through local media.

Raising awareness fed back into the one-to-one service as people became aware that they could record their wishes in a legally binding way. People who heard about *My Life, My Decision* through events and briefings were also able to signpost others to the service.

Accessing the service

Raising awareness of people's rights to plan ahead was vital to them being able to access the one-to-one support offered. Having local Age UK partners, including staff and volunteers, enabled us to champion the programme within the local community and among existing Age UK service users. It also allowed us to build networks with local organisations and healthcare professionals who were then able to refer people to the service.

Almost 50% of service users were signposted to *My Life, My Decision* from within the local Age UKs. Others were signposted to the service from Compassion in Dying's Information Line.

Just over a quarter of service users independently contacted *My Life, My Decision* for information and support which demonstrates that posters, leaflets, talks and media coverage advertising the service locally had an impact.

A significant minority heard of the service through their GP or other health and social care providers (7.15% combined) which demonstrates the importance of the multi-layered approach taken in seeking to raise awareness among the public and professionals as well as charities and community groups. However, developing relationships with GP surgeries, hospitals and hospices takes considerable time and if the programme had been longer we believe the proportion of service users referred from health and social care would have continued to grow.

Impact

My Life, My Decision has reached 6,824 older people in their communities through 554 talks and events.

“I didn't really know much about it before. It's the sort of thing that I thought I would do and wanted to know how to go about it.”

“My GP told me to get in touch with Age UK because he'd had another patient who'd done this Advance Decision thing with them. I wanted to do it but didn't know how, so when the GP told me that, I just went into the Age UK office and took it from there afterwards....”



Case Study:

Fousia – Community Development Worker at Women’s Health and Family Services

“I have been a Development Worker for Women’s Health and Family Services for twelve years. And I’ve been coming to this women’s group at the hall since I started. We lost funding for the group one year ago, but I still come regularly and encourage everyone else to. I fought for the group to continue to have access to the hall. It’s important. The women, many of them are quite isolated. When they come here they feel relief.

When my manager told me about the Compassion in Dying project and asked me what I thought, I said ‘I don’t think so,

when the ladies think about dying they will be scared’.

Then I spoke to my friend, she’s a student nurse, she said ‘they must do it, it’s important!’ She knows what’s going on in hospital, the difficulties people have.

So then we had the first session and I thought, ‘Okay this is reality, this is real life’, some of the women who used to come regularly have already passed away. Some already don’t come because of their health conditions. It’s important.

“Now they know they have a choice for everything. It has built up their confidence and they have been given voices.”

Many of them haven't got family and have no-one to speak for them. Having something written down is really useful. These ladies, nobody knows their culture, nobody knows what they like and don't like. They thought the only person who can make a decision is the doctor. They feel they have no choice at all. I even learned a lot myself.

The group work was helpful, because now they know they have a choice for everything. It has built up their confidence and they have been given voices. The one-to-one work is where they talked more. Often in the big group they hide.

I used to be an advocate and went to meetings with GP's. Family are often too shy to interpret for the older person and sometimes the person wants to say things that they do not want their family to know. Often they feel they are powerless because other people always speak on their behalf. But when they have this book [Advance Statement] it's like equipment for them to say, 'This is me'. Oh, and also I think the GPs will really benefit from the glossary.

Since we ran the group they talk more naturally about planning ahead. Before, they never did.”

New approaches to engaging diverse and minority communities

BAME and faith communities

Need

We knew when *My Life, My Decision* began that some people from certain faith and Black, Asian and Minority Ethnic (BAME) groups had lower awareness of their rights to plan ahead and more difficulty accessing information about their health and care than the wider population. A recent report by the CQC also identified that language barriers and a lack of understanding of religious and cultural needs can complicate already difficult conversations around end-of-life care.¹⁹

“Existing evidence suggests that BME groups may have more unmet end of life care needs than people from white backgrounds, and experience a number of barriers to accessing good and personalised care... The findings of our review support the existing evidence and barriers include a lack of understanding, knowledge and information about end of life care, lack of religious and cultural sensitivity, language barriers, and poor communication.”²⁰

What we did

We worked in partnership with other organisations to get a better understanding of the needs of different communities when thinking about planning ahead. Working with organisations who already had relationships with these communities helped us to get a better understanding of their needs and to establish a relationship of trust.

Workshops

We developed two innovative workshop approaches to discussing wishes for future healthcare with a group of older Somali women in Tower Hamlets in London in partnership with Women's Health and Family Services, and with a group of older South Asian women in Great Harwood (part of Age UK Lancashire). The women in both groups were Muslim and most of them either could not speak and read English or were not confident doing so.

It became clear through discussion with both groups that the women felt they currently faced significant barriers to accessing healthcare and making decisions about their healthcare. Communication difficulties and lack of accessible information are critical barriers which mean that, even though they have mental capacity to make decisions about their treatment and care now, they are often prevented from doing so.

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

Somali woman

As a result, the work inevitably evolved to cover their rights to make decisions about their health while they do have capacity, as well as in the future should they lack capacity to make decisions.

Case Study:

Suleekho, Tower Hamlets

“I am Somalian but I’ve lived here in London for 35 years. My sons were born here and I have lived in Tower Hamlets during all that time. I didn’t go to school; I just played outside with the other children. In the old days, girls didn’t go to school. But I did speak English when I came here; I learned English when my husband and I lived in Yemen.

I’ve got a community here. I was a dinner lady. I talk to people. I’m interested. We’re all family. We’ve known each other a long time. Some people are closed off. But I think, ‘what about over your eye, the other side?’ It’s interesting to know what other people want, why close the door?

I heard about *My Life, My Decision* when I just turned up at the group as usual – the project was a surprise! I came and I listened. To me, it’s very interesting. I have come to this hall for 25 or 30 years and I never heard of anything like this before. They call us in sometimes for a meeting but this is for us – for the future.

**“If I feel ill today or tomorrow
and I go to the doctor and I
can’t talk, I have my evidence.”**

“Some people don’t want to know, don’t want to talk about it, but you have to prepare.”

When my husband died, I missed him a lot, he was my other half. But you have to accept it; it’s the reality, it’s the truth. Some people don’t want to know, don’t want to talk about it, but you have to prepare.

I love my book [Advance Statement]; it’s my history. If I feel ill today or tomorrow and I go to the doctor and I can’t talk, I have my book – my evidence. You give it to them, it’s your story. That story you’ve written down, you keep it all. We don’t need someone reminding us, I’ve got it in my hand. I’ve shown my sons – one son lives with me and

my other son lives in Dubai with his family. They say it’s good, you’ve done well. I’m so happy and proud; I’ve done a good thing. It’s good when a person tells you you’ve done well.

It’s important – it’s like when you go to the bank and they say, ‘how do I know who you are?’, and you give them your passport. My book is the same. If a doctor asks, “Who are you?” I can say this is who I am.”

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

South Asian group member

For people who are not able to communicate (or communicate confidently) in English, and for those who have particular religious and cultural beliefs, an Advance Statement setting out these beliefs and explaining how they impact on care preferences can be particularly helpful should decisions need to be made about their treatment and care.

Participants from both groups worked together with staff to develop an Advance Statement that reflected each individual’s wishes and beliefs. The Somali women’s group developed a ‘Visual Advance Statement’ where their wishes were recorded in English alongside images that represented the statements in their form. The Asian women’s group developed a two-sided Advance Statement form, which they called ‘This is Me’. This prioritised key information about their cultural beliefs, care preferences, and people they would want contacted in an emergency.

“She says there is nothing else that could have made it [the process of the workshops and the one-to-ones] better, because she was able to say specifically what she likes and doesn’t like, and what she wants and what she doesn’t want, and that was really important to her. She feels now that she said that and that that has been recorded.”

Somali woman (spoken via an interpreter)

We also worked in partnership with Subco to deliver three workshops aimed at raising awareness and providing information about planning ahead to older men and women from the Asian Subcontinent. Over the course of three half-day workshops attended by approximately 50 Subco service users and staff, we provided information on Advance Decisions, Advance Statements and Lasting Powers of Attorney for Health and Welfare and facilitated discussions with the support of interpreters on key topics such as the role of family and religion at the end of life.

We also trained the Subco staff in the three CPD-accredited training modules so that they would be able to provide support to the Subco service users who wanted to record their wishes.

The work with Subco was ongoing at the time this report was published, but at the time of going to press seven service users were in the process of compiling an Advance Statement, Advance Decision or Lasting Power of Attorney for Health and Welfare.

Raising awareness

It was clear that the awareness-raising approach adopted elsewhere in the programme of holding events and talks was not sufficient to engage these communities. We therefore developed a different approach whereby we identified already established community groups and hosted discussion workshops. These took place over a number of sessions and were particularly effective in engaging people to think about the end of life and what is important to them. It enabled them to explore the issues over a period of time in a trusted environment before taking steps towards planning ahead.

The people taking part in all of the groups and the staff and interpreters involved made interesting suggestions around how to raise awareness amongst their own communities and the wider population. For example, one of the women in Lancashire brought her daughter with her to the sessions. The daughter commented that the younger generations also needed this information as they would play a big role in their parent's care:

“I’m the oldest in my family... I’ve got the responsibility for everybody. If you know the information before anything happens that’s better... the older generation they put it at the back of their minds, they don’t take it seriously do they? The younger generation that’s who you prepare as well – because they’re the ones who are taking the responsibility when the parent is ill.”

Daughter of a South Asian group member

“Also talking to my family, my sister, she said this was brilliant. She really thought this is what Asian ladies are supposed to know about... you could even advertise it in newspaper or the radio...Radio is the best source of spreading your word.”

Interpreter (South Asian group)

Impact

25 people across the two women's groups chose to make an Advance Statement that recorded the things they would want healthcare professionals to know about them if they lost capacity to make a decision. The Advance Statements covered preferences around diet, washing and dress, elements of their daily routine and particular observances of their faith at the end of life.

The groups provided the women with a space to share the things that were important to them and to talk about difficult experiences of healthcare 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 are informing the mainstream of what is ours.”

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?”

Understanding that the Advance Statement forms have a legal status, and that doctors have to consider them when making decisions about what treatment and care is in a patient’s best interests, was also important for the women’s confidence in considering potential future interactions with healthcare professionals:

“Everybody wanted to be interviewed [to receive one-to-one support to complete an Advance Statement]. They kept saying ‘I need my book, I need my book’. It had a really big impact on them. They feel like ‘This is my story and I will keep it with me and I will take with me when I am going to the hospital.’ It’s their thing - it’s who they are.”

Somali group interpreter

The women also recognised the importance of the Advance Statements in terms of their families’ understanding of their wishes for treatment and care at the end of life:

“Now everybody knows that Mum’s written down something. So they all know ‘this is what she wants in case’. It’s there always.”

Asian Group member

Participating in the workshops and completing an Advance Statement gave the women peace of mind in relation to future healthcare and a sense of empowerment that they had proactively taken steps to ensure healthcare professionals would know about their culture and their wishes for healthcare.

LGBT* communities

Need

We were aware when *My Life, My Decision* began that LGBT* people have a lower awareness of their rights to plan ahead and face additional challenges when accessing appropriate information about their healthcare (both at the end of life and more generally). This has been identified by Stonewall:²¹

“More than two in five (43 per cent) lesbian, gay and bisexual people are not confident that medical professionals would identify and consult the right person to make decisions about their care if they were unable to make their wishes known themselves; this increases to 50 per cent for lesbian, gay and bisexual people who don’t have partners. While 38 per cent of heterosexual people feel the same, there is no similar increase for single heterosexual people.”

NHS England has acknowledged that trans* people face particular problems in accessing healthcare, commenting: ²²

“Extensive engagement with the transgender and non-binary communities has confirmed that many people continue to experience health inequalities borne out of a lack of awareness of their needs and/or stigma amongst health professionals, and problems in accessing mainstream NHS services which are appropriate and personalised to suit the individual.”

What we did

During *My Life, My Decision* we worked with a group of older LGBT* people to develop a new publication on planning ahead, specifically for an LGBT* audience. The people we worked with are all service user Ambassadors for Opening Doors London, a charity providing information and support services with and for older LGBT* people.

The booklet, called *Your treatment and care: Planning ahead for the LGBT community* provides information on Advance Decisions, Advance Statements and Lasting Powers of Attorney for Health and Welfare, and provides case studies to illustrate how each could help LGBT* people.

Impact

At the time of writing, *Your treatment and care: Planning ahead for the LGBT community* had not yet been launched, so it was not possible to assess its impact. Compassion in Dying will continue to work with Opening Doors London and other partners to raise awareness of the publication within LGBT* communities.

However, learning from consultation with Opening Doors London Ambassadors and others involved in the work suggests there is a real need to raise awareness of the options for planning ahead among older LGBT* people. The Ambassadors shared stories of loved ones where the people who were the most important to them were not involved in their care, and in some cases healthcare professionals and estranged family members were involved in decision-making for individuals approaching the end of life.

Family members have no automatic right to make decisions unless they have been appointed Lasting Power of Attorney for Health and Welfare by the patient. However doctors will often ask family members for guidance on what the patients would have wanted if they have no valid Advance Decision or Lasting Power of Attorney. In cases where the patient and family have been estranged for many years, this is clearly inappropriate.

The Ambassadors emphasised the need for the publication, and for wider awareness-raising work in the community:

“I’ve seen friends be given treatment and care they would not have wanted at the end of life, because their wishes weren’t known and doctors involved their estranged family members in decision making. There is a real need for information about planning ahead for the end of life to be tailored to the LGBT* community so that others don’t have to go through this and so that we know how to retain control of decisions about how we are treated at the end of life...”

Opening Doors London Ambassador



Case Study: George, Lancashire

“Many months ago I attended a talk given by Janet from Age UK to a group of older learners in Lancaster University to which I belong. After the talk I asked to have a private chat about my own plans.

I had been admitted to a nursing home following an accidental fall, prior to that I'd been in reasonably good health, other than my treatment for diabetes, osteoporoses and leukaemia. I was independent and active, spending my summers sailing with my friend who has a yacht. We set off each year at the first high tide in June and spent the next few months sailing around Scotland and Ireland

and down to Spain. We spent the winters working on the boat and living on my canal boat.

I enjoy the lectures at the University and am a committed member of the local Quaker Community. I had a career in engineering and management and was a Mosquito fighter-bomber pilot during World War Two. I've travelled to Canada and the Far East and have enjoyed sailing as a hobby all my life and with my three boys as they were growing up.

“I feel much better having done so much pre-planning. The discussions have meant that all the people I cared about understand my wishes.”

I spent my recent Christmas holidays looking after my sister who had dementia so that her daughters could spend time with their own children. It was during one of the Christmas breaks that I fell, I then had a three month spell in hospital and rehabilitation before moving to this Care Home.

The care staff work with residents and encourage them to write about their own life stories. This activity prompted me to think deeply about how my story might end and I decided to do some more planning. I first spoke about planning ahead with Janet when I was feeling quite poorly and frail. I had to

get my affairs in order along with my three sons and my companion of many years.

I decided to start with an Advance Statement so I could get my wishes clear in my own mind before discussing plans with my family, friends and care team. I was clear that if my heart stopped I would not want to be resuscitated. I also have diabetes and it had taken a lot of trial and effort to get it stabilised. I don't want to have any changes to my regime in future. If the current management regime ever ceased to work I would want to give up with it all!

I then decided to make an Advance Decision to Refuse Treatment to give extra weight to my wishes about cardio-pulmonary resuscitation and the management of my diabetes. A member of staff at the home had discussed DNAR (Do Not Attempt Resuscitation) with me and gave me copy of a form to sign but I decided I needed something more, something legally binding.

So I completed the Advance Decision form and gave copies to the nursing home staff, hospital, GP, plus my sons and companion.

Two sons who live in Australia and New Zealand planned to visit me, plus a third from the UK. So Janet told me more about a Lasting Powers of Attorney. I thought this would be a good vehicle to bring my companion and family together to work as a team to support me and have face-to-face discussions. We lived together on our two boats at Glasson Dock for two weeks and the five of us agreed readily. Janet helped me prepare the forms. We had many face-

to-face discussions. They were finally completed during the visit and then sent off to be registered, as now accepted.

I really got a grasp of the whole thing when I asked what all the documents are that I need to get to grips with in my final years. Janet's support and encouragement was very important and I wouldn't have got through the process without her. It was a team effort with Janet, the nursing staff my family and my companion particularly.

I feel much better having done so much pre-planning. The discussions have meant that all the people I cared about understand my wishes. So hopefully they will all be included in any discussions, or decisions, if I lose mental capacity to make my own decision at some time in the future.

Equally I have taken all reasonable precautions and decisions, so I should not be surprised by either any problems or unpleasant occurrences.”

Training

Need

The Mental Capacity Act (MCA) 2005 gave Advance Decisions legal force and introduced Lasting Powers of Attorney. It also gave legal standing to Advance Statements by stating that the person's written wishes and feelings must be considered as part of any best interests decision made on their behalf if they lack capacity.

Despite this, it's clear that the MCA has not been as effectively implemented as it could have been. In 2014, the House of Lord's Inquiry into the implementation of the Act found that:

“The Act has suffered from a lack of awareness and a lack of understanding. The empowering ethos has not been delivered.”²³

The CQC has also found that healthcare professionals' understanding of the Mental Capacity Act is variable in relation to capacity assessments and in relation to how decisions are made for someone who lacks capacity to make decisions about their healthcare, including how to implement an Advance Decision or Lasting Power of Attorney for Health and Welfare.²⁴

“I give advice and support to people with Parkinson’s... and by the time I actually come to see them, they are aware and accepting of the fact that they have a degenerative disease, that they aren’t going to get any better, and so they are keen to put things in place and to plan ahead. I didn’t know much about it at all and I was getting asked the question more and more about powers of attorney and advance decisions. Being in the dark about it, I wasn’t very confident in giving advice about it”.

Charity advice and support worker

My Life, My Decision sought to address this lack of understanding both amongst the public and healthcare professionals.

What we did

Over the course of *My Life, My Decision* we have developed five three-hour training modules, three of which have received CPD-accreditation.

We also recognised that although the training was valuable, some healthcare professionals did not have the time available to commit to a three-hour session. As a result of this we developed a one-hour introductory briefing, which conveyed the key information on planning ahead and the Mental Capacity Act which healthcare professionals were able to attend.

We have also piloted a new approach to training in partnership with a GP practice in South Tyneside.

This approach had three tiers:

1. Patient awareness and one-to-one support
2. GP and staff awareness and training
3. Clinical Commissioning Group engagement and strategy

The pilot aimed to develop an effective way of providing GPs with the training they need to support their patients to plan ahead by having the confidence to start conversations and then giving them a service to signpost to.

Impact

We have provided training to 117 health and social care professionals, 145 Age UK staff and volunteers and 156 other community stakeholders.

Over 97% of those who attended the training rated its content and delivery as very good or excellent.

Participants were asked to rate their knowledge on a scale of 1 to 5 (1 being the least knowledgeable, and 5 being the most knowledgeable) before and after the training. On average, participants' knowledge of Advance Decisions went from 2.24 before the training to 4.19 afterwards. Similarly, on average, participants' knowledge of Lasting Power of Attorney rose from 2.41 before the training to 4.19 afterwards.

A further 3,790 health and social care professionals and charity staff have attended *My Life, My Decision* briefings and events.

Personal impact

The independent evaluators of *My Life, My Decision* commented: "It is of note that half the staff interviewed as part of this evaluation had decided to complete a planning tool themselves following the training, and reported having convinced family members to do the same."²⁵

Clearly healthcare professionals see the need to plan ahead, both for themselves as individuals and for their loved ones:

“It made me certainly think about things myself as regards to putting power of attorney in place...it certainly gives you food for thought because... you just don't know what is around the corner... It is something which I have passed on to family members. My own parents have both gone through the process – it's something which I am quite passionate about actually!”

“It has made me do one for myself and I have actually done one for my dad too ... well I'd had one done by a solicitor for my dad, and what I realised after the training was that the solicitor had completed the form wrongly and it wasn't what I wanted – so that was really important.”

Case Study:

Kate, Lancashire

“I was in the armed forces after leaving school, but I lost my job when it was discovered that I am a lesbian. I did various jobs over the years and entered a long-term relationship with my partner who lived in Lancashire. I moved to be with her and we had many happy years together until she passed away.

I decided to stay in the area as I had put down roots and had a good circle of friends. I’m in my late sixties now. I live alone with my dog for companionship, but I have a close friend with children and feel part of their family. I also have a relationship with another

woman who lives in Morecambe – we see each other two or three times a week. She has some health problems and is older than I am, so she relies on me increasingly for support. I have one brother who lives abroad - our relationship broke down many years ago.

I have arthritis and had three joint replacements which have been successful. In 2007 I was diagnosed with breast cancer. That was also treated successfully and I joined a survivors’ support group which encourages participation in exercise as a means of regaining health and wellbeing.

“I have strong views about not having male carers so I was glad of the opportunity to get that on the record.”

Janet talked to the group’s general meeting about the *My Life, My Decision* service and I decided to ask for a face-to-face meeting to find out more about ways of planning ahead in case I have health problems again.

Janet came to my home and as she talked I realised that there were lots of issues around end-of-life and care choices that I had no knowledge of. She left me some information to read and offered to come back and help with completing the forms if I needed that at some point in the future.

I also decided to discuss with my friend Sían as she is a specialist nurse for stroke patients and might be able to offer advice.

I had a couple of further conversations on the phone with Janet and we agreed that she would help me to complete an Advance Statement. I have strong views about not having male carers so I was glad of the opportunity to get that on the record. It took about two hours to complete the Advance Statement and I made copies and asked my friend Sían to keep a copy. I’ve decided that I will also make an Advance Decision in the near future.”

Understanding

Overwhelmingly the feedback has been that the training increased healthcare professionals' understanding of how to support their patients to plan ahead, and how Advance Decisions, Advance Statements and Lasting Powers of Attorney work in practice.

Participants commented:

“I was able to say to the ward staff that if somebody is saying they’ve got this document, we need to ask to see it, don’t just accept it at face value... Because people [staff] often are still a bit muddled with Enduring Power of Attorney, or just the Power of Attorney, and there’s a way of dealing with welfare benefits, which is by being the Appointee, so all those things are slightly different and I was able to be clear with people, it’s not about that, it’s about this.”

Palliative care social worker

“[My team] said they all found it very helpful. Because these tools are unfamiliar to the general population, we don’t often get asked about them, so people’s [the staff’s] knowledge base doesn’t get reinforced through use. I think having these sessions where people can really have an extended time to think about it helps with that...”

Palliative care social worker

“It gave me the baseline information, so I can now give that to clients, for them to be able to make an informed choice as to whether or not to progress any further. It has increased my confidence to be able to discuss it.”

Older people’s charity advice worker

Confidence

It gave participants the confidence to talk about end of life with their service users and patients as well as ideas about how to introduce the topic:

“It put me at ease a little bit, because I always used to feel that it was quite difficult to talk about it with my clients, but now it’s second nature. I’ve been able to embed it more into the assessment that we do, and feel a lot more confident.”

Age UK staff member

Signposting

It provided sufficient information for staff to be clear about the options available to their service users and patients and helped them to know where to signpost them for further information:

“I do a lot more signposting, so I don’t think it’s necessarily that I would fill in [the forms] myself, but I feel that I can talk confidently about it, and actually I have gone on to do some more work with Age UK and Compassion in Dying, because I do feel quite strongly about it. I think that [the *My Life, My Decision* service supporting people to complete planning tools] needs to be rolled out more.”

GP

Research and policy

Research

We commissioned two pieces of research through *My Life, My Decision*:

- Advance Care Planning and Muslim communities by the Woolf Institute – this was based on an analysis of two focus group discussions and a series of specialist interviews
- A literature review by the International Longevity Centre-UK on the impact of Advance Care Planning on care at the end of life.

Woolf Institute

We commissioned the Woolf Institute to produce a research-based report on Advance Care Planning and Muslim communities. Through four focus groups in London and Lancashire and specialist interviews with palliative care specialists in academia and healthcare, the report aimed to explore how Advance Care Planning is understood in Muslim communities and how organisations such as Compassion in Dying can improve engagement with the topic by Muslim communities. The report provided the following key findings and recommendations:

- In theological terms there is considerable support for Advance Care Planning and Muslim communities have a responsibility to stimulate discussions around the subject. Doing so through a range of initiatives that encourage conversation brings real benefit to themselves and their loved ones.
- The pattern of social migration for most Muslims means that understanding and decision-making are shared across generations. Information sharing and awareness-raising therefore needs to cover people of all ages as well as connect to grassroots communities.

- Charities such as Compassion in Dying have an opportunity to stimulate discussions and raise awareness amongst Muslims to further generate interest in this area. A series of short collaborative videos, explaining Advance Care Planning should be developed, as a resource for families. Access to specialist media and national events can bring these conversations straight into living rooms so that people of all ages, gender and ethnicity that may not be reached through more traditional places of worship can be reached. Face-to-face initiatives that bring in younger people both for themselves and for older family members would also advance these aims.

International Longevity Centre-UK

We commissioned the International Longevity Centre-UK, the leading think tank on longevity and demographic change, to conduct a review of the literature and data on the impact of Advance Care Planning on end of life care. In summary this found:

- For those with cognitive impairment and dementia, Advance Care Planning may reduce inappropriate hospital admissions and healthcare costs. There is evidence to suggest that Advance Care Planning should be promoted by active intervention of professionals early on in the care of someone with dementia, as well as by engagement with their families.
- Medical professionals and carers of those with mild or early stage dementia say planning in advance as much as possible is advisable. Carers stressed the importance of communicating Advance Care Plans to relevant care professionals and suggested that service providers should receive training in order to understand Advance Care Planning and the relevant documentation.



Case Study:

Joan and Carol, Oxfordshire

Written by Penny Beerling (pictured),
My Life, My Decision Project Coordinator

“When I first met Joan, she had recently been hit by a bus. Luckily she was not seriously injured, but this incident exacerbated Joan’s concerns for herself and her daughter Carol’s fears for her future. Joan experiences loss of short-term memory. She had a stroke that affected her right arm some years ago. This makes it harder to maintain the independent life that she wants. She is now more dependent on Carol and on friends to organise her life.

However, Joan remains fiercely independent and wants to retain as much of that independence as she possibly can.

At that first meeting, Joan was perturbed to think anyone should want to consider making decisions about their future health or welfare. She did not see why she wouldn’t be able to keep doing so herself. But as we talked about Joan’s health needs and preferences she began to realise how important it was to appoint someone she trusts to help her communicate her wishes if she could not speak for herself. She said that she often worries about being bed-bound, alone and in pain. She decided it was important to think about this while she still had “her marbles”.

Joan made it clear to Carol that she trusted her to make decisions about her medical treatment, because Carol has been the singular most reliable person in her life. None of this was new to Carol, but it was important to discuss. Joan decided she would appoint Carol as her Lasting Power of Attorney for Health and Welfare.

I asked Joan to think about what she would want if something happened to Carol which meant she was not able to make decisions for her. Joan decided, and Carol agreed, that Joan's grand-daughter should be the replacement Attorney. They discussed this with Joan's grand-daughter, so she understood what would be involved, and she agreed.

Joan and Carol are happy to share their story because they can see how important it is for people to get their affairs in order before anything happens. By appointing Carol as an attorney, Joan is much more likely to experience care and treatment at the end of life that is right for her: the

decision will be made by Carol, someone she trusts and who knows where she would like to live, who she would want to visit her and the kinds of treatment she would and would not want.

This case, like many, took time. But at the end of the process everyone is happy with what was achieved - it was time well invested. By creating a Lasting Power of Attorney, Joan can guarantee that Carol will have control over the decisions they both want for her when it counts.”

- Advance Care Planning provides the chance for better relationship building and can reduce future conflicts both within families and between families and care staff.
 - Healthcare professionals recognise the benefits of early discussions around Advance Care Planning, particularly so that people remain able to make decisions about preferences for the future. Early discussions also allow for Advance Care Planning to be done gradually before the onset of serious health problems. Many care professionals see Advance Care Planning as an important tool to enhance communication and aid decision-making.
 - Evidence indicates that Advance Care Planning can lead to cost savings for care providers, fewer unplanned or inappropriate hospital admissions and more people dying in their preferred place of care.
- i) Care in the later part of life is associated with high costs. A study assessing the impact of Advance Care Planning over a 12 month period in older patients found that it resulted in cost savings of £2,024 per person from avoiding unplanned hospitalisation.²⁶
- ii) A study found that in the last year of life, people with an Advance Care Plan had their chances of dying in hospital reduced by 70% and that dying outside hospital was associated with cost savings in the last 12 months of life of £3,569 per person.²⁷

Cost savings

When we apply this research to *My Life, My Decision* we can estimate that healthcare providers will save an estimated £1,521,733 over time as a result of the programme's work. These savings will come from a reduction in unplanned hospital admissions and a reduction in the chances of dying in hospital for the 475 people who have been supported to complete an Advance Decision, Advance Statement or Lasting Power of Attorney for Health and Welfare. At the time of writing a further 171 people who have been supported by *My Life, My Decision* have said they intend to complete an Advance Care Planning tool, if they do so the potential cost savings to healthcare providers of the project would rise to £2,071,270.

As the funding for *My Life, My Decision* was £1.1m this shows that within just two years the programme is yielding a return on investment. If we discount the costs of the programme during the start-up and wind-down periods and look purely at the running costs, then we can estimate that for an established service every £1 spent would result in cost savings of £2.24.

Literature is clear on the positive impact of Advance Care Planning and end-of-life discussions: in addition to increased satisfaction with overall care, people receive fewer aggressive medical interventions and have increased use of palliative care services.²⁸ All of these are proven to result in cost savings for healthcare providers, beyond those incorporated into the estimates above.

Policy work

Compassion in Dying has used learning from *My Life, My Decision* to influence numerous policy developments in the field of end-of-life care and mental capacity. Below are some examples:

NICE: Decision making and mental capacity – guideline scope

The National Institute for Health and Care Excellence (NICE) developed a draft guideline to help healthcare professionals provide support to people who may lack capacity to make decisions about their health and care. Compassion in Dying's response to the consultation on the draft guideline was heavily informed by our work in *My Life, My Decision*.

For example, our work with BAME communities has demonstrated the importance of supporting people who cannot speak, read or write English to communicate and showcased how alternative methods of communication (for example, visual aids) can be helpful for enabling them to make decisions.

We also provided comments on the cost-effectiveness of certain methods of support. Many methods do not require significant additional cost. For example, *My Life, My Decision* has demonstrated that for someone with fluctuating capacity or who takes medication, making sure that the visit takes place at a time that is right for them can have a huge impact on their ability to engage in decision-making.

Health Select Committee – investigation into end-of-life care

In June 2014 the Department of Health announced a new approach to caring for dying people in England during the last days of their lives. Following this, the Health Committee decided to take a broader look at the issue of palliative and end-of-life care.

Compassion in Dying's response focussed on the lack of coordination around end-of-life care policies and the limited information and awareness of Advance Care Planning both amongst the public and healthcare professionals. *My Life, My Decision* demonstrated possible solutions to these concerns.

The Committee agreed with Compassion in Dying regarding staff training and awareness-raising to make sure healthcare professionals can positively engage people in discussions and decisions about their care. The report also referenced statistics from our polling and Information Line monitoring that highlighted the need for more public awareness and information on people's rights to plan ahead. *My Life, My Decision* was also referenced in the report as an example of a project that was aiming to address some of these concerns.

London Assembly Health Committee – investigation into end of life care

This investigation was conducted in response to discussions with other stakeholders that stated the quality of end-of-life care in some parts of London was amongst the worst in the country.

Compassion in Dying submitted written evidence to this investigation in November 2015, focussing particularly on the work and learning from *My Life, My Decision* in East London and

Hillingdon. Our response addressed the challenges of ensuring good quality end-of-life care for older Londoners who live alone; additional challenges faced by people from BAME and LGBT* communities; the support necessary to make sure more people were able to die in the place of their choice; the effect of diagnosis on the quality of end-of-life care; how well-equipped London's healthcare providers are for dealing with an ageing population; and finally what the Mayor can do to ensure better end-of-life care for Londoners.

Conclusions and recommendations

Feedback from the individuals, healthcare professionals and community organisations who have engaged with *My Life, My Decision* shows that all elements of the service: one-to-one support to plan ahead for their future treatment and care; training for professionals; awareness-raising; community engagement; and the development of tailored information resources, **are highly valued by those that have used them.**

Academic research also indicates that Advance Care Planning results in: better, person-centred care; improved relationships and communication between patients, families and healthcare professionals; and reduced costs for healthcare providers.

Learning from *My Life, My Decision* has shown that the following actions need to be taken to make sure people are able to plan ahead to get the treatment and care that is right for them.

Training for professionals

Health, care and charity professionals who attended *My Life, My Decision* training rated it highly, and reported that **they felt more comfortable about talking to patients about their preferences for their health and care at the end of life** as a result of the training.

Recommendation:

- Commissioners and Health Education England should ensure that all healthcare professionals are provided with effective training to have the knowledge, understanding and confidence to provide people with information, and if necessary support, to plan ahead for their future treatment and care.

Compassion in Dying will work with Clinical Commissioning Groups and Strategic Clinical Networks to provide our CPD-accredited training to professionals on the Mental Capacity Act and Advance Care Planning.

Public awareness and education

Public awareness of the options for planning ahead to set out their wishes for treatment and care is very low. **People need to know they can plan ahead in order to do so.**

Recommendations:

- Much more needs to be done to educate the public on the benefits of Advance Care Planning and the reasons why someone might do this. Government, health and social care providers, and charities should work together to raise awareness.
- Awareness-raising should target different groups, including those who are particularly likely to benefit from planning ahead for their future treatment and care (such as those with long-term conditions, or who are facing a likely loss of capacity) or those who disproportionately underuse healthcare services at the moment.
- Across all of the groups we worked with through *My Life, My Decision*, there was a sense that whilst older people are perhaps most in need of support to plan ahead, everyone at any age would benefit from having conversations about their wishes for care and treatment. Going forward, more intergenerational work should be undertaken.

Compassion in Dying will build on learning from the My Life, My Decision programme to research these issues and launch a public campaign to raise awareness of how to plan ahead by setting out your wishes for treatment and care, the reasons why you might want to plan ahead and the benefits of doing so. We will also seek to raise awareness among groups facing a likely loss of capacity of the benefits of engaging with Advance Care Planning before the need to do so becomes urgent.

Tailored support services for individuals and communities

The one-to-one service provided by *My Life, My Decision* was largely used by those who needed this level of support, and who would not have been able to set out their wishes for treatment and care without it. The value placed on the service by the people who used it was clear; **it gave them peace of mind, and a strong sense of empowerment.**

Similarly *My Life, My Decision* showed there is huge value in reaching out to diverse and minority groups and enabling them to have a conversation about and record their wishes for treatment and care. Investing time and resources in this type of work has a hugely **positive impact on people being able to understand their rights to make decisions about their health**, and to receive the treatment and care that is right for them.

Recommendations:

- Different people have different needs and require different approaches in order to think through and set out their wishes for treatment and care. More research is required to identify those needs so that services can be developed to address them and ensure everyone in society has access to Advance Care Planning and the benefits it brings.
- *My Life, My Decision* provided a valuable opportunity for exploring new ways of working with people and communities, supporting them to be placed at the centre of their care. Across society, different approaches to raising awareness and providing support to plan ahead for treatment and care should be developed and tested.

- Tailored services that meet the needs of people who are particularly likely to benefit from Advance Care Planning (such as those with long-term conditions, or who are facing a likely loss of capacity) or people who may face challenges when accessing health services (such as BAME and LGBT* communities) should be funded and developed.

Compassion in Dying will seek to continue working with local partners to provide face-to-face support to plan ahead for those that need it, and to develop and deliver new ideas and approaches to supporting people and communities with Advance Care Planning.

Commissioning

Decisions on what services to commission have **huge potential to improve the information and quality of support people have to engage with Advance Care Planning**, as well as the quality of care they actually receive.

My Life, My Decision has demonstrated that partnerships between community organisations and clinicians can work effectively. Healthcare professionals valued both our training, and having a trusted local service they could signpost patients to for support with Advance Care Planning. The reality for many professionals is that they do not have the time to provide dedicated support to patients to plan ahead for treatment and care in the way the *My Life, My Decision* service did.

Recommendations:

- Commissioners should commission multi-layered services providing awareness-raising in the community; support to individuals and communities for considering priorities for care and completing Advance Care Planning documents if desired; and training for professionals. This kind approach where the skills and resources of clinicians and community organisations are put to best use would facilitate the delivery of person-centred end-of-life care, and deliver cost savings for healthcare providers.

Learning from *My Life, My Decision* demonstrates that its multi-layered approach to planning ahead care and treatment at the end of life had real value, both for the people who used the service and for the healthcare and community services that support these individuals. The different elements of the service: awareness-raising; engaging communities; providing one-to-one support and training professionals, also worked to reinforce each other.

Replicating this multi-layered approach would go a significant way to achieving the Government's national Commitment for end of life care,²⁹ which states that people will be given the opportunity and support to:

- Have honest discussions about their needs and preferences for physical, spiritual and mental wellbeing to allow them to live well until they die
- Make informed choices about care including access to clear information on quality and choice in end-of-life care

Wider rollout would also help healthcare providers meet the CQC's recent recommendations for improving end-of-life care, particularly for diverse and minority communities.³⁰

Compassion in Dying will share learning from the My Life, My Decision programme widely, and will seek to work with commissioners, stakeholders and local partners to develop similar services across England.

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.

Lasting Power of Attorney for Health and Welfare

A Lasting Power of Attorney for Health and Welfare allows a person to give someone they trust the legal power to make decisions on their behalf in case they later lack capacity and cannot make or communicate a decision about their health or care for themselves.

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.

About Us

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

Acknowledgments

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References

- ¹ The Government's response to the Review of Choice at the End of Life (2016)
- ² Choice in End of Life Care Programme Board (2015) What's important to me: A Review of Choice in End of Life Care and House of Lords Select Committee on the Mental Capacity Act 2005 (2014) Mental Capacity Act 2005: post-legislative scrutiny
- ³ Literature review on the impact of Advance Care Planning – produced by the International Longevity Centre-UK on behalf of Compassion in Dying (2016)
- ⁴ YouGov (2014) Who do you want to make decisions for you at end of life?
- ⁵ House of Lords Select Committee on the Mental Capacity Act 2005 (2014) Mental Capacity Act 2005: post-legislative scrutiny and Compassion in Dying (2015) Plan Well, Die Well
- ⁶ Care Quality Commission (2016) A different ending: Inequalities in end of life care
- ⁷ Literature review on the impact of Advance Care Planning – produced by the International Longevity Centre on behalf of Compassion in Dying (2016)
- ⁸ YouGov (2015)
- ⁹ YouGov (2011) Legal health rights at end of life
- ¹⁰ YouGov (2014) Who do you want to make decisions for you at end of life?
- ¹¹ Compassion in Dying monitoring of service users (2011)
- ¹² For example, the Opening Doors London Evaluation (2015) reports “Even within a dedicated LGBT* service, many members remain cautious about disclosing personal details. While the 18% of members who opt for the ‘prefer not to say option’ on the initial application form might appear high, research consistently suggests that approximately a quarter of people do not welcome a monitoring question regarding sexual orientation.”
- ¹³ Office for National Statistics (2015)
- ¹⁴ Independent Age (2016) We need to talk about caring: dealing with difficult conversations
- ¹⁵ Care Quality Commission (2016) A different ending: Inequalities in end of life care
- ¹⁶ *ibid*
- ¹⁷ *ibid*
- ¹⁸ Twocan (2016) Independent evaluation of the My Life, My Decision service
- ¹⁹ Care Quality Commission (2016) People from Black and minority ethnic communities – A different ending: Inequalities in end of life care

- ²⁰ *ibid*
- ²¹ Stonewall (2011) Lesbian, Gay & Bisexual People in Later Life
- ²² NHS England (2015) NHS drive for action to tackle trans inequalities <https://www.england.nhs.uk/2015/06/drive-for-action/>
- ²³ Select Committee on the Mental Capacity Act, House of Lords (2014) Mental Capacity Act 2005: post-legislative scrutiny
- ²⁴ Care Quality Commission (2016) A Different Ending: Inequalities in end of life care
- ²⁵ Twocan (2016) Independent evaluation of the My Life, My Decision service
- ²⁶ Baker, A., Leak, P., Ritchie, L., Lee, A., & Fielding, S. (2012) “Anticipatory care planning and integration: a primary care pilot study aimed at reducing unplanned hospitalisation.” *British Journal of General Practice*, 62(595): e113-120.
- ²⁷ Abel et al. (2013) “The impact of advance care planning of place of death, a hospice retrospective cohort study”, *BMJ Supportive & Palliative Care*, 2013; 00:1–6
- ²⁸ Brighton L, Bristowe K (2016) “Communication in palliative care: talking about the end of life, before the end of life”, *Postgrad Med J*, 2016 92: 466-470
- ²⁹ The Government’s response to the Review of Choice at the End of Life (2016)
- ³⁰ Care Quality Commission (2016) A different ending: Inequalities in end of life care

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