

**Compassion
in Dying.**

Your end of life. Your way.

Advance Care Planning with people from South Asian Communities



September 2023

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With thanks to Subco Trust members and families, their staff and volunteer team, who all contributed their expertise, experiences, time and enthusiasm to this work.

This report shares the experiences of Subco Trust members and their families of health, care and end-of-life planning. It provides reflections from members on how to enable more people to consider if advance care planning could help them and have meaningful support to do so if they need it. It is intended for health and care professionals, people in VCSE organisations, policy makers, commissioners and anyone with an interest in understanding the experiences of different communities when it comes to end-of-life planning.



Summary

In April 2022 Compassion in Dying and Subco Trust partnered with the University of Bristol's Good Grief Connects project, funded by the National Lottery Community Fund's Bringing People Together programme, to co-produce advance care planning workshops for South Asian elders. The aim was to create a safe space for South Asian elders of all faiths to talk more about death and dying and plan ahead for their treatment and care, should they wish to do so.

Advance care planning

Advance care planning is the process of discussing and recording your wishes and priorities for future treatment and care. It can include clinical decisions and preferences (for example through an advance decision, DNACPR form or the ReSPECT process) or broader wishes about anything important to someone in relation to their health and wellbeing (for example in an advance statement). In this project we mainly focused on advance statements.

What we already knew

Compassion in Dying has had an ongoing relationship with Subco Trust since 2016. Based in the London Borough of Newham, Subco provides innovative and practical support to South Asian Elders, their family, friends, and neighbours who are their carers. This support includes information on end-of-life care and advance care planning. In previous work alongside Subco Trust members, people told us clearly that while it was sometimes conceptually and culturally challenging for them to talk about planning for their care at the end of life, it was a topic that they considered important.

Our members told us that they were so happy that we were discussing death and dying. They were saying that it is important because nobody wants to talk about it... and they said that even if they were not ready to talk about it just now, it was good to know that they could come to Subco and staff would be willing to take on board what they were saying and have that discussion.

Subco Staff member 2016

We also learned previously that an inter-generational approach to planning ahead is helpful in overcoming some of the barriers that exist when having conversations with family about end-of-life care.

The people we are working with at the moment are from the first generation that came to this country, so they are used to extended families back home where everyone knew what everyone wanted. Now families are quite nuclear and the family setup is diminishing, so as time goes on, it is really important to get the young people involved... if all the family is on board it makes it much easier for the person to say what they want or don't want.

Subco staff member 2016

Additionally, both academic research¹ and learning from Compassion in Dying's information line has consistently demonstrated that if people are able to plan ahead for the end of life, and are supported to do so, it can help people to have a "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.² We also know that talking and planning for the end of life can support a loved one's experience of grief.³ Despite this, people's awareness of their right to plan ahead and their confidence to start these conversations remains low.⁴

Co-production and a workshop approach

We asked Subco members if they wanted to collaborate again on the topic of advance care planning. They told us they wanted the opportunity to learn more about advance care planning and understand how it could help them in the future. In addition, we wanted to understand further the experiences of diverse South Asian communities in Newham when planning ahead and making decisions about their treatment and care. With that in mind, rather than setting out to support everyone to complete an advance care plan, we wanted to:

- enable people to make an informed decision about whether taking part in advance care planning was right for them
- be aware of the documents available to do so and
- provide culturally and linguistically appropriate resources in order to support this

At every stage, Subco members were in charge of the direction of travel of both conversations and areas of focus, and the topics discussed were those they chose. We are not experts in co-production, but set out to ensure that the purpose of the collaboration was both clear and shared, and that decisions were made in partnership with members throughout.

With support from Subco Trust's team and translators, we held four workshops over a twelve-month period. The translators were known to Subco members and were familiar with the subject matter, which supported members to feel comfortable sharing their experiences.

The first three workshops were each attended by over 30 members. These sessions included an exploration of the barriers people faced when accessing information about both their health and options for care when at or near the end of life; the tools available for documenting care preferences and the benefits of and barriers to advance care planning.

The fourth session was inter-generational and attended by 5 family members as well as Subco members. Members and their families talked about their experience of discussing end-of-life care and planning ahead with each other.

Subco members were passionate about the project and this was in large part due to the organisation's leadership and a committed group of staff. Those staff members with personal experience of the value of advance care planning also played a key role. Subco Trust members also wanted the project to make a difference in the borough and be helpful for other South Asian people who are considering their end-of-life wishes.

The organisation's presence on Newham Council's End of Life Board ensures that the voices and perspectives of Subco Trust members continue to be integrated into the council's End of Life Strategy and the multiple barriers that members face when accessing information and support, alongside many other Newham residents, are acknowledged.

1 Brinkman-Stoppelenburg A, et al (2014) The effects of advance care planning on end-of-life care: a systematic review. *Palliat. Med.* 2014 Sep;28(8):1000-25 <https://pubmed.ncbi.nlm.nih.gov/24651708/>

2 Lancet Commission on the Value of Death, Jan 2022, <https://www.thelancet.com/commissions/value-of-death>

3 Detering K, et al (2010) The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ.* 2010;340:c1345 <https://pubmed.ncbi.nlm.nih.gov/20332506/>

4 Compassion in Dying (2018) I wish I had known <https://compassionindying.org.uk/resource/i-wish-i-had-known/>

Recommendations and findings: the experiences of Subco members



The insights shared by people painted a rich picture of what South Asian communities experience in relation to their health and end-of-life care. People told us what matters to them when thinking about advance care planning. Importantly, we also heard repeatedly that they face significant challenges when talking to doctors, finding and understanding information, making treatment and care decisions and accessing support.

Based on the experiences of Subco Trust members, the following recommendations detail ways to improve conversations about people's priorities for the end of life and increase opportunities for advance care planning by ensuring people understand how it can help them. The recommendations also explain both what Subco Trust members need in order to get crucial health information in a way they can understand and how to help ensure people can make informed decisions about their own health.

Underpinning all this is the importance of understanding and respecting what matters to each person as an individual. With that in mind, people need to be offered an opportunity to consider and make an informed decision about if advance care planning could help them. In addition, any decision to not take part in advance care planning should be heard, acknowledged and respected.



For health and care professionals and the voluntary sector

Advance care planning allows health and care professionals to understand people's religious and cultural beliefs. Emphasising this can help people understand the benefits of recording what matters to them:

People saw advance care planning as an empowering opportunity to communicate their religious or cultural beliefs. Ensuring health and care professionals know and consider this information felt hugely important. Clinicians must be aware of this and understand how to properly meet and support the faith and cultural needs of people and their families.

Explaining how making an advance care plan can help family members if important decisions need to be made can open up important conversations:

Family plays a huge role in South Asian communities and people thought of advance care planning as a 'kind' thing to do for their family. This was seen as one of the main benefits to planning for the end of life.

The idea that death is a 'taboo' topic should not prevent professionals from starting important conversations about advance care planning:

People repeatedly demonstrated that they were comfortable talking about advance care planning even if they were not comfortable talking about dying.



For clinical practice

If using common terms found in end-of-life care, professionals must check that people understand them:

Many people did not understand common terms used in end-of-life care and planning, such as 'DNACPR', 'hospice', and 'palliative'. This gap in understanding meant that sometimes people and their families were not able to make informed decisions about their health, did not know what to expect or did not know what they could ask for when nearing the end of life.



For commissioners, service providers and those developing health information

Providing access to interpreters and translated materials is essential for people to be able to make decisions about their health and care:

Information only being available in English and difficulties accessing interpreters meant that often people could not understand information during health appointments, ask questions or understand their options. The impact of this was huge and meant that some people did not feel able to make informed choices about their treatment and care.

Health information should be developed in a variety of formats, including video or audio:

A significant number of people told us that they prefer to listen to and watch information rather than being given written content. This was often because they then did not need to rely on someone to interpret or read it for them, which subsequently meant they felt more in control.

People need support to complete advance care planning documents

It was starkly clear that for many, a conversation and information alone is not enough. People need support to consider their wishes and complete advance care planning documents. This support would be meaningful if delivered through the VCSE sector and clinicians working in partnership.



Next steps

We believe the recommendations detailed in this report are fundamental to good care and without them, meaningful shared decision-making and personalised care will be hard to attain for many in the South Asian community. People told us clearly that they do not have adequate opportunities to take part in advance care planning because often the information and support available to them is not culturally or linguistically appropriate.

Subco Trust is a prime example of how the voluntary sector has been working in a meaningful way with their local community to challenge social isolation, digital exclusion, poverty and language barriers and enable people to get treatment and care that aligns with their individual preferences. However, the voluntary sector can't tackle these inequities alone.

Meaningful attention and investment at both a national and local systems level is urgently needed to provide culturally and linguistically appropriate information and support to people to consider their end-of-life wishes, plan ahead and participate in shared decision-making.

This investment should include developing information and resources in a variety of formats and languages. Local voluntary sector organisations with a deep knowledge of their communities must also be permitted to play a key role in the development of any information, strategy and service provision. This involvement must be meaningful and reciprocal and comprise not just feeding into consultations but participating in action planning and decision-making.

Not collaborating meaningfully in this way risks perpetuating or increasing the inequities which South Asian elders currently face. Without such investment it will continue to be mainly those who know they have choices with access to information and resources who are able to plan for and receive treatment and care in line with their wishes.

Experiences of advance care planning and end-of-life care in South Asian Communities

Faith and culture play an important role in advance care planning

Many Subco members found exploring what matters to them at the end of life in the context of their own cultural and religious beliefs important and empowering.

Subco Trust supports a diverse group of elders from South Asian communities and this diversity was continually reflected throughout the workshops in the varied range of views and preferences. While some people expressed a wish to have all available treatment towards the end of their life, others shared fears about their dignity. Some people expressed fears about being cared for outside of their own home, while others wished only to be cared for in a hospital or hospice.

Many members shared concerns that professionals caring for them would not know about these care preferences, including those in relation to food, faith and family involvement. These concerns led many to appreciate the opportunity to explore their preferences using Compassion in Dying's Advance Statement form.

It is really important to me that I have Halal food and that I am helped to stay clean and pray 5 times a day.

It is good to have a section on religion. I didn't know this was available.

I would like a female chaperone at all times.

I would like to be cared for by people who are culturally understanding.

People enjoyed sharing and celebrating aspects of their faith and culture. It was important for them to approach discussions about advance care planning by focusing on things that matter to them and what makes their life worth living. When we explained how advance care planning can help communicate these things when it matters most, people felt that doing so was both relevant and valuable.



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

Family dynamics featured heavily in our conversations about advance care planning and decision-making at the end of life. People shared that there was often an assumption that younger family members would make decisions for them, and that they themselves wouldn't always get the final say in who made those decisions.

Many people said that younger family members can be reluctant to have conversations about end-of-life wishes, and that meant that they didn't have many opportunities to talk about how they wanted to be cared for with the people who matter to them.



My children say 'why are you thinking like that', 'why are you scaring us' 'you are taking medication - you will be ok'.

Talking is difficult. If I were to say anything, my daughter would hug and kiss me and say what am I going to do if you go?

Some people reported that discussing the topic was emotionally challenging for their family, but despite this they had still documented their preferences so that if they lose capacity their family and healthcare team will know what their preferences are.

It was a sensitive moment. The children started crying. They got emotional. It touches their heart, so it was a difficult matter. Anyway, now I have my advance statement, the hospital has a copy and the GP has a copy, so if anything happens they know what I wish for. I haven't told other family members but I'll get to that.

Some people expressed regret at having avoided conversations about end-of-life care and how those experiences had made them more inclined to welcome such discussions now.

When my husband started talking about dying, I didn't listen and just said "where are you going? You aren't going anywhere, you will stay with me forever!" He kept saying his time was coming and that we needed to talk but I didn't want to. He then went to his brother about it all. He died about a year ago and I feel a little guilty for not listening. Why didn't I listen to him? I should have listened to him. Don't fight. Be together. Be happy. Because one day we all have to go. I do talk to my daughter now, it is so important.

One person talked about their concerns that family members sometimes give incorrect information or put pressure on their parents to choose them as a health attorney, and the importance of the role organisations such as Subco Trust play in providing quality information and support that is independent of family members:

Many people have extended family and have got elderly parents living with them, and often they are in their little world and don't interact with outsiders. For example they will say "Oh Mum, now you are old and Dad has passed away, can you sign this document for us?" And the guidance they give is often completely wrong. So what happens is the elderly mother, in good faith, says "oh my lovely son, I will sign this document" without reading or consulting anyone as she has no knowledge and does not know who she can consult. Having sessions for elderly people and slowly, slowly bringing in this information, like a coffee morning. If they know someone they could trust. They need to feel comfortable, they need someone independent to speak to, (like Subco) not someone they know (a family member).

Importantly, people felt that having an advance care plan would make things easier for family, avoid arguments and unnecessary burden by ensuring that, as far as possible, family members were all on the same page and did not have to make decisions in a time of crisis. This was seen as one of the main benefits of advance care planning. People told us they saw it as a 'kind' thing to do for their family. Health and care professionals who are starting conversations about people's end of life wishes should consider this when framing such conversations.

People were comfortable talking about advance care planning, even if they were not comfortable talking about dying

Members sometimes found talking about death and dying emotive. Some found the topic challenging because it felt distressing to imagine themselves or their loved ones unwell or dying.

All this talk made me feel more and more scared and I felt quite sorry for myself, thinking what my later life will be like.

Subco Trust provide holistic support for their members, whom they know very well. For any group considering running a similar project, it would be important to ensure there are opportunities for any participants to access support around any difficult emotions resulting from discussions.

The people who attended these workshops self-selected to do so. They represent the experiences of people who already had an interest in the subject matter and were at least somewhat open to discussing death and dying. It is important to acknowledge therefore that people who do not want to participate in conversations about advance care planning are likely underrepresented or not represented here.

Nevertheless, conversations with Subco Trust members reflected previous learning that many people view conversations about planning for future health decisions and conversations about death differently. We found that most people welcomed the opportunity to discuss and explore what matters to them and these conversations were viewed even more positively when framed around culture, community and faith.

People explained repeatedly that offering people a safe, non-judgmental space for discussion with a focus on what matters to them enabled them to discuss the topic of planning ahead freely. Workshops where community members already knew each other and felt at ease therefore set the scene well for people to share their experiences and talk openly.

I am sorry for crying but I had a fall six weeks ago and it was a big emergency for me. But I had spoken with my family about what I would like at the end of my life - to stay at home - and now really know how important it is to talk.

Conversations about planning ahead also highlighted various practicalities that need to be considered when thinking about preferences for care in the future.

Before I had decided I would like to go in a home because I don't want to be a burden on my kids. For enough years I have paid my taxes, so they can look after me and my kids can come and visit me. But now I am seeing all the stories about all the people in the homes suffering, now I am scared and I would rather stay in my own house... it is good to think about these things.

People frequently said that community-led conversations about end-of-life care and advance care planning were appreciated.

There should be more events like this in future.

We need more sessions like this as it is very informing and helpful.



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

Subco members speak a range of South Asian languages such as Bengali, Hindi, Gujarati, Urdu and Punjabi, with English as a second or third language. Many people find reading in English difficult or not possible. People said clearly and repeatedly that they prefer to listen to or watch information rather than absorb it through reading. For many this was because it gives them a sense of control as they do not have to rely on others reading and translating text for them.

People explained that they use WhatsApp most often to communicate important information between community members. Therefore, short videos in community languages were far more preferable than written information.

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.

Subco members also shared how digital exclusion is very real.

Online has taken over - but we can't use any of this.

I don't know how to find information on the internet. Doctors say to go online but I don't know how to. Children don't have time to do this because they are so busy with their lives. Short videos in my language (Urdu or Punjabi) would be best.

We heard that any 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 need such information.

However, for many accessible information alone 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 and be an option for everyone. The ability of the Subco Trust staff and volunteers to offer this service was therefore hugely appreciated by the members particularly as they were considered a trusted source of information and support.

People did not feel able to make informed decisions about their care because the healthcare system did not provide accessible information and support

There is often a power imbalance between health and care professionals and individuals. Some communities feel this more acutely. Subco members shared how language barriers between themselves and health and care professionals meant that conversations during appointments were challenging. Organising interpreters was at best not straightforward and at worst not an option. This meant that information about their diagnoses and treatment options were not always clear to them.

Many members felt they are not given enough time to talk during appointments and often feel rushed. They frequently said that processing information takes time and can be particularly difficult when stressed or feeling vulnerable. In addition, conversations take significantly longer when an interpreter is needed and appointment times rarely allow for this.

There was also a clear sense from people that the doctor's information is correct and that they should not be challenged or questioned. This meant that people were much less likely to have prepared questions to ask in appointments, or know the right questions to ask to be able to understand their options and make informed decisions. Furthermore, many people were very unused to feeling like they had a 'choice' in health matters because getting basic information or support that was accessible and in their language was such a struggle. This meant that people were unlikely to ask questions or articulate what mattered to them unless prompted.

Others shared that getting face-to-face appointments had been difficult since Covid-19 and that this was particularly challenging because they felt that language barriers were exacerbated over the phone.

I can't do telephone appointments because I sometimes can't understand what they are saying due to accents and complex words.

In light of the struggles they had with GP appointments, Subco members said they didn't expect doctors to have the time to talk about advance care plans and what mattered to them in relation to their future care and treatment. The valuable and complementary support offered by Subco Trust was mentioned by many who didn't feel able to navigate the health system by themselves.

The doctor won't talk to me about this. I will discuss with my family and then ask Subco for help.

People told us that thinking about making plans for the future was hard when they were struggling, in the present, with health issues and additional challenges, for example with their housing or benefits. Many people had recently been diagnosed with a range of health conditions. They explained how getting information and understanding their new diagnoses was challenging and this was a recurring theme throughout the workshops. Some felt it was impossible to see a doctor, access translators or get information in their language. Many people said they had no faith that the healthcare system would meet their needs after a diagnosis.

Many people do not understand end-of-life care terms and how decisions are made if someone lacks capacity: this meant people could not plan ahead or make informed decisions

Subco members, many of whom speak English as a second or third language, shared that they do not understand terms such as palliative care, DNACPR, Hospice, Advance Care Plan, Next of Kin, and best interests. They repeatedly told us about experiences which showed that not understanding these terms made it difficult for members to make informed decisions about their health, understand the benefits of planning ahead or know what to ask for/expect when being cared for at the end of life. Subsequently, not understanding these terms further magnified existing health inequalities.

We heard repeatedly and frequently that people wrongly believed that their family members could make decisions for them if they lost capacity. In addition, many people believed that the Lasting Power of Attorney for finance was the only document needed to make decisions on behalf of someone else. These very common misconceptions were a significant barrier to people understanding why advance care planning is important.

People also frequently came to advance care planning events with the expectation that as the 'next-of-kin' 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 a Lasting Power of Attorney or Advance Decision because the person they are caring for has already lost capacity to do so.

I lost my dad to dementia 3 years ago, and now my mum has been inflicted with the disease as well. Unfortunately the diseases can turn quickly and capacity is lost and it is too late to make plans. It's so difficult - my mum doesn't think I'm her daughter anymore. Not having paperwork about how my mum wants to be cared for has put us in a really awkward position.

The workshops focused on supporting people to plan for their end-of-life care but, as in the example above, 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 among Subco members and across the Borough of 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 aligned with their wishes.

We don't have any plans written down and I am constantly anxious that professionals will suddenly take mum away to a care home where none of her religious needs will be met. I really need help to know what questions to ask doctors, what documents I need like DNARs, so that I can get the right help and prepare ourselves properly.

Having the experience of supporting someone at the end of life prompted people to attend 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 might have otherwise been overlooked.

It also created an important opportunity to explain best interest decision making processes to Subco members 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.



Resources to support community organisations and health and care professionals to have conversations about advance care planning

As part of this and a wider project across the Borough of Newham, we developed a range of resources to support people to have conversations with diverse South Asian communities and other communities about Advance Care Planning. All these resources are available at <https://compassionindying.org.uk/acp-south-asian-resources>

- Two short videos on the benefits of advance care planning and how best interests decisions are made if someone lacks capacity. These are for people to share with their peers on messaging apps as and when needed
- Factsheets on advance care planning tools in 6 South Asian Languages
- Top tips for having important advance care planning conversations
- A series of three short films on advance care planning
- Awareness-raising slides on advance care planning that can be used by both health and care professionals and voluntary and community groups
- “What I would want...” wall guidance that can be used by both health and care professionals and voluntary and community groups

Many of the findings from this project are echoed in a separate report on a broader advance care planning project undertaken in partnership between Compassion in Dying and the London Borough of Newham, available at <https://www.compassionindying.org.uk/wp-content/uploads/advance-care-planning-newham-august-2023.pdf>

Compassion in Dying.

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.

Contact us

181 Oxford Street, London, W1D 2JT

T 0800 999 2434

E info@compassionindying.org.uk

W www.compassionindying.org.uk

f www.facebook.com/compassionindying

X @agooddeath

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Subco Trust

Subco Trust works with isolated and housebound elders from diverse South Asian communities in the London Borough of Newham as well as the local community. Our members speak a range of South Asian languages such as Bengali, Hindi, Gujarati, Urdu and Punjabi, with English as a second or third language. In response to the range of support required by our members, we offer advice and advocacy services; ageing well and end-of-life care support; day care provisions; dementia support; inter-generational work and support to carers. We have 30 years of experience developing innovative, culturally and linguistically appropriate services and remain committed to improving the lives of vulnerable Asian elders, their Carers and the local community.

Compassion in Dying.

Compassion in Dying

Compassion in Dying is national charity that supports people to make informed choices, start honest conversations about death and dying with loved ones, and record and revisit their wishes whenever they want to. We want people to be in control of their end-of-life decisions because there is no-one better to make them.



Good Grief Connects

Good Grief Connects is a two-year project led by the University of Bristol, UK, funded by the National Lottery Community Fund's Bringing People Together programme. Its overall aim is to help shift the public conversation around death and grief and create a more inclusive, compassionate and open society. Fundamental to this is exploring the experiences and needs of groups underserved by formal services, particularly Black, Asian and minoritized ethnic communities.