



Snapshot Insight Report
Barriers to
Advance Care Planning

February 2022

Introduction

Advance Care Planning (ACP) conversations are held between patients of any age, who may have significant health issues, and their family and healthcare professionals about their future wishes and their care priorities. Sometimes ACP conversations are not had, because the term can attract negative connotations. That means opportunities to capture the benefits provided by ACP are lost.

A group of GPs working with the Barnet Primary Care Training Hub, which oversees the education and development of the primary and community workforce, are working together to explore ways to improve ACP in primary care. This project is part of an End of Life and Advance Care Planning Programme.

From September to November 2021, 19 Barnet residents were engaged via one-to-one interviews to explore their views on ACP and their experiences of it. The aim was to recruit a broad range of participants, both people who had already experienced ACP and people for whom ACP was a new idea and who did not have any pre-existing health conditions. The balance of participants was to enable a wider understanding of the challenges.



Key Findings

1. Lack of Awareness and Definition

The interviews revealed a lack of awareness of ACP amongst participants, with many having never heard of ACP before.

Nothing – I've never heard of it but I can guess it's probably about while you're still healthy, how to stay healthy and avoid being seriously ill.

I presume it's for the elderly, I mean, to be honest, I know nothing about it.

Part of the reason for this lack of awareness is the terminology used. 'ACP' is considered clinical jargon and therefore not relevant to the ordinary patient in their journey. Specifically, there was some confusion around the word 'advance'.

It's that word 'advance' that is a bit off-putting. What does 'advance' actually mean? Why not call it 'care planning'? I do have problems with the phrase. Do you mean I should be booking a hospice? Should I be saving up for an undertaker?

However, those patients already utilising ACP due to their own lived experience of health issues had a good understanding of ACP.

Deciding, if you can't decide for yourself or lack capacity, what decisions need to be made if you are terminally ill. So, for example, DNAR, funeral. It's something that applies to everyone.

It's about coming together at the end-of-life. The care that people would like, whether or not they want to refuse DNAR. Their acceptance of death and the quality of the life they want that is remaining.

Creating your will, power of attorney, both health and financial DNAR. It would also involve thinking about ourselves, our children and how our finances are going to be managed."

Notwithstanding, participants were able to make a reasonable guess on what the benefits of having an ACP in place are, regardless of not being familiar with the topic before the interview, with many stating that it would provide a better idea of their care, particularly for older people and their families.

I think there are a lot of benefits, not just getting what you want but it's making life much easier for your family. They're not having to guess. I met someone whose mother had a massive stroke in her 60s, there were three daughters and they were fighting because they didn't know what their mother wanted.

My worry is about not having the capacity to make decisions myself, so I wanted the children and healthcare specialists to know that I don't want to be treated if I lack capacity.

I think it is peace of mind, to make sure they're not on their own, especially elderly people. Peace of mind really to make sure they're looked after, because there's so many elderly people living on their own now.



2. First Response to ACP

Once participants had ACP explained to them, the majority agreed that in principle they would respond positively to discussing ACP when their GP/clinician first made the approach to discuss ACP.

I would respond very positively. After my cancer treatment I had no contact from my GP, the GP never bothered to contact me, I never knew about Advance Care Planning.

If I was ill, I think positive, I mean definitely. These days there's so much out in the open now that things like this [ACP] are becoming much more in the pipeline, whereas years ago there was nothing like this.

However, some participants stated that they would react negatively when first approached. The reasons for the difference is multifaceted but included the GP's tactfulness in discussing ACP; at what stage of the conversation ACP was raised; and if the person was of a younger age. Each person is different and therefore a rigid standardised approach may not work well. This is an important consideration as the benefits of ACP are not solely for people during End of Life care and can be utilised earlier.

I feel I'm too young and I think there is a difficulty in later years of relying back on plans you've made some while beforehand. I would equate it with antenatal classes – so you have plans for the birth but actually they have no relevance whatsoever - at least they didn't in my case - it just showed my naive intentions before you knew what it was all about! So, if you're well how relevant would it be? In real time now I guess with people dying from COVID, I could see the point of it more, but I'm still too young.

I would be happy to talk about it, but then I'm the type of person who listens to lots of different opinions. But for many people it's very frightening, they don't want to think and it needs a really sensitive person to lead that interview.

It depends on how the GPs approach it. I've seen an example where, at the very first meeting with my mum's GP in the nursing home, the first words uttered by the doctor were 'Have you got a DNAR on your form?'. My mum was poorly at the time, and she was told this at the GP's weekly round, and he needed cover for signing the death certificate. Well, what a start!

3. Difficulties of Developing ACP

When conversations move beyond just the introduction of ACP, participants spoke about the barriers to moving ahead with organising an ACP, with many stating that it may upset their families and that they felt uncomfortable speaking about death.

If somebody takes into account their age, their present health status, and if you think somebody is going to die, how do you do it? The one thing for me is if my sister collapses and she dies when I'm here by myself. For me I find it extremely difficult to discuss.

I think it's fear of the unknown, and especially with the older generation I think it's definitely fear, whereas us young ones are more open to conversation and talk about these things whereas the elderly don't.

Most children, I was certainly one of those children, you don't want your parents to die and so not thinking about their death doesn't actually ward it off but stops you thinking about it. I think one of the problems for patients is that some GPs are not good at recognising or wanting to recognise that end of life might be approaching, and I think that's a problem.

I have an example of someone who's 92 in my family who, on the day he died, was still being home dialysed, whereas had he been referred to palliative care he would not have been having acute treatment up to the end of his life. It was really horrendous. That's just not the way to treat someone who's dying really, active treatment like that.

Cultural and religious taboos around the topic of death were also mentioned as being a barrier in discussing and progressing with ACP. There can often be conflicting views within a family may also hinder the start of ACP.

I think it's largely cultural, I don't think the English are particularly good at talking about death. To my mind, the only thing that is guaranteed is the end of life. What you don't know is the determination or the time limit of the beginning and end, so that's my attitude. That was certainly the case with my father-in-law, and I think my father too.

My father accepted that he was going to die, so yes, I think there is enormous pressure on the family to keep someone going for as long as possible, irrespective of the individual's dignity and wellbeing and whatever, because I don't think people understand. People are selfish in that respect, people think they're doing the best when in fact they could well be doing a disservice.

I have a close friend who is dying who absolutely won't face up to the fact. I think a lot of people are scared of it and they think if they don't talk about it, it won't happen. But in my experience, and from what I've read, if you have got all your plans in place, you're more likely to get what you want. Otherwise, if you haven't put plans in place people just assume you wanted to be cremated, and do that, then a few days later they find a will and find that actually she wanted to be buried.

Participants acknowledged the time constraints that health professionals, particularly GPs, face in discussing ACP during appointments. This too can present as a barrier because people do not wish to use GPs time when they are not acutely unwell. This attitude was present before COVID-19 but has now become more prevalent.

I suppose it's about health professionals really lacking the time, I think most GPs now treat what you go with, treat the symptoms, and if you're lucky enough to have it recognised that you're dying and get into palliative care, then they're the people that have those discussions.

Although I do know from when I've been in hospital that when they park you in hospital, they're supposed to ask you about resuscitation. I know the last time the nurse just didn't ask me that question and I thought that was really interesting, but I didn't tell her that.

Making ACP Conversations Easier

1. Conducting Conversations in person

To enable conversations about Advance Care Planning to occur more easily, participants suggested having this discussion in person would be more appropriate than over the phone due to the sensitive nature of ACP, and having a clear purpose for starting the conversation about ACP.

Speaking in person, I think there has to be a careful definition and recognition of what 'Advance Care Planning' means, because there's a great danger that when you speak to me about Advance Care Planning, I assume that's because I'm terminal. The danger is that it's the first time that I've heard that my illness is terminal. There needs to be a very careful definition of 'Advance Care Planning', is it chronic? Is it acute? The GPs need to define what it means.

2. Access to Literature and Resources

Participants would also like to be provided with printed and digital literature on ACP, ideally before formal discussions start, which they can peruse at their leisure, by themselves or with the family. This approach also allows people to reflect without the 'on-the-day' pressure. This would also improve accessibility for those who are digitally excluded, hard of hearing or deaf.

It would also be helpful if the GP could print out a very simple leaflet on ACP and say this is what it's all about, take it home and read it and discuss it with your family and then you can say to the patient 'phone to make an appointment' which puts it in the patient's ballpark and if they don't, they don't.

Or 'X member of staff will contact you to make an appointment', it's probably better to have a member of staff to do it or the patient won't bother or 'on your way out just talk to reception staff to make an appointment to find out more', you've got to be careful and emphasise not to start it [an Advance Care Plan] but to find out more about it and say 'we're not putting you under any pressure, this is a little leaflet' it's got to be 1 page A4, not double sided, with some simple FAQs.

If there was an explanation in writing - email or a leaflet of some kind. My hearing isn't very good but it has improved with my new hearing aid, but my writing is good.

One used to go into the surgery to make appointments and now you don't. So I'm not sure but I suspect there were leaflets about this in the surgery for example, and one of the problems about not going into the doctor's surgery, not seeing that and other useful leaflets when I used to go to the doctor and I think that's worth thinking about, that maybe the conversations are more difficult to have, and I do think quite strongly that these kind of conversations are not well held over the telephone.

And the recent report on GPs that Healthwatch Barnet just produced, I thought it was very good and made a lot of sense, I just think that's one of the things about the many downsides of digital exclusion and the move to digital consultations.

Maybe for someone like me if I could have a link to a specific web page which I could find for myself, that would give me a detailed understanding of all the different things an Advance Care Plan would cover, I could take my time to read it and familiarise myself with the idea. Then if there were still things that I needed answers to because every person's care plan is individual and it would be impossible for the web pages to contain information on every single aspect, then there should be a contact number for me to phone up and speak to someone about anything I remained unclear about.

This is a very personal discussion and everyone has their own specific needs.

The majority of participants were not aware of any good resources to facilitate ACP, however, some participants discussed the resources that they had encountered.

I have a form which you can get online but what I've understood is that there's something called Coordinate My Care which is online. You complete it and forward it to your GP and they have to sign it.

A lot of what you want is in there and that makes life a hell of a lot easier because then, for example, if you're picked up by an ambulance because you've collapsed on the street, the hospital has got it all online, even the ambulance staff have. They know all about your medical history and your wishes. I think that must make life a hell of a lot easier because what everyone's complained about for years is that healthcare and social care is not coordinated in this country. But on the other hand, an Advance Care Plan is not legally binding so even if you put in there that you'd rather be cared for at home than a care home or you'd rather die in a hospice than a hospital, it's just expressing your preferences.

Before I did my living will, I looked up Age Concern and, although I don't agree with them, Compassion in Dying does a lot of work on this and has a template.

Someone also told me the Royal College of Physicians had a good template as well, so I looked at that one.



3. Awareness Raising

Participants also stated that raising awareness of ACP through ‘death cafes’, online campaigns and the media could help to tackle the stigma in discussing death, enabling patients to initiate conversations about ACP more easily.

I think if it was less of a taboo. For example we ran a couple of death cafes for younger people, because they are more likely to face up to the fact that it's just something that needs to be done. Sometimes we've had younger people come along to death cafes because they've had experience of somebody older than them in their family quite often dying and not having put plans in place, and not having known what they wanted.

I think one needs to do something to remove the taboo of dying. I think the more it's talked about in the media, and it certainly has been on Women's Hour, the better it is. When I was a child people wouldn't use the C word for cancer because it was a death sentence. That, thank God, has changed, but I think there's still a taboo about talking about dying which is a shame because it is something that happens to all of us. It happens to me whenever I lead a workshop somewhere, that I'll have one person say 'well I'm not going to die' but everybody's going to, aren't they? You would always have a certain percentage who are in denial and they don't want to discuss it, it hurts them to talk about it, they'd rather not.

Some areas have death cafes, I don't know that there's been one locally in Barnet so maybe that's something for Healthwatch Barnet to think about doing.



4. Identifying a Suitable Timing

When discussing when the best time for an ACP discussion would be, most participants said as early as possible, with others stating it would be better when patients are older but still in good health. If ACP conversations only happen after a major health event or end of life is approaching it is often too late as the nature of a person's wishes could significantly be affected by the circumstances.

As early as possible, the younger the better. Because I discovered, for example, when I asked one of my sons about being one of my attorneys, he's quite happy to do that but he has no idea what I want. All that person gets is the legal right to make decisions for you, but if they don't know how you feel about prolonging life or organ donation or whatever, they can't really.

I think it's really difficult because nobody knows when they're going to die. So I suppose one time would be if you're well like I am but getting on a bit, or when you have a diagnosis of a serious heart or cancer or other disease where you can't put off thinking about what's going to happen next.

In my view, ACP should be part of patient information from day zero. So even if there's nothing wrong with you, you've heard the term care planning, you know what it means, you don't wait until somebody's got something. The problem with lots of illnesses, when you get the diagnosis, you are not listening to anything you're being told, and doctors know this. All you can think of for months is 'I've got cancer, I'm going to die'. And my consultant said to me 'I've got to go through all of this with you, but you're not going to remember it'. Even my wife was with me, and he said, 'you won't remember anything but I've got to tell you'.

So there's no point telling someone 'You have a diagnosis of cancer, this is your care plan', they won't take it on board, so it's got to start as part of a patient information programme. It's one of the things we're putting in place to help patients over the long term, you know. Make it something special. There's never going to be a good time, but the time to tell people is when they don't need it, so when they do need it, they've heard the term. If you have a diagnosis, it's months before you listen.

When I was first training to be on that [Future Matters] project, we were given homework to go home and talk to our family about it.

A lady who was in our group, she was really quite an elderly lady, was a great grandmother. Her daughter wasn't prepared to come to terms with the idea of her mother dying, which is very common, whereas her granddaughter was quite happy to talk about it. So I think the younger you talk about it the more matter of fact you can be because it seems so remote.

I think maybe not when they're ill, because then it becomes almost a fait accompli. It's something I wish I'd talked about with my husband, but I never expected the suddenness of the three to four weeks, three weeks, that he was in hospital. He deteriorated so quickly and put his foot down that he wasn't having any more treatment, or going to go to another bout of chemo; and that, in fact, he'd chosen a lesser type of treatment previously, which I hadn't appreciated.



5. Identifying a Suitable Person

When asked who would be best placed to discuss ACP with, a range of responses was given from family to health professionals. Some participants felt more comfortable speaking with a trained health professional with whom they had a good rapport, such as a nurse, instead of their GP. This strengthens the principle that each person is different and therefore, rather than a rigid standardised approach, individual approaches may be best, based on whoever has the best relationship with the patient.

The person who is in the caring situation and the person who is providing the most care, it should be done together.

I think it would be better for health professionals to do it because with family it's really awkward. I mean if you have an elderly person you have to tell, I think it's better from a healthcare professional, definitely.

It's difficult to know. I think one ought to be able to discuss it with the family you know, but yes, it will be good that the GP is aware of how one feels about whether they want to talk about it or not. One should be able to raise it and then the patient such as myself should say, no, I don't wish to, or yes. I think it also depends on your relationship with your GP.

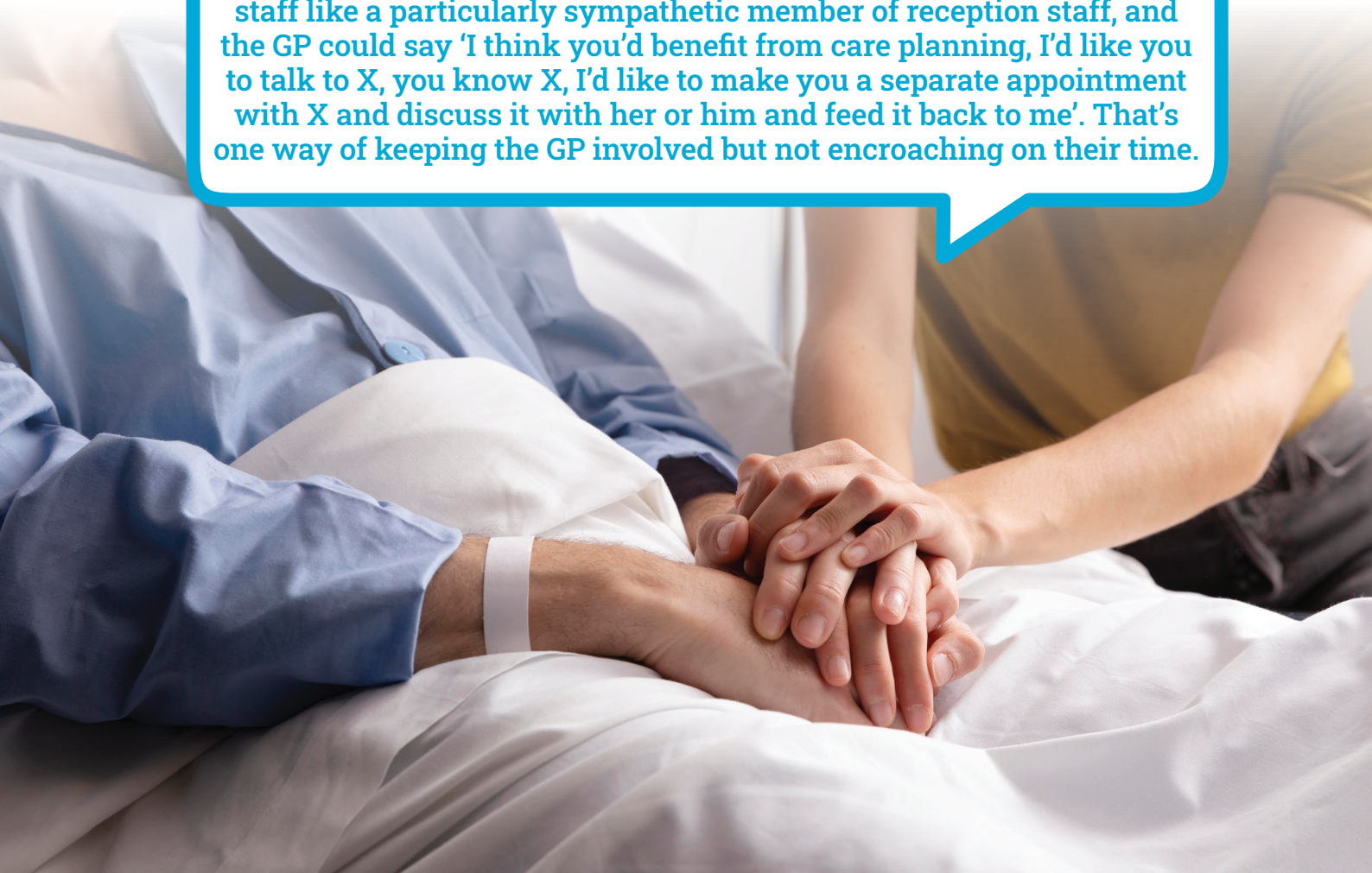
When my husband was in the hospital, he hadn't realised how terminal it was. One of the Macmillan nurses went to him and informed him that it was very terminal, and it upset him terribly. And he didn't want to see the person that upset him again, so the nurses told me. I knew where she came from, that was her role in a way, she came from outside, she wasn't hospital based, but she came on a regular basis.

And he informed the nurse that he didn't wish to see her again, because he and the nurse felt that she had put it to him in a bad way. In fact, I did after write a letter afterwards voicing my displeasure at the way she had gone about it.

Everyone is different, some people have a good relationship with their GP, it all depends on personal relationships. My view is you tell as many people as possible, tell them to talk to their GP. Some GPs would be good, some nurses would be better, I wouldn't restrict it to GPs. It's so personal and all depends on relationships, all the clinical staff should be equipped to deal with it. They should be prepared to say 'would you like to talk to your GP about it? He's known you longer than I have'. Some ladies might prefer a lady nurse than a male GP. It's who you feel comfortable with.

Like all things NHS, the communication is appalling, and it needs careful handling, with a trial maybe, and feedback from the trial to see what was good and what was bad. The danger is ACP is seen as another three-letter acronym program dumped on GPs by the NHS without any proper thought. What I'd do is say to a sample of GPs, 'What do you understand by ACPs?', I'd ask nurses and reception staff too and see how that gels with what patients understand. You may find its completely different views.

One way, maybe, is to have a member of staff. It could be non-clinical staff like a particularly sympathetic member of reception staff, and the GP could say 'I think you'd benefit from care planning, I'd like you to talk to X, you know X, I'd like to make you a separate appointment with X and discuss it with her or him and feed it back to me'. That's one way of keeping the GP involved but not encroaching on their time.



Next Steps

The Barnet Primary Care Training Hub Advance Care Planning group unanimously agreed that this report, highlighting the narrative, opinions and experiences of individuals in Barnet in their own words, was extremely powerful. It has been invaluable for GPs and the Training Hub to learn more about the challenges experienced by people locally. The plan will be to use the findings of the report to address some of these issues raised.

We hope to devise a short patient information leaflet that explains the process of Advance Care Planning, why it is beneficial, who may find it useful and how to access ACP via your GP. We hope the same interviewees will road test our leaflet and ensure that it will be a helpful resource for people in Barnet.



Acknowledgements

Healthwatch Barnet would like to take this opportunity to thank all participants for sharing their experiences and time with us to improve ACP.

Janice Tausig - Healthwatch Barnet Volunteer Interviewer

Dr Natalie Zhang, Oak Lodge Medical Centre

Dr Lorreta Chindo, East Barnet Health Centre

Dr Elizabeth Goodwin, Brunswick Park Medical Centre, adds her thanks, “We are grateful for the amazing work carried out by the Healthwatch Barnet team on the project”.



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