



MISSED OPPORTUNITIES

Advance Care Planning Report

**WE ARE
MACMILLAN.
CANCER SUPPORT**

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Foreword



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Over the past 20 years, I have supported people through the end of their life both as a clinician and a family member. My experience has enabled me to truly understand the benefits of planning for the end in advance. At Macmillan Cancer Support we work hard to support patients, families and healthcare professionals to achieve the best possible end of life care. Ultimately, we aim to give people a ‘good’ death at the end of their lives.

More than one in four cancer patients (28%) find it difficult to talk honestly about their feelings around cancer.ⁱ To achieve a ‘good’ death, however, it is vitally important that we have honest conversations. People with cancer should be given the opportunity to discuss their wishes with a professional who can understand their needs at the end of life. Planning for the end of life – known as advance or anticipatory care planning (ACP) – plays a vital role in ensuring a dying person’s wishes are met.

ACP conversations are important because they give people the chance to record their hopes, wishes and fears for the future while they are still able to do so. They also help to ensure people understand the legal options that are available to them. If we do not ask people what they want for the end of their lives, how can we help them to achieve a ‘good’ death?

When my own mother was told her oesophageal cancer could not be cured, I was struck by an exchange between her and her Macmillan nurse. She asked my mum what was important to her and where she wanted to be cared for.

After the conversation, Mum said, ‘I feel so much better now that I have talked about it. I know what to expect and where to get help. I also know that I want to die at home – but not in the bed your father will sleep in afterwards.’

As hard as this was to bear, I know this was a huge weight off her shoulders. ACP gave my mum choice and allowed her to take control of what was happening to her.

Macmillan knows that, sadly, not everyone is given the chance to have these vital conversations. **Thousands of cancer patients don't die in the place of their choosing**ⁱⁱ and, in some cases, people have little or no plans in place for other care preferences.

In this report we examine the role of ACP and explore the barriers to its implementation among people with incurable cancer as well as health and social care professionals. Our findings paint an eye-opening picture.

Death is the great inevitability but, with the right care and support, more people can experience a 'good' death. It's vital that patients and healthcare professionals are empowered to have ACP conversations while there's still time to meet people's wishes and help them to die well.



28%



More than **one in four** cancer patients find it difficult to **talk honestly about their feelings around cancer**ⁱⁱ

Executive summary

Advance Care Planning (ACP) – or Anticipatory Care Planning in Scotland – is a term used to describe conversations between a person and those involved in their care about their future wishes and care preferences. A person who is offered and engages in ACP is more likely to die in their place of choosing. They are also less likely to have emergency hospital admissions in the final months of their life, and more likely to have their wishes fulfilled.

Previous research for Macmillan found that there is a crisis of communication in the UK when it comes to death, and many of us face barriers that stop us from talking about death and dying.ⁱⁱⁱ **More than three quarters (76%) of people living with cancer have thought about the fact that they may die from their cancer, and around one in five have said they think about it ‘constantly’ or ‘often’.**^{iv} But worryingly, just over one third (35%) of people who said they had thoughts and feelings about their death had shared these feelings with anyone. **Only 8% of these people had spoken to their healthcare team about the subject.**^v

This reluctance to talk means that many people living with a terminal cancer diagnosis are not being given the opportunity to have early ACP conversations. As a result, they are not getting the support that could make a real difference to them, their families, and the wider healthcare system at the end of life.

Macmillan knows that, all too often, people are dying against their wishes in hospital.^{vi vii} In some cases, they might not even be aware that they have a choice about their care in their final days. Despite regular contact with health and social care professionals, people are often ‘waiting for’ professionals to start these conversations. They are also unsure as to who to speak to about planning.



More than **one quarter of cancer patients** told us they **feel guilty if they cannot stay positive** about their disease.

In fact, more than one quarter of cancer patients told us they feel guilty if they cannot stay positive about their disease.^{viii}

New UK research undertaken for Macmillan has found that there are a number of barriers preventing health and social care professionals from having early ACP conversations with people. One concern is that professionals do not feel they have the necessary expertise to introduce ACP in conversations.

Another is that they feel daunted and overwhelmed by the ACP process and are worried about 'having to do it all'. Some professionals worry that the people they support are simply not yet ready to talk about dying. Furthermore, professionals told us that they felt they had an important role to play in staying positive and supporting people to 'fight' cancer, and that this can prevent them from raising ACP.

As a result, health and social care professionals are missing vital opportunities to support people to have these early conversations.^{ix} The upshot is that these crucial discussions are often left until 'treatment is no longer an option' and the person is referred to a palliative care team. **In fact, of those people who had spoken to their healthcare team about dying, only 19% of conversations were initiated by a healthcare professional.^x** This means that it is often too late to effectively plan a 'good' death. It also overlooks the fact that, for patients, making plans while receiving treatment can provide a sense of control during an uncertain time.

At Macmillan, we believe it is time to talk about dying – and we are appealing for professionals to do so at an early stage. Only then can we make a real and meaningful difference to how a person experiences the end of their life, and give them the best possible chance of a 'good' death.

'It is not necessarily about dying, it's about living. But living in a way that is acceptable to people. They have got choices.'

Palliative care clinical nurse specialist

About this research

This report details two pieces of research undertaken on behalf of Macmillan Cancer Support.

The first, carried out by Revealing Reality, was commissioned by Macmillan to shed new light on people's first-hand experiences of ACP.

By exploring the needs of people living with cancer, carers and health and social care professionals, the aim of this research was to bring new clarity to an often poorly understood topic. In order to fully capture how this form of end of life planning is currently implemented, fieldwork was conducted across England, Scotland, Wales and Northern Ireland between May and December 2016. The research was qualitative and took an observational approach to capturing the experiences of people living with cancer and health and social care professionals. The research had two stages:

-  For the first stage, researchers visited five sites across the UK including England, Wales, Scotland and Northern Ireland. During these visits, researchers observed and interviewed professionals in different health and social care settings such as hospices, oncology units and support groups.
-  For the second stage, researchers conducted a series of in-depth interviews with 13 people living with terminal cancer diagnoses. The interviews were spread over four months and typically involved two face-to-face visits and follow-up telephone calls.

Macmillan Cancer Support also commissioned YouGov Plc. to survey 2,005 people with a previous cancer diagnosis, and 1,878 people answered questions relating to death and dying. Fieldwork was undertaken between 20 and 29 March 2017. The survey was carried out online. The figures have been weighted to be representative of the population of those living with cancer.



What is advance care planning?

Advance care planning (ACP) – or anticipatory care planning in Scotland – is a term used to describe conversations between a person and those involved in their care about their future wishes and preferences.

It is a voluntary process and, if the person wishes, their family and friends may be included in the conversations. It is recommended that, with the person's agreement, the discussions should be documented, regularly reviewed, and communicated with the key people involved in their care.^{xi}

An advance care plan can consider the individual's worries, values, and preferences for their care. For example, an ACP discussion might include:

- the individual's concerns and wishes,
- their important values or personal goals for care,
- their understanding about their illness and prognosis, and
- their preferences and wishes for types of care or treatment that may be beneficial in the future.^{xii}

As part of the ACP process, an individual may choose to complete an advanced statement, which documents and records their preferences and wishes. **Advance care plans and advance statements are not legally binding documents, but rather statements** of wishes and preferences. Advance care plans may also cover decisions about a preferred place of care, a preferred place of death, religious or spiritual requests, and do not resuscitate (DNR) requests.

An individual may also choose to create a **lasting power of attorney (LPA)**. A LPA is a legal document that lets an individual appoint one or more people known as 'attorneys' to help them make decisions or to make decisions on their behalf if they lose the ability to do so. LPAs are covered under legislation across the UK^{xiii} and can pertain to issues such as financial matters, the welfare of the person, and more.

A person may also complete an **advance decision to refuse treatment** (known as an advance directive in Scotland). This is a decision to refuse specified treatment that is made in advance by a person who has capacity to do so. This decision only applies at a future time when that person lacks capacity to consent to or refuse the specified treatment. It is legally binding.^{xiv}

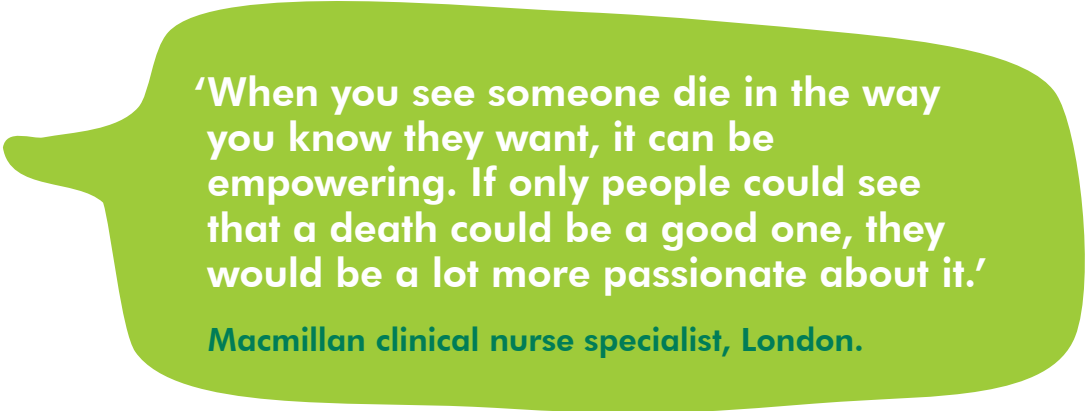
While ACP itself is a voluntary process, the opportunity to undertake end of life planning should be available to everyone.

This, however, requires people to be aware that ACP is available to them, to know about the documents that can support ACP, and to know who they can turn to for help. It also requires health and social care professionals to take every opportunity to engage people in these conversations – and to do so as early as possible.



Achieving a 'good' death

A 'good' death is often not something people associate with cancer and end of life. However, the professionals we spoke to with experience in initiating ACP conversations spoke of the benefits of future planning for anyone living with a terminal diagnosis. Many said that ACP can enable patients to have a greater sense of control at a time when many can feel powerless.



'When you see someone die in the way you know they want, it can be empowering. If only people could see that a death could be a good one, they would be a lot more passionate about it.'

Macmillan clinical nurse specialist, London.

Sadly, for many people, care and support at the end of life is not something they know they can plan for. Instead, many people fear the pain and isolation they will experience in their dying days. For example, Steve had no idea that pain management was something he could plan for and spoke to us about fearing pain so much at the end of his life that he did not know if he could cope.

At Macmillan, we know that future planning can help people to discuss the types of fears they have as well as plan for them. We also know that future planning is strongly associated with lower rates of hospital death, having other care preferences met and avoiding emergency admissions. It is also associated with other outcomes that relate to better quality care at the end of life.^{xv}

'I never really understood what the phrase a "good" death meant, until it happened to our family. When someone you love has terminal cancer, it can feel like all power has been stolen away from you. In that context, giving someone genuine choice about how they are cared for, and where they spend their last days and hours, can have a huge impact not just on the individual, but on the people around them. My family are testament to that.

Once we knew my mum's cancer was incurable, no one could stop her dying. But they could – and did – give her a 'good' death. It is one of the greatest gifts anyone has ever given our family.'

Grace

Having a record of someone's preferences in advance of their death can also significantly impact their experience. **For example, Macmillan has found that when staff have a record of where someone would like to die, that person is almost twice as likely to die in the place of their choosing.^{xvi}** This is significant given that, with the right support, 64% of people with cancer would like to die at home but only 30% currently do.^{xvii}

We know that ACP can enable and facilitate a 'good' death. We know that commitments have been made by the NHS and national governments to promote planning ahead as an important part of a person-centred health service. However, national clinical audits of case note reviews found that, though three quarters of deaths are expected, ACP discussions are recorded in fewer than half of the deaths registered.^{xviii} These disproportionately low figures suggest that there are still considerable barriers to ensuring ACP is well understood and undertaken by professionals and patients.

Steve, 54, Wales

The third time that Steve went to hospital about his excruciating back pain, he was adamant that something was wrong with him. When the MRI came back, he was expecting to find out whether he'd slipped a disc, but instead he was told he had multiple tumours on his spinal cord.

Steve told us he was incredibly anxious about dying and he worried about the pain he might experience. Though he was determined and remained keen to 'go on every trial that's on this earth', he did not want to experience 'end of life'. Steve had a mixed relationship with his healthcare professionals as he felt that they were not forthcoming with information. His own ability to plan was confounded by wider personal issues.

Steve liked one doctor who had 'a nice way about him', however, none his doctors or health and social care professionals had broached end of life care planning with him. This was despite the fact Steve was feeling a considerable amount of anxiety and distress around the end of his life.



Jessica Pugh, Macmillan Clinical Nurse Specialist in Palliative Care

'Barbara had a long, brave battle with cancer. She was initially admitted for feeling generally unwell, but it quickly became evident through assessment and scans that she had significant disease progression and, sadly, no further treatment options were available.

Barbara was a self-confessed glamazon, and her biggest fear was dying without her lippy on. Her other main concern was telling her family about the reality of her diagnosis for fear she would be perceived as giving up. She asked if I could support her in having the conversation with her family to tell them that she was dying.

I supported Barbara to break her bad news to her family, and seek out whether she could die at home, surrounded by her family, her dogs and her "pretty things". Her family were understandably upset, but afterwards they said they all knew but were too scared to say in case they upset Barbara. This is a prime example of the burden that families feel when it comes to open and honest communication.

After seeking consent, I liaised with Barbara's GP and community team and put Barbara's wishes onto the electronic advanced care planning document.

When it became evident that Barbara was actively dying, we successfully discharged her home. She died three days later. Her symptoms were well managed, she had a face full of make-up, and she was surrounded by her family, her dogs and her "pretties".



Barriers to advance care planning

At Macmillan, we feel passionately about the need for the public and professionals to have early ACP conversations because we know the real and meaningful benefits they can bring.

For this reason, we sought to better understand the real-life experiences of people living with terminal cancer diagnoses, and the health and social care professionals who support them. Through the course of these conversations many common barriers to ACP emerged. Some of them were specific to people with cancer, but many could apply to people with other life-limiting illnesses.

1. 'Fighting talk' can prevent effective ACP discussions

Our research found that one of the biggest barriers to beginning ACP discussions is the perception that professionals feel they need to stay positive and support people to 'fight' cancer. It is a commonly held belief that describing people with cancer as 'fighters' or thinking of cancer as a 'battle' keeps people's spirits high and instils in them a sense that they are working hard to combat the disease.

'Part of the barrier is that our job is to identify and deliver active treatment options. We're moving towards ever greater science specialisation, new treatments, the hope of clinical research and trials. All those things mean that we talk to patients in a way which is about what we can do for them. How we can help them combat and fight the illness over and above the more therapeutic element.'

Consultant medical oncologist, Merseyside

However, our discussions revealed that the longer these fighting conversations go on, the harder it is for both the person and the professional to shift discussions towards ACP. The irony is that while professionals feel frustrated that they cannot be frank or honest with the patient, the patient finds the effort of keeping a brave face exhausting. **In fact, more than one quarter of cancer patients told us they feel guilty if they cannot stay positive about their disease.**^{xix}

'My consultant is so lovely. She always tells me I've been brave and I'm a real fighter... I guess sometimes that can be a bit tiring.'

Margaret, living with cancer



Kelly, 38, England

Initially diagnosed with breast cancer in 2012 when her children were only two and four-years-old, Kelly went into remission in 2014. During recovery from a post-operative infection following a double mastectomy, Kelly learned that her cancer had spread to her bones and was not curable.

One of Kelly's most pressing concerns was getting a divorce from her husband to ensure some control over the lives that her children might have after she has died. Kelly had not thought about care and support at the end of her life, and she felt an extreme lack of control over her ability to do this.

'I didn't want to talk about it. But I could go to sleep one day and wake up the next sick as a dog and, if I didn't come through that, then I might be at the end stage. I think someone should have talked to me about it by now.'

Kelly's health meant that she was often extremely tired, and what energy she did have, she put into looking after her children. Kelly felt extremely scared about both what might happen to her, and what might happen to her children after her death. However, no health and social care professional had ever spoken to her about her options. In fact, some had actively said that they had not broached such topics with her because she is a 'fighter' and they didn't want to damage her spirits. This means that the professionals working with Kelly reinforced the narrative about 'fighting' cancer to the point where both she and they viewed it as a failure to talk about end of life.

'I spoke to the district nurse yesterday and she helped me review my meds. She told me she hadn't spoken to me about end of life care because I'm a fighter and she didn't want to take that away.'



2. ACP – whose responsibility is it?

Given that activities related to end of life are associated with palliative care, many health and social care professionals who don't work in palliative care were unclear as to who was responsible for ACP. The impact of this uncertainty meant professionals along the patient journey were concerned they did not have the expertise or the capacity to broach the topic of planning with their patients.

'End of life isn't really my bag. I am more focused on treatment. I would have thought planning is more the remit of the palliative care teams. They are the ones with the advanced communications training.'

Chemotherapy nurse

This often led to situations where local palliative care teams and associated hospice teams attempted to upskill health and social care professionals and raise awareness of ACP within their individual Trusts.

'What I try to promote is that it isn't one person's responsibility. But the danger of that is it becomes no one's responsibility and people can quickly look to the next person, despite them being a fundamental part of someone's care. We're trying to get everyone involved. Certainly, the GPs and Macmillan nurses, some specialist nurses, secondary care consultants. We're trying to say to them, you've got a really important role. Even if it's just the identification – pass that on.'

Palliative consultant, Northern Ireland

8%



Only **8% of people** with cancer who have thought about **death and dying** had **spoken to their healthcare team** about the subject.

In fact, it became apparent throughout this research that hospices are the most successful in fostering open conversations between people, their loved ones, and professionals. Here, discussions about end of life are actively encouraged and deemed acceptable.

Unfortunately, access to hospice care remains a challenge for many people.^{xx} Of the people we spoke to, few had reached a hospice until the very end of life, meaning they had been unable to access vital sources of support at an earlier stage.



Alistair, 54, Scotland

Alistair was diagnosed with a brain tumour in October 2015 after experiencing headaches and losing concentration in his work as a builder. In early 2016, he underwent major brain surgery to remove the tumour and had a single round of chemotherapy. Alistair and Margo, his wife of seven years, never spoke about his prognosis. This was partly because he didn't want to know and partly because they both worked on the assumption that he would fight the disease.

Margo spoke of the surprise and sadness that came with knowing you will outlive your partner – a prospect she had never envisaged when they first met at a dance club.

In September 2016, Alistair began to deteriorate and was in and out of hospital for a few months. In December 2016, he was rushed to A&E where he began being sick and could no longer move. He was transferred to a hospice for a week of respite, before passing away just before Christmas.

Margo and Alistair hadn't heard of ACP, despite being clear on several wishes they both wanted recorded and fulfilled. Margo was incredibly upset about not being able to fulfil Alistair's wish of dying at home. She felt that, as a carer, she lacked support and information about how to support this decision-making process.

Margo told us that she felt that all information was guided towards Alistair's treatment and medication needs with little in the way of human planning. If any one of the many health care professionals involved in Alistair's care in the last few months had taken the opportunity to offer ACP, it may have been possible to fulfil his wishes.

'We haven't heard of advance care planning. Should someone have told us about that? No one has really spoken to us about anything.'

Margo, Alistair's wife



3. Sharing information – the data challenges

Many NHS and social care organisations can be involved in supporting patients who have an end of life care plan. These can include GPs, hospitals, community nurses, care homes, the ambulance service, and hospices. Ensuring all organisations can access a patient's up-to-date end of life care plan is vital if we are to ensure a person's choices and preferences are acted upon.

However, as our research found, many people were unsure where their details were being stored and circulated. This was particularly the case for those who moved between Trusts to receive treatment. The result was people having to constantly repeat their wishes, as well as their symptoms, to various health and social care staff. Similarly, many health and social care professionals told us that it was not always clear if people had spoken to any other professionals about their wishes, and therefore they were not sure what was appropriate to say or ask.

It was also common for health and social care professionals to speak of the frustrations of sharing information between care environments. There was evidence of patient information being lost between communication systems, especially between those who use computers and those who share documents via fax.

'From a sharing point of view, we make photocopies and fax them, send copies to the ambulance service and so on. To be honest though, it seems obvious to me that there's an IT solution to this. It's ridiculous that we're faxing things around.'

Palliative consultant, Wales

Better digital solutions are integral to the progress of ACP. Electronic Palliative Care Coordination Systems (EPaCCS), or similar systems, enable the recording and sharing of people's care preferences and key details about end of life care. These can be shared with everyone involved in a person's care if the person wishes, and they can give professionals greater confidence in engaging in ACP discussions.



Isobel, 54, Scotland

After being diagnosed with breast cancer in 2010, Isobel returned to Scotland from the Middle East to be closer to her family. In 2013, Isobel was diagnosed with terminal cancer. She was given a prognosis of between two and twenty-four months.

When her doctor retired, Isobel was not seen by the same regular doctor, and said she often felt like, 'nobody is really following what is going on.'

Isobel was frustrated by the fact that she often spends her appointments updating the doctor on her condition, as opposed to the doctor discussing it with her.

She found that in all aspects of her illness, from ensuring she got the right scan or biopsy to finding out about power of attorney, she had to be proactive and question things. While her main source of information about her illness was the internet, she feared that some of the information she found was incorrect as things can differ between Scotland and England.

No health care practitioner had approached Isobel about her plans for the end of life. She believed that 'continuity of care' was one of the biggest challenges facing her when it came to organising her plans for the end of life.

In areas of England where EPaCCs have been implemented, they have helped as many as 80% of people identified on the system to die in their preferred place.^{xxi} However, there are still many parts of the UK that do not use such systems. This means that even if ACP conversations do take place, a person's wishes may not be shared across all of those involved in their care.



In England, the government has committed to work with the NHS to ensure shared digital palliative and end of life care records will be rolled out in the majority of local areas by the end of 2018 and all areas by 2020. This will support the sharing of information and promote personalised care.^{xxii} However we know from the government's own progress report on the *Review of Choice in End of Life Care* that progress on this has been far too slow.^{xxiii} There is still a long way to go if the government is to meet the 2018 target.



In Scotland, a Key Information Summary (KIS), currently hosted on the GP IT system, enables the development of an electronic Anticipatory Care Plan from the GP system. It can also be accessed across other services in acute and emergency care. Work is being led through Healthcare Improvement Scotland to support more effective use of the KIS and to raise the profile of and mainstream ACP.



In Wales, one of the seven themes in the Welsh Palliative and End of Life Care Delivery Plan is improving information. The plan aspires to ensure that NHS Wales' clinical record systems are accessible and link with other relevant IT systems, eg, GPs and ambulance systems. However, there was little reference to information and/or data sharing in the Welsh government's recent annual statement. Where it was referred to, the language is more ambiguous than in the delivery plan.



In Northern Ireland, the KIS is now being implemented on the GP Clinical System. This will give health and social care staff more effective access to any wishes expressed by people with long term conditions about end of life care.

Good practice – Coordinate My Care^{xxv}

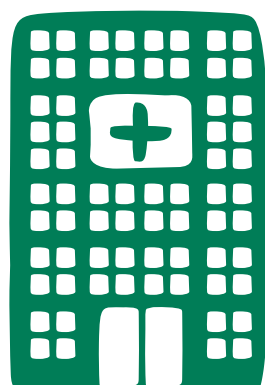
Coordinate My Care (CMC) is a London-wide clinical service which facilitates the creation of urgent care plans, including advance care plans for patients with a life threatening or life limiting illness. Underpinned by a digital information care exchange, CMC allows patients to record and share their medical details, advance care plans and wishes¹ with all their healthcare providers in real time.²

CMC acts as the Electronic Palliative Care Co-ordination system (EPaCCS) for London.³ Currently, 50,709 patients have CMC urgent care plans – 22,263 of whom have died.⁴ Only 19% of patients have died in hospital (compared to the national average of 47%) while 78% of patients died in their preferred place.

A CMC evaluation of 6,854 care plans, showed that patients are more willing to engage in urgent care and ceiling of care (CoC) planning, which is part of the ACP process. A CoC plan aims to provide guidance to staff on a person's expressed wishes, and/or the limitations to the treatment they would like. For patients, the benefits of possessing a CoC include an increased likelihood of dying in their preferred place and a better chance of dying outside of a hospital setting. Given this broader planning and decision-making process, patients are also more likely to receive appropriate treatment and less likely to have interventions that are inappropriate, distressing or contrary to patient wishes.⁶

The CMC approach gives patients the autonomy and ability to live and die the way they choose.

Only 19% of patients have died in hospital (compared to the national average of 47%)



while 78% of patients died in their preferred place



4. Low awareness and missed opportunities

Through our conversations, we found that both professionals and people with cancer believe the most appropriate time to begin ACP is when treatment is no longer deemed an option. However, for the people living with cancer that we spoke to, treatment continued until the final weeks and even days of life.

Waiting until treatment ends means people with a terminal diagnosis are denied the opportunity to have early conversations about their wishes and preferences. We believe the earlier the discussions occur, the greater the opportunity for those wishes to be fulfilled.

'My late husband's care during his last few days was quite good. It was not to a standard he could have had at home, and he didn't have the peace he so needed. Him being in hospital was traumatic for me, and the experience made my grief so much worse, in that I had no control in making sure his wishes were met.'

Pam

While professionals often wait for an explicit cue such as finishing treatment to commence ACP discussions, these rarely present themselves. Vital opportunities to have early ACP discussions are therefore missed during the lengthy treatment phases.

'There is a tendency to not want to take away the hope from people. We have had patients getting injections the day before they have died. This means we are still giving people expectations that they are going to get better.'

Geriatrician

This view that ACP is a one-time activity to undergo at the very end of life ignores one of its core principles. **That is that it is a plan to be frequently revisited and updated as people's wishes change over time.** This research highlighted the fact that making plans while receiving treatment can, in fact, provide a sense of control during an extremely uncertain time. This sense of control can also extend to family and friends.

Many of the people we talked to spoke about the relief that families feel when they do not have to worry about plans such as arranging or paying for funerals.

'My father died of cancer at home in accordance with his wishes, he would've hated to die anywhere else, in doing so I believe the whole experience was better for him and our family.'

Ian

Claire, 37, England

Claire was first diagnosed with cancer when she was seventeen years old and had an operation to remove a tumour from her ovary. Shortly after starting work in Leeds in 2010, Claire began to experience back pains. A CT scan revealed she had a lesion on her back. After chemotherapy failed to shrink the lesion and two unsuccessful courses of molecular therapy and external radiotherapy, Claire was given a prognosis of two years.

Claire felt strongly that it was important to get her plans in place so that everybody could know her wishes and not feel like they were having to make difficult decisions on her behalf. She did not want to end up in a hospital and instead picked out a hospice that she would like to go to.

Every month she visited the hospice where they talked about symptom management and she had treatments such as aromatherapy. She said that the support and care she received at the hospice was 'amazing.' Although Claire felt that she was well enough at the time to organise her wishes for the end of her life and the future, she acknowledged that many people with more advanced cancer were unable to as they were so unwell. From her experience, Claire felt that doctors were sometimes ill-equipped to discuss advanced care planning, as such conversations should not be clinical in nature. Claire passed away from cancer in April 2017, having documented how and where she wanted to be cared for.

'It makes me feel better that I'm in control of it and I've done it and nobody else has to worry about it. If I let myself think about it too much then it upsets me. So I just try not to and carry on and deal with it like a project that I've got to get sorted.'





5. People want to talk

While conversations about end of life can be emotional and difficult, we discovered that many people do actually want to talk about their wishes and preferences. This is despite the fact health and social care professionals commonly perceive patients to be in denial about the reality of their illness or too fragile to discuss planning for the end of life.

'The hardest patients are those who are in denial about their diagnosis. Or their loved ones won't accept what you're telling them. Denial is a huge barrier to planning.'

Clinical nurse specialist

Ultimately, people require support to make health and care decisions. Therefore, all professionals have an essential role to play in supporting and educating their patients about the health and care-based decisions they could make, and what they mean in practice.

'Making someone's last wishes happen is the most dignified and compassionate thing you can do. I have seen patients plan their last days and the calmness and peace they achieve cannot be ignored. Each person is unique, each death is unique.'

Diane, an oncology nurse

19%



Of those **people with cancer** who had spoken to their **healthcare team** about **dying**, **only 19%** of conversations were initiated by a **healthcare professional**.







Aoife, 34, Northern Ireland

After being initially diagnosed with lung cancer in 2013, Aoife found out she was terminally ill in 2015. A keen gardener and dog lover, Aoife had major surgery in 2016 to remove a tumour that had spread to her lymph nodes.

Aoife was reluctant to talk about dying, and often refused to directly refer to being terminally ill, preferring to talk around the issue.

'I haven't spoken to anyone about end of life plans. Who would I talk to now? I assume when I'm about to kick the bucket and dealing with palliative care is when that will all start. They're the ones who know how to deal with that.'

Aoife found interactions with healthcare professionals difficult because she felt that they were judging her for her lifestyle choices. She told us that she had lost trust in the system and felt that doctors had labelled her as difficult without attempting to offer her the support and care she would have liked.

Aoife was very anxious about the future but was adamant that planning was not important to her and she was not interested in formalised care processes. Despite this, through conversations about her fears for her dogs and her house, we found that Aoife did have preferences and wishes about her death. This was a conversation which begun not by asking her about how she felt about the end of life, but what mattered most to her in her life.

'My attitude was, "I just want to get up, get the chemo, go home, get on with my life, back up in three weeks, do it again, go home". You know, just leave me alone in between.'

6. Access to community-based end of life care

During this research, we found that some health and social care professionals worried that if they recorded certain wishes on behalf of patients, they might be unable to fulfil them. At Macmillan, we know that a person's preferred place of death is as individual as they are. For this reason, it is important that ACP conversations fully capture people's wishes to ensure that they can be fulfilled.

'I feel that it is vitally important that a person's last wishes are listened to. My brother died in a hospice and my stepfather in hospital, but both had been given the option to do so. I found the staff at both caring and responsive to their needs.'

Alison

Access to community-based end of life care is a preference for the majority of people at the end of their lives. Community-based end of life care means people can remain in their own homes, in hospices or in their existing care homes. They do so with the support of community nursing, palliative care, primary care, their local pharmacy, and occupational therapy, plus they receive access to specialist support when required.

Many professionals are concerned about documenting a preferred place of care as, in many cases, dying at home may not be realistic and there are often limited hospice beds available. Professionals worry that advance care plans may raise expectations among people with terminal diagnoses about the kind of support they may receive.

'People are worried that if professionals talk about these things to patients, they create an expectation that might not happen. But it's important to discuss options even if you can't make promises.'

Communications lead, Wales

This is a legitimate concern given the challenges health and social care services are facing across the UK. **This is not the responsibility of individual health and care professionals, but an issue that needs to be considered in the broader context of the funding and resourcing of personalised community-based end of life care in the UK.**

However, it is essential to note that not only is community-based end of life care the preference for most people, it is also one of the few interventions shown to reduce reliance on emergency and acute care.^{xxvi}

Despite this, Macmillan is extremely concerned that we continue to see an enduring gap in the resources needed for community-based health and social care services. These services are essential to supporting patient choice at end of life, and the need for this type of support is only set to increase.^{xxvii}

If we want to further empower health and care professionals to have the confidence to discuss people's wishes but also ensure these wishes can be real and meaningful, **more must be done at a national level.**

We want every person approaching the end of their life to have the opportunity to discuss their wishes and goals for their end of life care in advance. We also want to ensure real and meaningful opportunities exist for these wishes to be fulfilled.

At Macmillan, we know the real impact that access to community-based end of life care services can have. This is both in terms of supporting a person to die in their preferred place but also in reducing pressures on already overstretched Trusts.

Good practice – The North Manchester Macmillan Palliative Care Support Service (NMPCSS)

Prior to this service launching in North Manchester, the number of deaths in hospital for patients with life-limiting conditions was higher than the national average. There is no hospice in the local area and research finds that 70% of people would prefer to die at home.

This service, which is delivered by The Pennine Acute Hospitals NHS Trust, was launched in April 2015 to ensure patients with life-limiting illnesses can access the care and support they need at home. The team comprises professionals and trained volunteers who work together to deliver a full package of support to patients in the heart of the community. Improved communication and information-sharing are central to improving patient care and meeting their needs.

This service takes a multidisciplinary approach and is led by a Macmillan consultant in palliative care who supports the dedicated professionals working with patients and carers. The service works collaboratively with the local hospitals and primary care.

Deaths are now reviewed to assess whether patients achieved their preferred place of care, and, for anyone who do not, to investigate the reasons why. The consultant and team also regularly review patients' case notes when admitted to hospital to determine whether this could have been prevented. 82% of patients on the caseload died in their recorded preferred place of care in 2015/16, compared with 59% in 2014/15. For patients on the caseload, average deaths in hospital reduced from 21% in 2014/15 to 13% in 2015/16.

SENSE OF PURPOSE





Opportunities for change

This report – and the experiences shared within it – highlight the vital nature of early ACP discussions. They also demonstrate the consequences of leaving these conversations too late or not having any conversations at all.

ACP discussions can give control to people during lengthy treatment phases. They can also encourage people to explore their wishes and preferences, and support them to think about the type of death they would like to have. Leaving this until treatment ends means people with terminal illnesses and their families miss opportunities that could have supported their wishes.

At Macmillan, we know health and social care professionals can find ACP daunting and overwhelming, however, we want to reassure them and alleviate many of the concerns they have. For example, we want to end the assumption that professionals need specialist skills to initiate ACP conversations as, in most cases, they are not necessary.





'Any interaction between a health care professional and a patient is an opportunity to discuss ACP. Otherwise it may be a missed opportunity that may not present itself again.'






Any communication skills training that most health care professionals have is certainly adequate to get the conversation started.

As health care professionals we have a responsibility to change the culture about the way in which ACP is delivered. This way more people can get the benefit of what ACP can do for them.'

Dr Peter Nightingale Macmillan GP Advisor

While we know that many challenges exist when it comes to ACP, we believe that so too do many opportunities.

For health and social care professionals, the following simple considerations could make a big difference for people with a terminal diagnosis:

-  Taking responsibility for an ACP conversation may be as simple as recognising that you might not be the right person to introduce ACP to a patient. You can then attempt to find out who is.
-  Supporting people to develop an advance care plan does not require a set of unattainable skills. Health and social care professionals should not feel they will be held to account if they are personally unable to fulfil each individual wish.
-  Health and social care professionals involved in a person's care should consider opportunities to introduce the benefit of planning. A good time to do this is during active treatment as this is often when the greatest need for control is evident.
-  Health and social care professionals should not assume that a patient who presents as 'difficult' or 'in denial' does not want to plan ahead. Everyone deserves the opportunity to be made aware of the benefits of ACP.
-  ACP is an ongoing exercise, and one which does not need to be completed in its entirety. Promoting ACP must be an ongoing activity, and the planning journey should evolve and change over time – much like any future wishes or plans would for other aspects of life.

Macmillan has developed a number of resources to help professionals start ACP conversations^{xxviii}

These include:



Your life and your choices: plan ahead¹

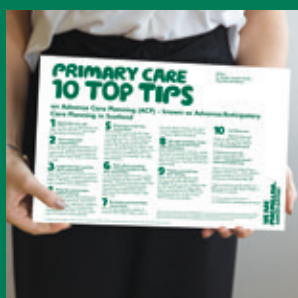
A booklet developed for patients to explain how they can plan ahead for their future care.



An ACP e-learning resource²

This toolkit has been designed to help professionals with ACP conversations. It covers a range of topics including:

- the process, benefits, and barriers of ACP,
- starting ACP conversations,
- the legal framework of ACP, and
- other ways to plan ahead.



10 top tips for primary care professionals on ACP³

This useful factsheet is a quick read for professionals but could make a huge difference to their practice.

ACP across the UK – responsibilities of governments and policy makers

At Macmillan, we recognise that the responsibility for ensuring ACP conversations take place does not fall solely to health and social care professionals.

Indeed, we believe more must also be done by the respective governments and policy makers to fulfil existing commitments on the roll out of ACP and support for professionals to have ACP conversations.

In particular, we want to see:

- >** Action to ensure better digital solutions are effectively rolled out across the UK to enable the recording and sharing of people's care preferences at the end of life. This would help in making sure ACPs are acted upon.
- >** The adequate provision and funding of high-quality end of life care and support in the community. This would reduce unnecessary emergency admissions and the number of people dying in hospital when they do not want or need to.



Northern Ireland

In 2016, Palliative Care in Partnership was established to provide a single structure, and clear direction for palliative and end of life care in the region. Among the priorities set by the Regional Palliative Care Programme Board is for everyone identified as possibly being in their final year of life to have the opportunity to engage in ACP. Several items have recently been progressed through the Programme to improve ACP usage across Northern Ireland. These include operational guidance for healthcare professionals on both end of life care and ACP. A regional ACP training framework has also been developed, targeting all health and social care staff. A draft Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) operational policy has been presented to the Chief Medical Officer.

Recommendation

The next NI Executive should ensure its Programme for Government commits resources to developing a new cancer strategy. This should target the provision of high-quality palliative and end of life care in all settings on a 24/7 basis. Everyone diagnosed with cancer should be offered ACP opportunities at the earliest possible stage.



Wales

The Palliative and End of Life Care Delivery Plan^{xxix} sets out the Welsh government's strategy for end of life care, including ACP. The ability for people in Wales to plan appropriately for their death is an aim of the plan, and references to ACP are found throughout. Within the plan's seven themes, priority actions – including ACP specific actions – are laid out. For instance, under the second theme, 'Detecting and identifying patients early', the Health Boards in Wales are tasked with identifying clinical leads for ACP. Implementation of the plan is monitored by Macmillan in Wales. While we welcomed its first annual statement in December 2017^{xxx}, we also expressed concern that 63% of people nearing end of life did not have an ACP. Macmillan's support for ACP facilitators in health boards across Wales aims to address the barriers to ACP take up through early identification of people at end of life, staff training, initiating better conversations, etc.

Recommendation

Macmillan Wales believes that to achieve the delivery plan's ambitions around ACP, we need an unwavering focus on early identification of people nearing the end of life. We must offer timely ACP before a person's health deteriorates, and record patients' wishes in an advance care plan that can be accessed easily between healthcare settings and acted upon by healthcare professionals.



Scotland

In 2015, the Scottish government published the *Strategic Framework for Action on Palliative and End of Life Care*. This made a commitment to giving everyone who needs it access to palliative care by 2021. Priority is given to ACP planning within the framework and, in particular, to ensuring e-health systems are upgraded so that end of life and ACP conversations and preferences can be shared effectively. The framework outlines that there is a need for greater support to help people talk sensitively, openly and honestly about deteriorating health and death. To support this, Health Improvement Scotland produced an ACP toolkit called *My ACP* to encourage a more consistent approach towards anticipatory care across Scotland.

Recommendation

Macmillan Cancer Support in Scotland supported the development of the Strategic Framework, and we are now looking to consider the progress it has made as we reach the midway point. One way we want to measure performance is by calling for the VOICES survey to be carried out across Scotland. That way we can measure who is receiving palliative care in Scotland and what their experience of care is. To achieve the ambition of the framework, we want to see an increased focus on ensuring that better quality information is recorded in the Key Information Summary and ACP. We also want the current system to evolve to allow broader information sharing among the multiple stakeholders that are involved in care.



England

In July 2016, the government in England made a 'National Commitment' to end variation in end of life care. This was in response to the 2015 independent *Review of Choice in End of Life Care*. If delivered, the commitment has the potential to improve the quality and personalisation of care for everyone at the end of life. It includes ensuring everyone is offered a way to express their care choices and preferences in advance. It also commits to ensuring staff responsible for the delivery of end of life care have training focused on the key elements of their roles which enable choice such as ACP.

Recommendation

Nationally, we must see renewed action to ensure the recommendations in the government's National Commitment to improve choice at end of life are implemented. This must include Health Education England training those involved in end of life care, the acceleration of the roll out of EPaCCS and sufficient investment in community-based health and social care to ensure real and meaningful choice.



Conclusion

At Macmillan, we know that too many people's preferences at the end of life are not being met. In some cases, people might not be aware that they have a choice about their care in their final days. ACP conversations ensure people are given the chance to record their hopes, wishes and fears for the future. However, the evidence presented in this report has revealed that there are many barriers to enabling these vital conversations.

It can often be unclear as to whose responsibility it is to initiate these discussions, and some professionals feel they do not have the expertise needed to introduce ACP conversations. Awareness of ACP is also low, which means opportunities to plan ahead before a patient is in touch with palliative care services are often lost. What's more, ACP discussions can seem at odds with conversations around treatment and 'fighting' cancer.

A failure to plan for an individual's final weeks and days can have numerous and costly consequences. The feeling that a patient didn't die in the way they wanted can have a significant impact on their loved ones who are left behind.

In contrast, some of the stories that have been bravely shared in this report show how giving someone genuine choice about how and where they are cared for in their final days can allow them to achieve a 'good' death. However, a shift is required in how health and social care professionals view ACP. Responsibility for it must be shared more widely across the patient pathway and it should be seen as an ongoing activity. Alongside this, further action is required from governments across the UK to ensure professionals are better supported for ACP conversations and the system is adequately resourced to meet patients' preferences.

'My dad died at home. He was nearly admitted to hospital by a sweet GP even though he had an Advance Care Plan. We kept him at home, I slept in the bed next to him and, on the fifth night, he died peacefully and in a dignified way, with the sea outside the window.'

Deb



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- ii In 2015 in England and Wales, 37% of people aged over 28 days who died from cancer died in hospital (55,256 people), 30% died at home, 17% died in a hospice, 14% died in a care home and 2% died elsewhere. ONS, Deaths Registered in England and Wales in 2015 (Released November 2016, accessed April 2017) <https://www.ons.gov.uk/file?uri=/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsregisteredinenglandandwalesseriesdrreferencetables/2015/drtables15.xls> ISD Scotland. Place of death for cancer. <http://www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/Place-of-Death/> (accessed March 2018). In 2015 in Scotland, 43% of people who died from cancer died in a hospital (6,983 people), 30% died at home, 19% died in a hospice and 8% died in a care home or elsewhere. Equivalent data not available for Northern Ireland. On this basis we estimate that more than 62,000 cancer deaths occur in hospital each year in the UK.
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You'll know that cancer can affect everything. Health, relationships, finances, and more. At Macmillan, we've been helping to ease the practical and emotional consequences of cancer since 1911. Today you can call on us whenever you feel the people in your care would benefit from extra support.

As the UK's leading cancer support charity, we can provide a range of services to complement your vital work, giving you the resources you need to help people live as full a life as possible

Working with you, we can be there for people during treatment, help with job and money worries and will always make time to listen if someone needs to talk. Whatever's needed – be it help with benefit applications or emotional support for the whole family – we can work together to transform how people live life with cancer.

From diagnosis, for as long as we're needed, we're here to help you support the people in your care and their loved ones. Visit [macmillan.org.uk/professionals](https://www.macmillan.org.uk/professionals) for more information about our services.