

**Compassion
in Dying.**

Your end of life. Your way.

Advance Care Planning in Newham



August 2023

Contents

- 3 Background and Conclusions**
- 4 Five approaches for a successful advance care planning strategy**
 - 4 Community leadership is vital for raising awareness of advance care planning
 - 5 People need clear messages on advance care planning
 - 5 Using a “What I would want...” wall helps people think about what matters to them
 - 6 Starting conversations with an Advance Statement helps people understand what advance care planning is all about
 - 6 Amplifying people’s voices helps professionals and the public to understand what matters to people at the end of life
- 7 People’s experiences of advance care planning and end-of-life care in Newham**
 - 7 Faith, community and culture play an important role in advance care planning
 - 9 People were comfortable talking about advance care planning, even if they weren’t comfortable talking about dying
 - 10 Information and support needs to be accessible in different languages and mediums - not doing this creates inequity
 - 10 People want the opportunity to plan ahead as early as possible
 - 12 If people do not trust ‘the system’ to meet their health and care needs, planning for future care is not seen as a priority
 - 12 People are often not aware that an advance care plan can be made for free, and that a solicitor is not needed
 - 13 People frequently do not know how decisions are made if someone lacks capacity
 - 13 The role and responsibilities of family play an important part in advance care planning
 - 14 In order to make informed decisions, people need to better understand the language used in advance care planning and end-of-life care
 - 14 Health and care professionals want to feel confident supporting their patients with advance care planning
- 16 Annex: Resources to support professionals to have advance care planning conversations**

Background and Conclusions

In April 2021, Compassion in Dying was awarded a grant from Newham Council to work with the Adults and Health Commissioning Team and other Newham-based organisations, including local community, faith and voluntary sector groups, to provide information, support and training on Advance Care Planning.

Advance Care Planning is a voluntary process of person-centred discussion between an individual and their care providers about their preferences and priorities for their future care, while they have the mental capacity for meaningful conversations about these.

The outputs of these discussions may include an advance statement; an Advance Decision to Refuse Treatment (ADRT); the nomination of a Lasting Power of Attorney (LPA) for health and welfare and/or context-specific treatment recommendations such as emergency care and treatment plans, treatment escalation plans and cardiopulmonary resuscitation decisions.

Adapted from the Universal Principles for Advance Care Planning 2022

For 12 months from April 2022, we worked with a range of community organisations and the people they support to learn about their experiences of advance care planning. We completed awareness raising workshops and webinars for Newham residents and health and care professionals. During this time, 32 events were held, reaching approximately 700 residents and health and care professionals in Newham.

“I feel completely better, but I’m really in this place of like, you have to prepare for the future or for dying. So I’m so thankful that you guys had this service and that, you know, I’m coming this day to find out more information because it’s exactly what I needed. I’ve had conversations with people about what I would want if something is serious and I wasn’t really able to make decisions for myself. Now I can write it down and just in case anything happens, it’s there. It makes me feel a lot more confident in this health journey that I’m taking.”

“You see we don’t think about these things until it’s too late, after your meeting we thought we need to do something about this, so we completed our forms and gave two to a family friend as well as they are in the same situation as us. And the GP was so helpful, he said it was good we had it on our file and shared it so everyone has something to refer to – we are really pleased.”

Compassion in Dying has had an ongoing relationship with the London Borough of Newham since 2016. It is one of the most diverse areas in the UK. Over two hundred and forty languages are spoken and seventy percent of the population are from black and minority ethnic groups. It is apparent that there are significant barriers that often prevent the majority of the people we met from making advance care plans. As a result, these individuals consistently voiced concerns about their wishes, and particularly their faith and culture, not being known about when health and care decisions need to be made. If we are serious about respecting what matters to people and helping them make informed decisions, then advance care planning and the conversations it opens up are essential.

In order to address the issues that Newham residents told us about, we need to increase the confidence of people working in health, care and communities to have conversations and find ways to make advance care planning more accessible to all. Without this, health inequalities will continue to grow. It will continue to be mainly those who know they have choice with access to information and resources who are able to plan for and receive treatment and care in line with their wishes. Moreover, if we want to support more people to have positive experiences at the end of life, we all have a responsibility to make sure the law around decision-making at the end of life is known about and followed.

This report, prepared for Newham Council at the end of the project, highlights what we have learned from the residents in Newham about their end-of-life care experiences and provides reflections on ways to continue this vital work.

With thanks to the Newham residents who contributed their time to help with this work especially Carers First, Chinese Association, Newham co-production forum (Adults), Disability Reps forum, Heal Together, Newham Older People’s Reference Group, Senior Learning Disability Carers, and Subco Trust.

Five approaches for a successful advance care planning strategy

External research and learning from Compassion in Dying's information line have both consistently demonstrated that if people are able to plan ahead for the end of life, and are supported to do so, it can help individuals to have "good death"; in a place they choose, with the people who matter, having the care and treatments that they want, and not the ones they don't. We also know that talking and planning for the end of life can support a loved one's experience of grief. Despite this, people's awareness of their rights to plan ahead and their confidence to start these conversations remains low.

With this in mind, the project aimed to offer Newham residents the opportunity to learn more about advance care planning so they could understand how it might help them in the future. The project did not aim to enable everyone to complete an care plan, such as a Lasting Power of Attorney for Health and Welfare, an Advance Statement and/or Advance Decision to Refuse Treatment, rather it hoped to ensure people could make an informed decision about whether taking part in advance care planning was right for them. It was clear early on that there was appetite amongst Newham residents to learn more about this.

We already knew that inequity in levels of advance care planning exists because much of the information and support available does not meet the needs of everyone who wants to plan ahead. In order to learn more about this we focused on collaborating with communities who face barriers such as social isolation, digital exclusion, language barriers and poverty. We specifically aimed to work with Afro Caribbean people, the LGBTQ community, people with learning disabilities, carers and people recently diagnosed with dementia who were identified by the Council as traditionally having a low uptake of advance care planning.

Below are five approaches that we have identified as helpful for creating a space for these important advance care planning conversations to take place.

Community leadership is vital for raising awareness of advance care planning

The direct and personal involvement of the Adults & Health Commissioning team in developing and implementing the Council's Advance Care Planning strategy contributed greatly to the collaborative approach adopted for this project. As trusted leaders within the community, their presence and visibility at local events alongside the Council's Reward and Recognition Scheme played an essential part in demonstrating to Newham residents how valued their time, experiences and insights were and how much work still needed to be done to normalise advance care planning. In short, the Commissioning team provided a valuable stamp of authority on the project.

"I was surprised, because normally they wouldn't like to attend a workshop like this. I think this time the Council's reward scheme made them willing to stay"

Community leaders have many competing priorities and we heard that end-of-life care is sometimes considered "irrelevant to the people we support" or "too depressing" to discuss. However, when a strategy on advance care planning is led by a person of influence, with a commitment to regularly and meaningfully involving community members and a willingness to try and test a variety of approaches for raising awareness of advance care planning, true progress becomes possible. Moreover, the diversity of experience gathered from across the Council's 'task and finish' groups which also included residents and local voluntary and community organisations helped foster momentum and a shared vision between the Council and Newham residents for the work undertaken in the borough.

The Council's leadership of the Advance Care Planning strategy has also meant that efforts to embed it within the borough's case management system are now underway, thereby helping to raise awareness and provide more opportunities for conversations in a systematic way.

People need clear messages on advance care planning

Clarifying in simple language what advance care planning is all about, is vital for successfully engaging communities. Equipping voluntary and community groups with key messages to use when introducing the subject of advance care planning to the people they work with, meant that even those who worried about their lack of confidence or knowledge were still able to share information on advance care planning.

“I think a leaflet is really good way to start the introductory sensitive conversation. You can hand it over and say, just go away and think about it, you know, and use these resources, think about it in your own time and then you can get back in touch for more help if you want”

We developed an A4 sheet of ‘top tips’ that could be adapted alongside Newham residents in order to make it relatable in different communities. In doing so, attention was placed on using positive language (e.g. “important” not “difficult” conversations); normalising advance care planning as something available to everyone, not just for people who are unwell or approaching end of life; emphasising the benefits such as how planning opens up conversations, makes things easier for loved ones, and conveys personal information on faith and culture to clinicians; and on clarifying that plans can be made for free/or at low cost without the need for a solicitor. These top tips also sought to address known misunderstandings and incorrect assumptions about advance care planning, which was identified as a real need throughout the Newham community.

See Annex for a list of the resources we developed through the project.

Using a “What I would want...” wall helps people think about what matters to them

The “What I would want...” wall, based on the “Before I die...” wall first developed by Candy Chang (<https://beforeidieproject.com/>), proved to be a simple and effective tool for enabling people to share what matters to them at the end of life. By inviting members of the public to pin a card to a wall detailing what would be important for people caring for them to know about if they were not able to make and communicate decisions for themselves, we were able to capture what good end-of-life care means to people in the community.

“... to die at home not hospital”
“...Halal food”
“... to have video calls with my family abroad”
“...someone who speaks my language”
“...for my son to make decisions for me”
“...no not be fed by a tube and to not be resuscitated”



The wall provided an opportunity for people to share what they wanted and what was important to them and their identity, which often naturally led on to the kind of things they didn't want. Hearing and seeing what other people shared, enabled people to think more deeply about their own needs. Written forms and legal jargon can be intimidating for some people so having something simple that everyone could contribute to (with help of interpreters when needed) provided an engaging and positive way in to discussions.

Starting conversations with an Advance Statement helps people understand what advance care planning is all about

We found that starting conversations about advance care planning by using an Advance Statement to focus on what matters most to people helped to build trust with and interest in the topic of planning ahead. Furthermore, the questions and prompts in the Compassion in Dying Advance Statement form also opened up helpful conversations about how likely wishes are to be followed, what support people need to make fully informed decisions and how to document these choices.

These conversations were also valuable for discussing the practical aspects of end-of-life care and for explaining that not all care and treatment preferences (for example being cared for at home) could be guaranteed. These honest conversations about what to expect in reality have proven to be vital for enabling people to make informed decisions about what care and treatment is right for them.

Amplifying people's voices helps professionals and the public to understand what matters to people at the end of life

We wanted to ensure that Newham residents' voices – professionals and lay people - were front and centre of all initiatives to get people thinking about advance care planning. At the start of the project, a questionnaire was disseminated among health and social care professionals, commissioned services and voluntary and community groups to gather baseline information on their knowledge of and confidence with advance care planning. Responses were received from staff involved in a variety of roles including finance and property, health and social care, social prescribing and safeguarding. While many of the respondents were aware of the various advance care planning tools available, very few had experience of using them to support people in their community. However, it was noteworthy that a majority of the respondents, holding diverse responsibilities within the borough, said further training and guidance on advance care planning would be welcomed. The diversity of the respondents and their appreciation of the topic clearly reflected the principle that advance care planning ought to be everyone's business.

We then worked with the Council's co-production team, local voluntary organisations and Newham residents to adapt a range of awareness-raising activities to reflect the unique experiences, preferences and perspectives of the residents. For example, the Chinese Association explained to us how the Mandarin speaking community in Newham preferred community events to webinars. We also ensured that any training for health and care professionals contained numerous case studies of the lived experiences of Newham residents.

A series of webinars were delivered in response to the questionnaire, integrating learning from Newham residents through quotes and audio recordings. The webinars covered *Advance Care Planning and The Mental Capacity Act* and *How to have Important Conversations*. The final webinar was a multidisciplinary event and provided an opportunity to collaboratively develop practical solutions on advance care planning that can be integrated into day to day practice. A range of practical resources were developed for health and care professionals.

The webinar attendees included occupational therapists, Social Workers, Senior Frailty Care Co-ordinators, Nurses, Resettlement Managers, Housing Managers, community group leaders and Social Prescribers. When asked if there were opportunities to raise the topic of advance care planning and what they would do with the learning the responses included:

"I am much better placed in the Primary Care Network to raise awareness in the community as an occupational therapist"

"Yes I can definitely raise this in our frailty service"

"I will provide the patient with information on making an Advance statement a link to the 'My wishes' website depending on the persons capacity"

"I would do a home visit, have a discussion and complete the document"

"I will be informing friends, colleagues and clients about Advance Care Planning"

"I will share this with the service and staff so that people are made aware of the support and advice available"

People's experiences of advance care planning and end-of-life care in Newham

The conversations we had and the feedback we gathered from Newham residents and health and care professionals provided rich and diverse insights into how advance care planning is perceived and how the Council's Advance Care Planning strategy could evolve in the future. People told us about their experiences and what they feel needs to be done in order to raise awareness about how to access treatment and care in line with their wishes.



Faith, community and culture play an important role in advance care planning

For some Newham residents, their cultural or religious values made it uncomfortable to talk about their deaths. For others, discussing death is seen as likely to extinguish hope, inviting bad luck or causing anxiety.

"It's not up to us to decide when or how death happens"

Other Newham residents shared that it was important to consider in advance how faith influences the choices we make about care at the end of life before it is too late.

"... The patient, you know, can make an inquiry and question religiously, is it something that we should be doing? What are the implications? And when it comes to making that decision of switching it (artificial ventilation) off, religiously, can we do this?"

One resident explained how a decision had to be made about switching off her mother's ventilator and how this was a religious issue but one that was never talked about. She explained that the guilt and trauma she still feels may have been lessened if such things had been discussed while her mother was well.

A reluctance to discuss end-of-life care was also noted by health and care professionals. One social prescriber explained that:

“It’s part of the risk assessment that questions on advance care planning are asked. And most of them usually decline to answer or they say I don’t wish to continue or some say they don’t want to talk and some say their family have put things in place.”

Nevertheless, Newham residents believed it was important to explain the value of planning using the right language and the right tone.

“In a lot of ethnic groups it’s still very difficult to get elders to talk about these things, for example appointing their children to be responsible for their health and wellbeing... it’s really hard, I know this because I am from the West Indian community and I know that many parents are very reluctant to talk about anything to do with end of life and it can be problematic as the problems that they face in the future can be monumental”

“We need to think about the concepts in other languages - how would these phrases be said – and how would we modify them?”

“With parents, it will help to chat about this in a light-hearted way”

It was clear that one size would not fit all. As a member of the Co-Production Forum said:

“You just gotta get out there and try every which way! Some people like to plan and some don’t and that’s ok, but we must give it a go”

Newham residents suggested using real life examples from their community of what happens when people don’t plan as a helpful way of enabling people to fully understand the benefits of advance care planning.

“My dad died a few weeks ago and we didn’t have any paperwork in place. I feel it caused a lot of additional stress and arguments between our family. I never knew things like this [Advance Statement] existed, it would have made things a lot easier”

“My mother was admitted to hospital in an emergency. She wasn’t able to communicate. The doctors made decisions about her treatment. I don’t think it was what she would have wanted. It’s important that residents know about advance care planning”

Focusing on making it easier for their families was a message that resonated with residents of Newham:

“You put others and other people’s needs first, you can’t think about yourself and so don’t make plans for ourselves...but then what would happen to our loved ones if something happens to us? How do we deal with their fears and stuff? So you see we don’t think about these things until it’s too late- that’s not ok”

People were comfortable talking about advance care planning, even if they weren't comfortable talking about dying

Conversations with Newham residents reflected previous learning that many people understand conversations about planning for their health and conversations about death to be different things.

We often observed that a workshop on "Planning ahead for future care and treatment" was much more likely to engage community groups than "Planning for end-of-life decisions" or "end-of-life care." Also, people automatically associated end-of-life with wills, funerals and bereavement rather than care. However, once they understood what advance care planning was about, they became more interested in talking about end-of-life care in detail.

Importantly, people needed a safe, non-judgmental space with a focus on what matters to them in order to discuss end of life wishes. Workshops with community groups where people were already at ease, provided an opportunity for people to share their own experiences and openly talk about what they would and wouldn't want if they were unwell.

"In 2007 I had the beginning of my own health scare. I actually think I'd been unwell for a long time...Brain fog, stomach issues, whatever, just small things. You don't really think about it. Um, and then I started to notice that my muscles were getting weaker and I was struggling to walk and slurring my words. It was so scary. So I didn't understand what was happening. And that's when I really just became aware of like, you can be healthy one moment or think you're healthy, and then things can completely change. And I kind of just took this journey of trying to see doctors and specialists and whatever and trying to get my health back on track. I feel amazing now. I have a baby now and I'm so grateful, you know, and I still have so many things I want to do. I feel completely better, but I'm really in this place of like, you have to prepare for the future or for dying. So I'm so thankful that you guys had this service and that, you know, I'm coming this day to find out more information because it's exactly what I needed. I've had conversations with people about what I would want if something is serious and I wasn't really able to make decisions for myself. Now I can write it down and just in case anything happens, it's there. Makes me feel a lot more confident in this health journey that I'm taking"

"I was nearly dying in a hospital and at the time, I remember – I will never forget – feeling so shocked – there was this whole machine on the front of me ...after that, I feel it is such a good idea to make this care plan because no one knows how long I'm going to live with this world. The Quran says every soul will have the test of death."

The conversations about planning also highlighted the practicalities that need to be considered when setting out individual care preferences.

"I think it's really important to have wishes recorded, my son says he wants to die at home and he doesn't want to go into a hospice or into hospital, but he would like me to care for him at home. But for me as a disabled person, I think I would need support... we need to talk about this..."

The Covid pandemic had also led many people to consider their care and treatment wishes but many lacked accurate information on how to go about it, as explained by this resident:

"Well, I'll be honest with you, for a long time I had never thought of making a plan. But most recently, with the news about Covid you find people want to make things easier for loved ones... but it's very difficult, all these legal things like LPAs"

Newham residents also shared that they would welcome these conversations with health and care professionals:

"If they (doctors) had, you know, spoken to me perhaps in a gentle way and said, look, we're trying to do this for your mom, but in reality, this is what could happen. I mean, you need to be aware of it so you can discuss options. I think maybe I would have been upset initially, but I think it would have been a positive thing to do, that professionals could have done."

Information and support needs to be accessible in different languages and mediums - not doing this creates inequity

Any genuine commitment to providing information on advance care planning needs to be met with investment in developing resources to meet the diverse needs of all communities who want such information.

As many Newham residents speak English as a second language, audio-visual information on advance care planning and end-of-life care more broadly was considered more accessible than written formats. People told us repeatedly, for example, that short videos that could be shared on WhatsApp would be far more useful than a leaflet.

“Because paper they can just put away... ok later on I will read. But when its video they can see and hear it, it’s a very good idea.”

“We have been working hard over the last year and have had lots of feedback about how empowered members of the Disability Forum feel. But there is a big underlying issue relating to language and digital barriers which means that in practice, advance care planning may remain in a visionary world.”

“Leaflets can be useful but only if they are in a language they can understand. They need to be published in 4-5 languages at least.”

“Everyone’s talking digital. And it’s funny because even my own mum, she was complaining this morning, she said to me she missed an appointment and she said the hospital have rung her and she said well I never received a letter because usually she receives a letter, takes a copy of it and sends it to me. So I’m aware that she’s going and I then kind of like make time to read it to her. But she received a text. Now she wouldn’t look at text. She can’t read texts. So we have the these obstacles.”

Newham residents shared that translated materials were needed for a wide range of end-of-life care topics, not just to support the person, but for their families too:

“There are a lot of misconceptions about this (DNACPR) in our community because they think you’re giving them permission to allow someone to die. But that’s not really what it is because I have gone through it myself. You know what was very difficult? Even though I speak both languages perfectly well, it’s very difficult to interpret or translate things like chest compression and what it feels like. How do you explain that if there is not a word for this? And so to have something like this (DNACPR explanation) properly written in a way that they understand, I think would be really great and it puts a bit of pressure off you and, you know, the one designated translator in the family...”

It was useful to note that many Newham residents didn’t know that if requested in advance, a GP is able to book an interpreter using a professional interpreting service such “Language line” and that the requirement for an interpreter can be put on an individual’s medical record so that it is routinely put in place.

However, accessible information is not enough. Support to complete, share and update advance care planning documents is vitally important if advance care planning is to be done meaningfully. It is for this reason that health and care professionals were also included in advance care planning training sessions and webinars, so they could build their confidence and know where to signpost people for support if needed.

People want the opportunity to plan ahead as early as possible

When offered the opportunity to share experiences about end-of-life care in a safe and non-judgmental space, Newham residents made it abundantly clear that early conversations and clear documentation can be incredibly helpful for people and their families.

“I am so glad I had LPA for my dad, people should do this as early on as possible, as you just don’t know what could happen”

“...I think going back ten, fifteen years for me when all of this started, I mean, when the body starts to get sick - I think that’s when those conversations should have started happening in terms of going forward specifically what will be happening and gradually preparing you, you know?”

Another resident who had an LPA for health and welfare for her father explained why early conversations and plans were so valuable:

“People should do this as early on as possible, as you just don’t know what could happen. It all depends on how much mental strength they have - if they become too ill then it becomes more difficult to talk about. If someone knows about what might happen early they may decide no I don’t want to put up with this! But not everyone knows they have choice. You can tell them how it benefits before so they are mentally prepared.”

One resident shared how when the reality of her father’s illness kicked in, it was so stressful she found it difficult to think straight. She wished she had known about advance care planning and had the conversation with her dad much earlier and how bad he would have felt knowing how stressful it was for them:

“And, you know, when he’s screaming and crying, you know, and all the other changes that go on, you’re thinking he’s not well, he’s in pain, he has wet himself. You’re worried about that, not thinking about advance planning. It’s too late. Yes, way back down the line when he was first diagnosed that’s when it should have been done.... I know Dad would have wanted it to be lot less stressful for us than it was, he wouldn’t have wanted us to have to go through these battles. People have been dying for years, million and millions of years, people need to be educated on it, people need to stop saying they can’t talk about it, yes you can and you need to. It’s such an important part of life.”

People also shared the importance of having a clear understanding of what happens as a condition progresses and what the treatment options are:

“I mean, at that point (in intensive care), obviously the decision has to be made very quickly. So I think our conversation around ventilators needs to happen way before it comes to that point. Patient’s family and the patient need to be made aware, that these are the implications of being on a ventilator. ...But I think a conversation needs to happen way before it comes to that point. So you are fully informed what it means emotionally and physically, for yourself and for your loved one.”

Most importantly, Newham residents shared the peace of mind they felt after documenting their care preferences:

“After your meeting we thought we need to do something about this, so we completed our forms and gave two to a family friend as well as they are in the same situation as us. And the GP was so helpful, he said it was good we had it on our file and shared it so everyone has something to refer to - we are really pleased.”

“I have already done my end of life plan. I called a meeting, I called my family together and I said to them “It’s important that you do this with me, because you just don’t know what’s going to happen and I don’t want any fighting!” And now I don’t need to worry and they are so happy with me”

If people do not trust 'the system' to meet their health and care needs, planning for future care is not seen as a priority

Making plans for the future can be hard when you are struggling with day-to-day living. People often talked about how difficult it was to get appointments with GPs and so questioned if a health and care professional would have time to take note of their advance care plan. Many people didn't realise they could book double appointments for complex support needs. Some also talked about how difficult it was to have interpreters for regular appointments and how the current system didn't provide adequate support for people who don't speak English as their first language.

"The question is, would a doctor recognise this form? We fill the form, but then what? Can we trust the technologies? I feel a bit lost. Not sure I trust it all or have the confidence that it will all work."

It is often not until an individual is faced with the consequences of caring for someone who has left it too late to make a plan that they actively seek support.

"When you are caring for someone, if your home environment isn't such that you can care the way that you want to for family members, then it is really difficult to think about the wider issue, such as advance care planning"

People are often not aware that an advance care plan can be made for free, and that a solicitor is not needed

One of the biggest barriers shared by Newham residents in relation to documenting their care preferences was the assumption that it was complicated and costly. Dispelling this myth and sharing the free support available was an important part of making advance care planning accessible.

"In my experience, of course culture and religion is important, first we need to ask residents what their beliefs are, everyone is different, but also see what they know, they think it's expensive and complicated you see."

"That's so helpful to know that some people can register a Lasting Power of Attorney for free - that's fantastic. And I'll be making sure I share that."

"I looked but thought it was too expensive so I just did my will and told everyone about my funeral"

"I am now my wife's Lasting Power of Attorney for Health and Welfare. I didn't realise all this info was available for free in Newham. We thought we had to use a solicitor..."

"There's an assumption that you have to go to a lawyer to do all this when really you just need guidance and you know, there are professionals out there that can actually support you..."

However, advance care planning being free is only a benefit to people who can access information and support that meets their needs. It should be noted that for the majority of Newham residents we worked with, they struggled to understand how to find the support they needed due to language barriers and digital exclusion. This needs urgently addressing.

People frequently do not know how decisions are made if someone lacks capacity

The project focused on supporting people to plan for their end-of-life care but for many people, their first encounter with end-of-life care is when a loved one needs support and may have lost capacity to make their own decisions. A repeated need identified in Newham is that people caring for someone without capacity do not know how decisions are made for their loved one, or how to support them to get end-of-life care in line with their wishes.

People frequently came to advance care planning events with the expectation that as the carer and/or family member of someone who has lost capacity to make treatment decisions, they will be able to make an advance care plan for them, appoint themselves as their Power of Attorney and/or have the automatic right to make treatment decisions on their behalf. They didn't realise that it was too late to complete an LPA, Advance Statement or Advance Decision to Refuse Treatment because the person they are caring for has already lost capacity to do so.

"My wife has dementia and is very muddled. I think I should make an LPA for her."

However, having the experience of supporting someone at the end of life prompted people to attend awareness-raising workshops on advance care planning and make plans for themselves. It was therefore a valuable chance to offer information and support to a group of people that may have otherwise been overlooked.

It also created an important opportunity to explain best interest decision making processes to Newham residents and to inform them that even without a documented advance care plan, the law requires their involvement in the decision-making process to ensure that what matters to the person is central to the decisions made about their care.

The role and responsibilities of family play an important part in advance care planning

Family dynamics and the rights and responsibilities of family members featured heavily in our conversations about advance care planning and decision-making at the end of life.

Some people felt that documentation was not needed because family members knew what mattered to them and wrongly believed that next-of-kin or the eldest male in the family could make decisions:

"I don't need to do anything, my daughter knows what I want."

Others shared experiences of finding it difficult to choose an attorney who was genuinely able and willing to take on that role or feel pressurised into nominating a particular family member:

"My elder brother said it (Lasting Power of Attorney) should be in his name..."

"Just in my own experience, I have come across so many situations where, there's just so many disputes going on between families. So I think, that point for me is so crucial – be careful about who use chose [as an attorney] and making sure they get on."

Newham residents shared distressing experiences of disputes that occur at a time of crisis because they are not clear about how decisions are made when someone lacks capacity.

“I witnessed a family during the pandemic, a member had cancer, and there was argument between the wider family and the next of kin. The next of kin said they shouldn’t switch off the ventilator. The other part of the family said because he’s suffering and he wouldn’t want to become a cabbage, they should switch it off... so there were arguments as there was no power of attorney. Unless the next of kin has the power of attorney, the doctors will decide. People need to know this.”

Examples of how people feel like they have failed their dying loved one, as a result of not being able to make final treatment decisions, were also shared by Newham residents to highlight why a better understanding of the law is needed.

“I used to work as an NHS complaints advocate, and a lot of family members came in because they felt that there was something that might have gone wrong because what they wanted didn’t happen. But that’s the law, you know, that’s the legislation - family members do not have an automatic right to make treatment decisions. But a lot of people didn’t know that. These advance care plans are things that you need to do early - and we find that in our community - a lot of them don’t.”

In order to make informed decisions, people need to better understand the language used in advance care planning and end-of-life care

Newham residents, many of whom speak English as a second language, shared that they do not always understand terms such as palliative care, DNACPR, hospice, Advance Care Plan, Next of Kin and Best Interests, which makes it difficult for them to know what to expect, make informed decisions and ask the right questions.

“I didn’t know what palliative care was and I had no idea what it meant. I thought it was a really good thing and she was going to get better.”

“I go to different groups and we don’t discuss these things - what is a hospice, what is palliative care. First we need to raise awareness of these things. The doctor might tell them when the time comes, but people need to know before.”

“Someone I spoke to this week talked about how DNR and palliative care were mentioned at a late stage. It was only after their family member died that they googled and fully understood what they meant. They said if they had known what these words meant then they would have talked with their family member and encouraged them to consider what they did and did not want.”

Language barriers also impacted on Newham residents’ understanding of their diagnosis and the care and support choices available to them, preventing them from making informed decisions.

Health and care professionals want to feel confident supporting their patients with advance care planning

The fact professionals in Newham considered advance care planning to be everyone’s business and that any care professional can start important conversations about care planning was a valuable message to get across during the training sessions conducted. Even if some did not feel confident having detailed discussions about treatment options, health and care professionals told us that the ability to signpost patients was useful.

Annex: Resources to support professionals to have advance care planning conversations

As part of the project, we worked in partnership with Newham council to develop a range of resources that are available via the **Newham Training Hub**. These resources are intended to support anyone who may be having conversations about a person's end-of-life wishes:

- A recorded webinar **of Newham resident's talking about advance care planning**
- A recorded webinar for an **introduction to advance care planning**
- A series of **three short films** on advance care planning
- A guide to help raise awareness of advance care planning in Newham
- A top tips guide for having important advance care planning conversations
- A guide for supporting non-English speakers with advance care planning
- Information on best interests decision-making
- Guidance and signage to make a "*What I would want...*" wall

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Your end of life. Your way.

At Compassion in Dying, we want people to be in control of their end-of-life decisions because there is no-one better to make them.

**We champion everyone's right to make informed decisions.
Free of cost and free of judgement.**

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