My Life, My Decision: Planning for the end of life
A new approach to engaging people and communities

SUMMARY REPORT
January 2017
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 was launched 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\(^1\), with the aspiration that the programme would test new approaches to engaging members of the public and professionals with early Advance Care Planning.

My Life, My Decision 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.

The quotes used throughout this report are from our service users and others who accessed the programme. This Summary Report covers activities delivered during the full programme period, July 2014 to October 2016.
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 communities

Our recommendations are set out in more detail on pages 19-21 but in summary the experience of My Life, My Decision shows a need for:

- 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
- tailoring services that meet the needs of different groups who face challenges when accessing services
- commissioning local support services for individuals alongside training on Advance Care Planning for professionals
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.

Research 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.

Activity and impact: summary

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

Supported 1,251 people

Delivered 1,798 one-to-one sessions

Helped complete 767 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

Reached 7,113 people in their communities through 574 talks and awareness-raising events

Provided accredited training to 143 health and social care professionals, 157 Age UK staff and volunteers and 190 community stakeholders

Raised awareness among a further 4,351 health and social care professionals and charity staff through briefings and awareness-raising events

83% of people supported to make an Advance Care Planning document said it had reduced their worries about the future

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Activity and impact: raising awareness

Need
It is clear from the My Life, My Decision programme, Compassion in Dying research and other sources that public awareness of the ability to plan ahead is lacking. For example, 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 of planning ahead we know that only 4% of adults have made an Advance Decision or a Lasting Power of Attorney for Health and Welfare.

Activities and impact
Through a community based approach, 7,113 older people in their communities were reached through 574 talks and local awareness-raising events. People who heard about My Life, My Decision through events and briefings were also able to signpost others to the service.

“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.”

We learned that some groups are more likely than others to want to make some form of Advance Care Plan. For example, 21% of our service users in the second year of the programme were in the early stages of dementia. People diagnosed with dementia and their carers were particularly receptive to our planning ahead services and saw it as a matter of urgency as they were facing the prospect of losing capacity to make decisions in the relatively near future.

Activity and impact: supporting individuals with advance care planning

Need
Different people have different needs, which is why there continues to be a strong push for care to be personalised. Advance Care Planning is no different.

Moreover, for many people, the process of thinking through their wishes, discussing these with their family, and then recording them, is not easy. 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.

Activities and impact
My Life, My Decision provided direct, face-to-face support to 1,250 people to think about their wishes for end-of-life care. We delivered 1,798 one-to-one sessions and 767 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 service was largely used by people who needed support and could not have completed a planning tool without it. The value placed on the service by the individuals involved was clear. Of clients who completed an Advance Decision, Advance Statement and/or Lasting Powers of Attorney for Health and Welfare, 83% said it had reduced their worries and given them greater peace of mind and a strong sense of empowerment.

“…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…”
Case Study: Phyllis

“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 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.”
Activity and impact: reaching and engaging with minority communities

BAME and faith communities

Need
We know 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 Care Quality Commission (CQC) has 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.

Activities and impact
We undertook a range of activities in partnership with organisations that already had relationships with faith and BAME communities, which helped us to get a better understanding of their needs and to establish a relationship of trust.

We adopted diverse 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 in collaboration with Age UK Lancashire. We also worked in partnership with SubCo to deliver workshops about planning ahead to older men and women from the Asian Subcontinent. All of the participants in the BAME workshops reported feeling more confident discussing their end-of-life wishes and 83% of participants across the two women’s groups chose to make an Advance Statement.

We learned that developing alternative ways to enable people to express their wishes, such as providing people with a way to visually express their views so that they can be translated into written format was particularly valuable. The programme demonstrated 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.

“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)
LGBT* communities

Need
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.

Activities and impact
We worked with Ambassadors for Opening Doors London, a charity providing information and support services with and for older LGBT* people to develop a new tailored publication on planning ahead.

“...There is a real need for information about planning ahead for the end of life to be tailored to the LGBT* community so that...we know how to retain control of decisions about how we are treated at the end of life...”
Opening Doors London Ambassador

We have learned 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.

*The asterisk indicates the full spectrum of non-binary and gender nonconforming individuals who identify under the very diverse umbrella term of trans.

Activity and impact: training and engaging with professionals

Need
Whilst healthcare professionals play an important role in helping people understand their rights and the medical implications of any conditions they may have, they have limited time to support individuals to plan ahead. My Life, My Decision, demonstrated how clinicians and community organisations can work effectively together.

Activities and impact
We provided Continuing Professional Development (CPD) accredited training to 143 health and social care professionals, 157 Age UK staff and volunteers and 190 community stakeholders. A further 4,351 health and social care professionals and charity staff have attended My Life, My Decision briefings and events. On a scale of one to five, workshop participants reported that their knowledge of and confidence to use Advance Care Planning documents went up from 2.24 before the training to over 4 afterwards.

Professionals who engaged with the My Life, My Decision service recognised that the ability to refer patients to a community service that could support them with Advance Care Planning helped limit the many demands on their time and ensured patients received high quality support from a trusted local service.

“I do a lot more signposting...I feel that I can talk confidently about it...I think that [the My Life, My Decision service supporting people to complete planning tools] needs to be rolled out more.”
GP
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.

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 GPs. 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.”

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

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:

- 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.  
- 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 of £3,569 per person.

My Life, My Decision supported 669 people to complete an Advance Care Planning document and at the time of writing a further 83 people are in the process of doing so. When we apply the above research to the programme, we can estimate that healthcare providers will save an estimated £2,407,160 over time from a reduction in unplanned hospital admissions and a reduction in the chances of dying in hospital.

My Life, My Decision received £1.1m and within just two years the programme is yielding a return on investment. For every £1 spent on the project we estimate that £2.09 will be saved over time and if we look purely at the project running costs, we estimate that for an established service every £1 spent would result in cost savings of £2.71.

Literature is clear on the positive impact of Advance Care Planning: in addition to increased satisfaction with overall care, people receive fewer aggressive medical interventions and have increased use of palliative care services.

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.
Public awareness and support

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 would not have been able to set out their wishes for treatment and care without it. People valued the service because 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 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:**
- People have different needs and priorities when thinking through their wishes for treatment and care. More research is required to identify those needs so that everyone in society has access to Advance Care Planning services and the benefits it brings.
- My Life, My Decision explored new ways of working with people and communities, supporting them to be placed at the centre of their care. Different approaches to 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.
Training for professionals

Health, care and charity professionals who attended *My Life, My Decision* training reported that they felt more comfortable 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 trained to provide people with information and 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.

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.

**Recommendation:**
- 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 should be commissioned. Combining the skills and resources of clinicians and community organisations would facilitate the delivery of person-centred end-of-life care, and deliver cost savings for healthcare providers.

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.

Final thoughts

Learning from *My Life, My Decision* demonstrates that its multi-layered approach to planning 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, 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.

Most importantly, these efforts will contribute to achieving a world in which each individual gets the end-of-life care that is right for them.
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.

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.

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

Resources
As part of the My Life, My Decision programme we produced the following new resources:
• Your Treatment and Care: Planning ahead for the LGBT* community
• Your Treatment and Care: Planning ahead for the Jewish community
• Tea, Talk and Samosas: Planning ahead for the end of life with the South Asian community
• Tie your camel first: Planning ahead for the end of life with the Somali community
• A new Advance Statement form
• A planning ahead leaflet in six Asian community languages
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@compassionindyng.org.uk

Acknowledgments
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References
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