

**Constructing the End of Life:  
Tools, Conversations, Ideas of Home**  
**2018**  
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## Who is Healthwatch Essex and what do we do?

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Healthwatch Essex is an independent charity with responsibilities under the Health and Social Care Act (2012) to provide a voice to the people of Essex, regarding health and social care services.

The research team conducts studies on the 'lived experience' of patients, social care users and citizens to inform improvements in local health and social care commissioning and provision.

## Acknowledgements

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Attempting to work with people at the end of life can be challenging. One of the greatest difficulties of doing research on the end of life period is recruiting participants who are willing to be observed and/or interviewed during a vulnerable stage in their lives. Thank you to the doctors and nurses who facilitated the research, explaining the research to patients, asking permission for us to observe ward rounds and clinical consultations. Without their support, the research would not have been possible, and we are grateful. Thank you also, to the patients who allowed us to attend their ward rounds, observe their clinical consultations and who spoke with us during a difficult period in their lives. The friendly, welcoming attitudes of patients was both a wonderful surprise and very appreciated; thank you.

In this report, there are case studies and references to particular patients with whom we worked over the research period. All identifiable details have been changed, including the names of all the participants. The research was approved by the Health Research Authority and full ethics clearance was granted (IRAS ID 231109).

## Glossary

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| <b>DNACPR</b>                                    | Do not attempt cardiopulmonary resuscitation.<br>The purpose of a DNACPR decision is to provide immediate guidance to those present - mostly healthcare professionals - on the best action to take or not to take, should the person suffer cardiac arrest or die suddenly.<br>If a person has signed a DNACPR, it means a doctor will try to honour a patient's wishes and not resuscitate them in the event they need it. |
| <b>Renal medicine</b>                            | Medicine relating to the kidneys and kidney problems.   |
| <b>Palliative medicine</b>                       | Doctors in palliative medicine provide holistic, quality-of-life care of patients with serious, advanced progressive illnesses and for whom curative treatment is no longer possible.   |
| <b>Comorbidity</b>                               | The presence of one or more additional diseases or disorders co-occurring with a primary disease or disorder.   |
| <b>Conservative management in kidney disease</b> | The health care team continues care without dialysis or a kidney transplant. The focus of care is on the quality of life and symptom control.   |
| <b>Haemodialysis</b>                             | Dialysis usually using the blood vessels in the arm to purify blood. A fistula - an artificially formed link between an artery and a vein - is created to allow dialysis to take place 3 times per week.  |
| <b>Peritoneal dialysis</b>                       | Type of dialysis that uses the peritoneum in a person's abdomen as the membrane through which fluid and dissolved substances are exchanged with the blood.  |
| <b>Low-clearance clinic</b>                      | A renal clinic for those with kidney function of less than 15%  |

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# 1 | Introduction

A significant part of the world and the UK population is reaching an older age. Improved technologies and medical knowledge mean more people are able to live for longer, with a better quality of life. Yet, as more people reach an advanced age, they are more likely to die from long-term health conditions and have co-morbidities. This means that the end of life period can be extended, and also more complicated.

One element that makes the end of life period more complicated is navigating the places a person will be cared for, and eventually die. The NHS recommends that, where possible, people die at home - a place most people choose as their preferred place of death. One of the primary methods promoted by the NHS for improving end of life wishes, outcomes and getting people to be at home, is to do advance care planning (ACP). Yet currently, 53% of people die in hospital and 21% at home. These figures demonstrate that there is an apparent mismatch between wishes and intentions, and practise<sup>1</sup>.

Healthwatch Essex researchers conducted a study on the challenges that patients and professionals experience in trying to complete ACPs. In this report, we show how planning for the end of life is more complicated than it is imagined in the form of making a single, written plan.

The ways patients and staff talked about planning indicates that the notion of home being the best space for a dying person, or that it is the place most people wish to be is complicated.

In this report, we show how home as a place is not necessarily the best space for people at the end of life. Rather, certain affects - feelings of safety, security, comfort and reassurance - become critical to people's conceptualisation of a 'good death'. Importantly, those feelings also incorporate the way that patients' families feel. Thus, we also show how the experience of families is an essential element in constructing a good end of life period.

Part of making families feel at ease, is managing their expectations and knowledge of the dying phase. We suggest that the families of patients who have reached the dying phase, need to be better educated in what end of life experiences can look like and entail. As we grapple with the complexities of planning, ideal spaces for end of life and the role of families in care, the research findings ask us to rethink the ways planning is understood, practiced and conceptualised by policy-makers.

As we explore the dynamics of planning, support, home as best and care broadly, we ask whether State or family are responsible for care at the end of life.



## 1.1 Research & Method

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Healthwatch Essex conducts research on topics that are pertinent in the county. Topics could have been raised by media, local people, or more broadly, via national calls for attention on particular health and social care concerns. End of life care, and the lack of planning associated with this stage of life were raised by local and national health care providers as a key challenge in UK health services.

The Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020 was developed as an addition to the five year forward view. The plan was created by NHS England and it drew attention to end of life care challenges. As such, Healthwatch Essex undertook research on planning end of life care during the mid-way point of the end of life framework timeline. The research therefore speaks to the broad national framework to improve end of life care and offers a means of understanding people's experiences of the end of life planning process.

Research took place at Basildon and Thurrock University Hospital's palliative medicine and renal departments. We spent 16 weeks in two clinics and wards; renal and palliative medicine. After gaining verbal and/or written consent from patients, we observed clinic consultations and ward rounds two to three days per week.

We observed approximately 150 consultations and attended almost 100 ward rounds over the course of the fieldwork. We interviewed staff formally and informally over the 16-week research period, who we had observed and informally interviewed patients. We interviewed GPs across Essex on their views and experiences of end of life care planning and its challenges.

### Death in hospice and the compassionate death movement

The history of 'dying well' is complex. Anthropologists and sociologists studied the process of dying in hospitals in the late 1960s and the ways death is organised according to institutions and structures.

Dying, it was discovered, had a duration and shape and was deeply inflected by highly technologised processes. Elizabeth Kubler-Ross (1969) made the voice of patients a critical part of dying decisions, crafting death as an event that could be shaped by patients themselves and valued as part of an identity-making process<sup>2</sup>. Dying gently and without life support were key markers of patients' experiencing a patient-centred death: the good death.

Today, there often exists a polarisation between the 'natural' good death and a highly technologised 'bad' death. Medical-technological intervention has come to symbolise inhumane and unnatural deaths. Yet it is not as simple as this, which we explore in this report.

### Why is talking about death so difficult?

Communication challenges come in multiple forms. Cultural conversations around death often establish discomfort and ambiguity towards end of life goals. This complicates medical care, establishing mismatches in goals, expectations and results. It also makes it hard for staff to engage patients in end of life discussions.

Critical gaps in understanding of ACP, expectations and communication exist between care providers and patients. Thus, there are difficulties in understandings between carers and care-receivers. Often, the translation of NHS policies and recommendations to the practice of EoL and ACP is not straightforward or necessarily taking place. The literature demonstrates that communication constitutes a major challenge in the enactment of ACP and EoL care<sup>3</sup>.

More specifically, communication issues reflect several mismatches: doctors and patients do not know how to begin ACP discussions and feel the other is responsible for starting a dialogue, and there are differing views on the importance of ACP. Yet, the expectations, socially appropriate approaches to dying and differing views on speaking of death complicate notions of a straightforward conversation with clear roles, parameters and trajectories.

# 2 | Key Findings

*Through our research, the following key findings emerged. Details of these findings are expanded on in the report.*

## 2.1 Disruptions

Plans are easily disrupted by life circumstances and the unpredictability of life. Illness and changes in family caused planning to be inappropriate in terms of timing with care-givers.

It is therefore vital to:

- Allow enough time for unpredictable circumstances to be taken into account when thinking about planning.
- Check-in with patients about emotional state and life circumstances at each meeting.
- Ensure support is available where patient lives to help.
- Allow time to discuss plans between meetings so patients have time to internalise ideas and thoughts.
- Recognise that plans change.

## 2.3 Communication

Talking about plans for end of life when death is imminent was often upsetting for patients and was hard to initiate. Typically, health professionals used metaphors and analogies to 'soften' the discussions on death. Similarly, planning was often done in stages rather than as one large discussion and remained as a verbal conversation not a written document.

It is important to recognise that:

- Planning is often about the journey of accepting and making plans rather than having a concrete plan.
- Writing down plans can be scary for people because it makes it seem solidified without the option of being able to change.
- Planning is more usefully understood as a tool rather than a goal.

## 2.2 Complicated Decisions

Planning is not only about the individual dying; family and friends influence and are affected by the choices a patient makes. Similarly, family can impact the decisions the patient makes for their end of life care.

When we think about making plans for end of life we need to:

- Recognise that planning is not done in isolation from family.
- Support more than just the patient in coming to terms with a diagnosis.
- Realise that patient's 'wishes' might not always be what they want but what the family want. Different treatment options, deciding whether to continue with treatment and deciding on the best way to plan for end of life must be done jointly.

## 2.4 Ideas of home

Home is typically understood as a place, and the space most people hope to die in when they reach their end of life. Often though, people did not want to die at home, preferring to stay in hospital where they felt safe and cared for by professionals. While it is more economically beneficial for the state to move people home to die, it is not always the preferred place even though initially stated as such.

We need to acknowledge that:

- The place people state where they wish to die can change.
- Home is often about the feelings associated with home rather than a specific place; and hospital can become more home-like for people.
- People do not want their family to struggle caring for them and be emotionally distressed from helping someone to die at home. Therefore, thinking about what dying means for family and patient is critical.

# 3 | Unpredictability & Disruptions

## What do we mean by planning?

The kinds of planning that took place in our study were not just about advance care planning (ACP) and end of life. One's end of life cannot be separated from the rest of life, health and illness. Yet, ACP is often constructed and understood as a specific event and form of conversation - which to some degree it is - but the ways planning took place for illnesses such as renal failure or cancer allowed people to live for years, did not account for planning of health needs long-term and how, indirectly, planning for end of life was linked with treatment plans and healthcare choices.

For example, choosing dialysis over conservative management determined the kinds of care that would be required for the end of life period, even if that was years later. Therefore, the distinction between end of life planning and planning in healthcare is not as clear cut as it might appear and the timeliness of different kinds of planning overlap, connect and sometimes, clash at different stages.

## 3.1 Planning & unpredictability

### Case Study: Eliza's plan

Eliza was always accompanied by her husband and son-in-law and had come to the low-clearance renal clinic for several years. She had chosen conservative management and came to the clinic every few weeks.

When I met Eliza, Miranda, her consultant and Millie, the renal nurse specialist, had decided it was time to have a DNACPR discussion because her kidney function was declining.

When Eliza and her family members entered the room that wintery morning though, Eliza seemed down and as the consultation progressed, it turned out she had recently had an infection and had lost her hearing partially, she was tired of taking so many pills and she was sad because her twin sister had recently died.

These factors had contributed to Eliza's feelings of melancholy and as such, the consultant did not do the DNACPR discussion. She did ask to speak to Mark, Eliza's son-in-law briefly, explaining they needed to think about DNACPR but the timing had been inappropriate. Miranda and Millie spoke afterwards about how they needed to complete a DNACPR if Eliza was willing so they would try and do it next time.

In the next consultation, a month later, Eliza was still 'down', but Miranda went ahead with discussing the possibility of a DNACPR, explaining why it was important to make a decision and why she felt, from a clinical perspective, it was the right choice for Eliza. Eliza agreed almost immediately to the DNACPR but her husband was very upset, crying, because he

thought the DNACPR meant they were no longer going to care for Eliza and she would die soon.

Millie bent down close to him, explaining that this was only for certain cases if Eliza's heart should stop and they would try and keep Eliza well for as long as possible. The family left, deciding to discuss the matter at home where everyone would be calmer.

In the next consultation, several weeks later, Mark asked the consultant before the consultation, to please bring up the DNACPR as they had discussed it, but he did not wish to bring it up as it made Eliza's husband upset. Once in the consultation, Eliza agreed to the DNACPR and also discussed deciding on some plans for her end of life. While Eliza's case did not result in some planning, it took six months for a plan to be made. That Eliza was in the low-clearance clinic also meant her planning had actually begun a lot earlier.

According to her consultant, when people entered the low-clearance clinic, from the regular renal clinic, they were already on a pathway in which, dialysis choices were slowly introduced because renal function was poor.

Planning moments in the form of discussing the necessary surgery in preparation for dialysis, or not choosing dialysis, were many kinds of planning along the way which the consultants tried to plan for early.

Yet, certain plans took months to be made for particular reasons.

The cases in our research demonstrated that planning can be unpredictable. The intention to plan for end of life can exist, but it is unpredictable in terms of when it can take place, due to contexts, circumstances and people.

It is also unpredictable in terms of how it will unfold and be interpreted. It is often assumed that the most unpredictable element of end of life planning is when a person will die. Yet, in many ways, planning itself is unpredictable. As we show, planning is difficult when the event being planned for and planning itself are both inherently unpredictable.

### 3.2 Disruptions to plans

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In Eliza's journey, planning was in some ways about 'un-planning' or declining treatments and procedures. She had already chosen conservative management, the non-dialysis route, for people with renal failure.

Now that the time to plan further appeared to have come, her DNACPR discussion was in many ways not actually about her. She was clear that she did not want to be resuscitated and it was her husband who became distressed, needing explanations about the medical team's commitment to her current, and ongoing care. She was also sure of where she wanted to be when she died: at home. The latter was the verbalising of an already made decision.

In some cases, patients were not upset by talking about their end of life plans but their family members became distraught when the topic was raised. Similarly, family circumstances added to the complexities of planning. Family members dying or being ill, made the patient upset. This delayed the planning process because it was no longer appropriate to discuss end of life planning when a patient was grieving.

### Case Study: Simon's holiday

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Simon came to clinic happy that he was about to go on holiday in Italy but his consultant wasted little time showing him his latest kidney function results on the screen: they were not good.

She made Simon sit with her so that he could see the results, and their plotted decline, on the graph. Apart from wanting to get Simon into the necessary treatments, the consultant was very concerned about his travelling for a number of reasons. The chances of his needing to start dialysis at home were high and when travelling due to a change in routine and diet, the chances were made greater; as the doctor put it, "any dips right now will really set you back". He had also not had the surgery yet to create the opening for peritoneal dialysis and it would need a few weeks to heal before dialysis could begin.

Simon's results indicated that he could start dialysis now and his doctor reiterated the importance of having surgery. They had a spot available in two

### 3.3 Different plans in life

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In other cases, planning could take place, but illness upended plans and time-orientated expectations for an illness's trajectory. The case below demonstrates.



**...he was shocked at having his surgery in two days and cancelling his long awaited holiday.**

days-time - a rare occurrence - but it meant 'bumping' another patient, who was not critical, off the surgery list. The consultant explained that she felt it was extremely important Simon agree to the surgery and forgo his holiday. It was also critical that if he made the commitment, he stuck to it, as another patient would be affected by this turn of events.

Initially he did not seem to take it all in and continued to explain the holiday had been booked. Millie suggested they talk about it while the doctor made some calls to establish whether he could definitely have the surgery that week. Millie returned an hour later to say that Simon had called his wife and he was going to have the surgery.

Simon said afterwards that it was an enormous shock and not only had he been unprepared for how quickly his kidney function had declined, after a long period of stability, he was also shocked at having surgery in two days and cancelling his long-awaited holiday.



Simon's story is an example of planning 'getting in the way' of other life plans. In four other cases, patients were prevented from going on holiday or had to change their plans because of their illness and a serious change in the plans for their condition. These cases demonstrate that in cases where long-term planning is in place and an illness is being managed well, planning can still go awry. Simon's example asks questions of what constitutes planning and when end of life planning begins.

In cases where life-sustaining treatment was available along a (hopefully) long journey to end of life with a life-limiting illness, those treatments could up-end other life plans. Planning is clearly complex with different kinds of planning at odds with one another. Healthcare planning overlapped with long-term end of life planning - dialysis would prolong life and without it a direct end of life discussion would become imminent.

Thus, healthcare and end of life planning were connected and, in this instance, one set of plans disrupted other kinds of planning.

## What is the difference between advance care planning, advanced decisions & power of attorney?

Advance care planning (ACP) is understood as a 'wish list' which is flexible and not legally binding. An ACP will include details of where a person would like to die, with whom and the care a person would like to receive. It can exist as a written document (this is the ideal version so that it can be shared with all healthcare providers) or as a verbal communication in which a patient makes their wishes known to their health professional. An advance decision (AD) (also known as an advanced directive or a living will) is a legally binding document that allows a person to write down their wishes for treatments should they lose the ability to make and communicate decisions. Lasting power of attorney is a legal document that allows another person to make decisions for you if you no longer want or are able to do so. The latter two are usually used when people may lack mental capacity in the future, whereas an ACP is a plan everyone can do, even when mental capacity is not in question and it is not legally binding.



# 4 | Complicating Decisions

## Case Study: Peter's Story

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Peter came to his first palliative medicine consultation in pain. The consultant had asked how he was doing and Peter immediately described the pain he was experiencing. He used analogies of running marathons and losing ones' sense of strength to describe his pain.

At each consultation, Peter, his wife and doctor tried to adjust his medication and try new combinations but when one kind of pain stopped, another kind started. Peter's wife, Lily, was very involved in her husband's illness. She spoke about how she had recently retired as the couple were about to go travelling, when Peter became ill. Her 'job' now, she said, was caring for her husband. Lily anticipated Peter's needs, giving him water whenever she noticed his mouth was slightly dry, standing to help him before had had even begun to stand up. She was also more knowledgeable of the medication Peter was taking than he was himself.

In many ways, Lily internalised Peter's cancer saying "we need to concentrate on getting better" or, "I have so many tablets, it's hard to keep track" - using language that made it her own. Over the months in clinic, Peter's health did not improve. Some days he walked into consultation ashen-faced from pain and clearly thinner than he had been previously. Initially, Peter was determined to get well enough to have chemotherapy but as the months passed, he became less focussed on getting better and more concerned with pain relief. Lily remained positive throughout the months though and on some occasions, Peter would speak indirectly about the possibility of his not getting better or not 'being around'. Lily always quickly changed the subject or spoke about elements of Peter's illness they could 'work on'.

Peter eventually needed to go to day hospice to manage his pain and his consultant spoke to Lily too, saying it was good for her to have a break from caring for Peter all the time. The couple soon received news from their oncologist that treatment was not working and Peter stopped coming to the palliative medicine clinic because he was receiving effective pain relief at the day hospice.

## 4.1 Family, partners and health care providers

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For many people, making plans for end of life requires acknowledging and accepting that one is getting older, or that treatment is not working. Accepting these circumstances is not always just about the person experiencing them though. Sometimes patients did not accept a prognosis or did not want to begin planning for their end of life because it was upsetting for their family.

In other cases, a patient accepted their need to begin planning but family members or partners did not. It was upsetting to hear that a loved one would not get better and they had run out of treatment options and most patients had family members who were acutely involved in their care (see table 1).

In Peter and Lily's case, there were times when Peter seemed to want to talk about the possibility that he was dying but Lily prevented these conversations by focussing on his getting well.

Some relatives wanted to continue pursuing options, no matter how slim the chances were of treatment extending life. Family did not want to hear about options regarding the stopping of treatment. This made it difficult for a patient to plan their end of life and importantly, to admit that they wanted to stop treatment. It was hard to admit to themselves, and those they loved, that they wanted to stop. Such a decision could look like 'giving up' to family members. 'Giving up' was also hard from doctors' perspective.

A renal consultant spoke about how, when they tried to explain treatment was not working and they needed to think of end of life plans, patients could interpret this as being 'given up on'. Thus, planning can be disrupted by the people who are part of a patient's life, understandably, not wanting them to die. These themes address the fact that people are often not alone in their decision-making. Planning then, has to factor in families, their motives and feelings.

## Accompaniment in Clinics

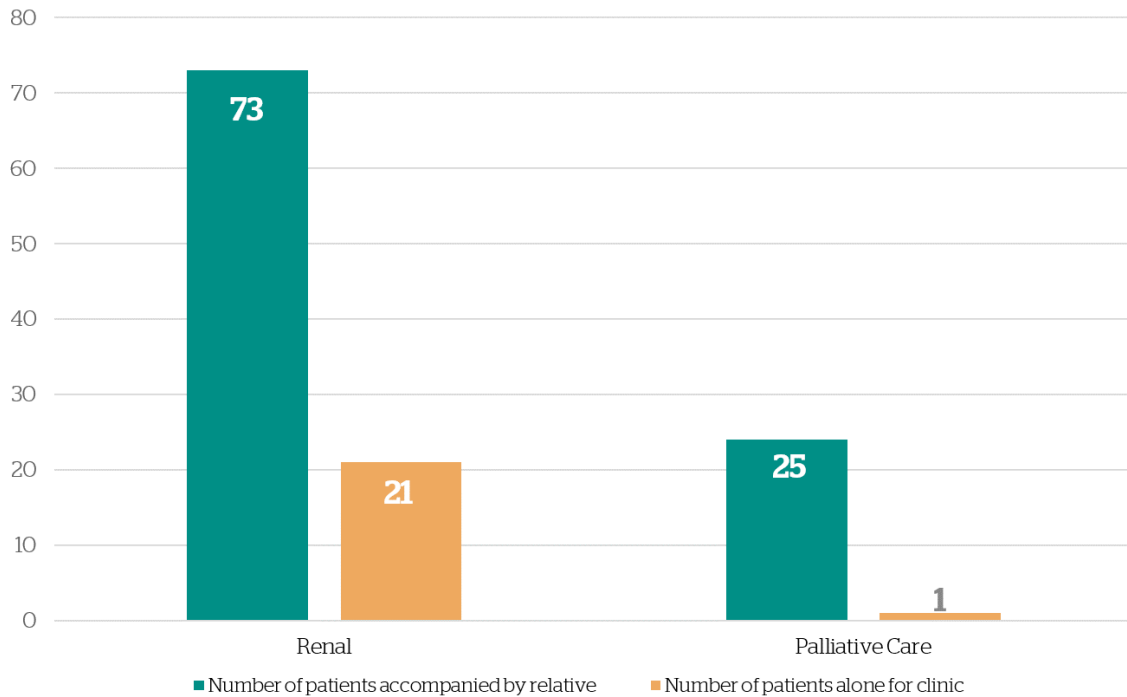


Table 1

### 4.2 Time

All of the medical staff with whom we worked for the research, struggled with questions patients asked them about time.

Patients in the renal clinic asked how long they had before dialysis would become necessary to keep them alive. Others asked how long dialysis would work. For those with terminal illnesses, questions were framed around how long they had to live. These questions were difficult to ask and answer. Patients often asked questions indirectly such as, “will I make it home for Christmas?”, or, “dialysis is a long time away isn’t it?”.

Doctors found these questions hard to answer because they could not know for definite. One doctor explained to a terminal patient that they can loosely predict how long a person has in terms of their decline. If a person’s health is changing over months, they may have months left, and the same for weeks and days. This was only an estimate and was often wrong. This is one example of the way time can make planning difficult: no one knows how long a person has left and most people wanted more time.

Another time factor was the length of time planning itself took for some patients, like Eliza, intentions for planning were established years in advance and more active planning, months ahead. Yet, it still took the medical team over three months to get a DNACPR organised for Eliza due to her circumstances. Simon’s illness took an unexpected turn, making dialysis immediately necessary.

For other patients, similar circumstantial changes made planning take place over a longer period. For example, a patient in the palliative medicine clinic gave cues that he was ready to discuss his end of life but they did not have a discussion. The doctor explained afterwards that even though he had recognised the cues, he had felt it was inappropriate to bring up the conversation, only having just met the patient.

In this way, time and relations make planning complicated. Time was needed to build rapport for a sensitive conversation but illness and changes in contexts made timing about more than building rapport - one could not always guarantee that at the next clinic meeting, the timing would be appropriate due to circumstances.

Therefore, time is a critical part of what makes planning possible and how it unfolds. Time and relations with others are connected to one another.

**Time is a critical part of what makes planning possible and how it unfolds.**

# 5 | Language & Communication

Besides the few DNACPR documents that were filled out, and the ACP of the only patient who had formally created one years ago, there were no written plans to see over the research period.

On the surface, because there was no written evidence of planning, it could appear that no ACP planning took place. Yet, we witnessed many conversations of planning. Very few however, were formally understood as planning conversations or named as such. This is because planning was often, ironically, unplanned and occurred when a patient gave cues or indicated that they were wanting to talk about their future.

It was difficult at times to know whether a planning conversation was taking place because a consultant would talk about a patient going home or ask about where they would like to be cared for but there would be no more discussion besides place of care during that encounter. In other words, planning discussions did not follow a straightforward trajectory, did not encompass all aspects of end of life planning, could not always be predicted and took place in stages.

On some occasions, particularly when a definitive diagnosis was confirmed, doctors in the palliative medicine ward would meet with a patient and their family to discuss 'the way forward'. In these instances, a specific conversation on end of life care and a person's wishes was initiated. The fact that a clear diagnosis was part of these conversations gave discussions on end of life planning an 'obvious' entry point.

Similarly, in the renal clinic, a discussion on the next steps took place when kidney function reached a specific level of decline. Yet, written plans were still not made.

In the following sections, we unpack some of the complexities that come to bear on communicating end of life planning. There were sets of language that constrained or facilitated discussions.

## 5.1 Language use and naming

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Talking about the end of a person's life was not easy for hospital staff, even though they all had experience with these kinds of conversations.

During clinic consultations, consultants often made use of metaphor as a method of engaging hard conversations with patients. Consultants would explain bad results by using common phrases such as '*another change could tip you over the edge*', or '*we have a window of opportunity before things can't be changed*'. They also used euphemistic language repertoires such as '*when your time comes*', '*you're at a turning point*', '*its on the horizon*', or '*let nature take its course*'. These phrases were used at the beginning of difficult conversations on dying.

As conversations continued, or a patient was not understanding the consequences of what was being



said, doctors often used different kinds of language. At these times a distancing form of language was used: 'we're asked to advise', 'its legislated' were ways doctors tried to explain and express the reasons they needed to have a conversation with a patient, particularly when other methods had proven to upset a patient. Language was used in these instances as a mode of distancing doctors from a hard conversation and as a method for delivering news that might shock and upset patients.

In a similar vein, planning conversations were not named as such and were often done informally and without prior planning. The practise of not naming a conversation worked to further soften and distance people from end of life discussions.

Language, and specifically, particular language sets, were used as tools by medical staff to engage with conversations that were hard to initiate and sustain. All of the medical staff interviewed explained how they had developed techniques and styles of engaging in end of life conversations. Some said they followed a particular format that they felt worked for them.

Language, formulas and techniques provided a mode of distancing that enabled doctors and nurses to provide the space and conditions for dying discussions. The skill was in maintaining a sense of care and 'humanness' while distancing themselves enough that these kinds of conversations

were indeed possible. It was hard to have these conversations without upsetting people. As writing down a discussion or plans often symbolised the concretisation of decisions, the additional layer of the written word could be frightening to patients and conversations often remained as verbal ones.

## How do we define the good death?

For many people, dying well is defined by four main factors: experiencing no pain, no suffering, being surrounded by family and often, at home. Dying well can mean different things for different people. Organisations such as Dying Matters, encourage planning so that people can talk about and write down their wishes for end of life and how they wish to be remembered, the funeral they want and how they would like to die.



## 5.2 Verbal versus written planning

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ACP is typically understood as a written document in the literature and is problematised on the grounds that while people support ACP, only 8% of people have a written ACP document. In many ways a written document streamlines planning<sup>4</sup>.

One of the challenges to ACP is making a person's plans known to all care providers. Yet written documents are also challenging. People understood written plans to be 'set in stone' and legal, as was the case with Eliza's husband, who thought a DNACPR meant her clinicians would stop caring for her.

The symbolic work of written communication can make planning too formal and can feel like a commitment that cannot be changed. Unpacking and shifting ideas of the power of the written word over the verbal is critical then to ACP challenges and planning.

For many clinicians, having a verbal discussion was more important than getting written confirmations because it was often about the journey of planning - getting patients to think about their wishes and plans, rather than the plan itself. The reason journeys were considered more important than the plan was because very few plans occurred as they were envisaged.

Our findings showed that doctors understood an outcome that was the same, to be qualitatively different when the outcome was based on a thought-through process rather than a 'default' decision (i.e. not making a decision). This was because patients who had thought through plans, even if their plan was to make no plans, knew what to expect and felt in control. This was particularly pertinent in cases of staying in hospital. Patients expressed concern at not knowing what decision to make in terms of treatment options or where they should go after they had been treated in hospital. Some were scared of being without medical support and did not want their families to have to experience caring for them as they died. Some patients preferred to stay in hospital by not making a decision to leave. These cases, while understandable, were qualitatively different for the doctors, from a thought-through choice to stay in hospital, because it was the best place for that person.

Control, expectations and the journey towards understanding and knowing what to expect were critical then to planning work, rather than the outcome itself (often constituted and defined as the good death).

Doctors explained that sometimes, just the act of thinking about plans and then choosing not to make any is enough, because end of life has been thought about.

Planning as a concept rather than a practise suggests that it is not having a plan that is as important as the

process of thinking about what one wants, even if that means negating a plan. A non-plan is better than reaching a point where a patient has no idea about anything because there has been no conversation. A non-plan is differentiated from the absence of a conversation and is therefore critical in the work the doctors were doing.

This finding shows that different people want different things. Therefore, planning as a conceptual tool can be about making opportunities possible for discussing end of life rather than 'making a plan'. It is important to recognise that planning is, in some contexts, more accurately understood as a tool rather than as a goal.

Planning works as a tool which hinges onto ideas of control and the ways people work to make themselves and others feel secure and contained.

## 5.3 Wishes versus plans

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The statement of wishes is important and can be differentiated from planning. In both clinics, doctors and nurses raised a particular element of planning, such as DNACPR, as a way of beginning conversations on planning more broadly.

Topics around end of life are often sensitive and therefore, conversations often need to be conducted in stages. Thus, encouraging patients to discuss their wishes was one method medical staff used for opening conversations with people. Therefore, even though plans were not necessarily written down, the doctors knew after Eliza's discussion and signing of the DNACPR, that she wanted to be at home at the end of her life. All of the relevant details of her end of life plans were not discussed but some of her wishes were made evident in her medical team and family so they knew.

Thus, planning can take on different forms over an end of life journey. Sometimes, stating ones' wishes is enough for some people rather than developing a full plan. Wishes do not necessarily translate to the best plans because it is someone's wish - the conflation of wishes and plans is at stake.

## 5.4 Defining 'planning'

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Planning is a complicated term and can mean and be used in multiple ways. It is helpful to bear this in mind when thinking about advance care planning as there are many people involved in the process.

Those in professional roles, government, patients and family may all have different perceptions of planning and its consequences and implications. We have shown that wishes and plans are not necessarily connected, and written and verbal forms of planning carry different symbolic weights.

# 6 | Home as a concept, home as a place

## The conceptual separation of home and hospital

There is often an assumption that for a good death to take place, it must occur at home. The assumption is premised on the work of Kubler-Ross (1969) who offered a critique of the medicalisation and over-technologisation (life support and treatments that keep a person alive, although often unconscious, who would otherwise have died) of death in hospitals.

The assumption was that a non-medicalised death was peaceful, natural, surrounded by friends and family and calm. These ideals are associated with home; a space where medicalisation is not possible in the ways it is at hospital.

An easy connection between home and peaceful death, and hospital and medicalised death is created. A binary between home and hospital is also established. The boundaries however, are blurred and home exists as a concept rather than a space.

As we attended ward rounds, patients often had their families with them. There were flowers and cards beside the bed; the usual 'get well' items. Beside these items were other familiar objects. There were chocolates, novels, magazines, vitamin supplements and for some, a framed photograph. Such items offer insight into the ways people were able to cope in hospital; they brought in objects, food stuffs that were enjoyable and familiar to them. They were often surrounded by those they loved.

One day during ward rounds, the consultants went to see a woman who was almost ready to go home. As we got there, she had a friend with her and both women were sitting on chairs beside the bed drinking tea and in conversation with one another. Other patients had their wives sitting beside them knitting or watching television with them. These observations indicate that in hospital, people make their space as home-like as possible, by having objects near them that are familial and often, from home. Food stuffs, a powerful marker of home and sensorially oriented, bring home to hospital.

It is often assumed that most people want to be at home when they die. Research shows that home is stated as the preferred place of care when people approach end of life yet our observations and interviews suggest that such preferences are not as simple as they appear.

Many patients who were not close to the end of their life - they had several months to years left - by terminal illness standards, were anxious to get home and most ward round conversations were orientated towards getting people home or reassuring them that medical

staff were working on getting them home.

For those that were more ill, often sedated or in pain, they did not wish to go home. Others, who were not critically as ill, expressed concern about going home because they did not want to burden their families or did not feel comfortable and safe in their homes anymore. Hospital, for these patients, had become their most comfortable, safe and familiar space.

Interviews with consultants suggested that while it was important to honour people's wishes, getting people home was often not the best or preferred option for many patients when it came to the end of life, even if it might have been when plans were made. One of the consultants spoke about the idea of home being a concept more than an actual space.

Our observations of patients in hospital and their conversations with medical staff confirmed this. Thus, we explore some of the findings on home and ideas of home at the end of life.

**...getting people home  
was often not the best or  
preferred option for many  
patients when it came to the  
end of life...**

## Case Study: Michael & John | Families & Planning

Michael was desperate to go home; during each ward round over a period of two weeks, he would ask if the doctors were any closer to getting him home. He was still able to move and care for himself but needed some support at home. The consultant said they were still looking for appropriate places or carers for him. After the ward round, the consultant told us that Michael's daughter's concerns about taking on care for him without support structures in place were causing the delay.

John was ready to go home but did not want to leave hospital. He knew he was dying and his wife was at home and willing to care for him. John however, had cared for his first wife at home when she died and had found the experience extremely traumatic. He did not want his new wife to go through that process while caring for him. During each ward round, as the doctors tried to plan John's discharge, he became distressed at

the thought of making his wife his primary care-giver.

Even with support at home from other family members or nurses, it was impossible to predict John's final care needs and when he would actually die and he did not want his wife to be alone when that happened. John eventually agreed to move to a hospice, but this was difficult as there were very few beds available and a person could only move to hospice when they were close to dying rather than weeks and months ahead.

The unpredictability of health at the end of life made planning for a move from hospital to home and then hospice difficult. Yet, this was still a preferred option for John, unpredictable as it was, than staying at home where his wife would have to care for him.





## 6.1 What makes for a good place to be at the end of life?

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Things, people and emotional engagements were contributing factors that affected how a person felt. The feeling of being 'at home' was often connected to families and the people in a patient's life.

During our observations of ward rounds, patients who were in the process of being discharged from hospital frequently raised concerns about who would be caring for them. An elderly spouse at home was often not well enough to care for a newly discharged partner. Patients sometimes had children who were unable to care for their parent, as was the case for Michael. Other times, families wanted and were able to care for a patient but the patient did not want to 'burden' their family. People like John found the thought of being cared for by a spouse or child, at the emotional expense of family, distressing.

Family were therefore critical to imaginings of being able to go home, home being the 'best place', making a house feel home-like and making being at home possible. Being willing and able to care for a patient at home by family was an important part of whether a patient was made to feel good at home. Feeling 'at home' is therefore partly constituted by how a patient interacts with and feels about their family, as well as their own experiences of caring for others at home.

Apart from concern for family, patients who were very ill expressed discomfort at the thought of leaving hospital because they felt they needed full-time medical care and support that would not be available at home. Feelings of fear and anxiety were common for patients being asked to make decisions about their care once they left hospital. The thought of having to manage pain relief and wait for nursing staff to visit was a frightening thought for many.

Our research showed that the ways people feel is often a critical factor in what makes 'home' for them. Therefore, feelings of safety, security and comfort, if experienced in hospital more than in their residence, could make hospital 'home' for some patients. This was particularly pertinent for many patients having haemodialysis in hospital three days per week for four hours. In these cases, as the renal nurse specialist with whom we worked explained, patients often saw the medical team more than their own families.



***Feelings of safety, security and comfort, if experienced in hospital more than their residence, could make hospital 'home' for some patients.***

Spending 12 hours per week in hospital every week ensured patients had a good rapport with staff and renal nurses were often saddened when a patient died because they had got to know them well, sometimes, over years. These situations offer insight into the ways a series of affects are produced and how patients formulate feelings associated with 'home'. Being around people with whom they were comfortable alongside feelings of safety and reassurance marked 'home' for patients. Such feelings could not necessarily be produced in patient's actual houses.

Thus, this finding demonstrates the complexity of 'home' as a term used to describe the set of affects people hope for, when they state they would like to die 'at home'. Such feelings exist alongside the experiences they hoped their families would not have to engage in producing a sense of ideals in end of life care.

## 6.2 Family and the good death

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The production of a certain set of affects (safety, reassurance and comfort) is at stake in thinking about honouring people's end of life care wishes.

Good care, in an ideal scenario, goes further than producing a positive set of feelings for the patient, and a 'good death' experience. Good care also reduces negative feelings for family members, which is integral to providing patients with a good death, in terms of their wish to not 'burden' family. The work of 'the good death' and the idea of 'home' is therefore asked to instantiate a series of 'positive' emotions and remove a set of 'negative' ones - not engaging with family experiences when thinking about planning makes the latter difficult.

In other words, at the core, patients are concerned about people - staff who are able to care for them, family who are with them and their families' needs. Thinking about the place of family is an important component in planning and engages questions of relations with others in planning work.

It is therefore critical to ask how and why relations and home are connected in planning discussions but home is understood as a best place for end of life. Home is rarely understood as a marker or symbol for the facilitation and nurturance of relations with others and the fostering of particular feelings, and why these relational connections are not supported more.

# 7 | Conclusion & Recommendations

## Conclusion

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In this summary, we have outlined the ways that planning can be obstructed due to the inherent unpredictability of physiological and social processes, contexts and the circumstances that shape the ways planning conversations take place, or not at all. We have described the ways that planning is often about the journey patients take in thinking through their wishes and expectations for end of life, rather than about the plan itself. Therefore, while end of life discussions took place over the course of our study, these were rarely a single conversation encompassing the entirety of end of life planning. Nor were the patients, symbolically concretising their choices. The discussions and *journeys* of planning were in many ways more important to patients and their medical team than the outcome of a formal written document.

Family and the deep involvements they shared with a loved one undergoing medical care contributed to the complication of planning. This was because planning was not about the patient alone. It was difficult for patients to admit they would like to stop treatment and make plans for end of life because it appeared they were 'letting down' their family. Yet, it was family that were most closely linked to patient's ideas of home when they discussed leaving hospital or where they would like to die. Patients did not wish to burden their families - this was critical to them - and many did not want to go home because that would mean family would bear witness to and be part of the end of life care process. People initially described home as the place they wanted to be at the end of life, but as people became more ill, they understood safety, security and comfort - all feelings typically associated with home - to be at hospital although this does not mean such feelings can only be experienced in any one space, or in a place where constant medical care and support was available. The creation of a series of feelings for patients and their families was therefore critical to their construction of 'home' and this is worth bearing in mind when thinking through end of life care and planning.

Our research shows that the 'good death', understood as taking place at home, needs to be rethought. The nurturance of relations and feelings can take place anywhere. Despite the economic imperative that neatly and seamlessly hinges onto home as the best place for end of life, because it is initially described as a person's wish, this does not necessarily mean that the best place for end of life medically, emotionally and socially is based on the alignment between economic drive, home and initial wishes. Wishes, planning and best practice do not always align, yet economic imperative suggests they do and home is considered best.

Thus, the question of whether State or family are responsible for caring for the dying is asked, and resources, skills, education, expectation and skills necessary at the end of life period are tied to this inquiry and are worth bearing in mind.

While home is not necessarily the 'wrong' place, place needs to be looked at more critically when thinking about end of life care, the support and education families need and the feelings of comfort, safety and security hoped for by patients when they speak about 'home'. In doing so, all spaces of care may become better equipped to engage the physiological, mental and emotional elements of dying.

# Recommendations for policy makers

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## Education

Many people do not know what the process of dying looks like or what to expect. It is common for people to imagine dying as a peaceful event in which a person falls asleep. The more distressing aspects of dying are often not known and importantly, are unanticipated by families.

If families are to care for their loved one at the end of life, they need to be supported to do so. This includes, specifically, providing education to families on what the end of life period can look like, what to expect as their relative enters the dying phase, for people caring at home, when and when not to call for help and what support is available.

## ACP as a conversation, not a goal

Planning for end of life is an important component of end of life care - it begins the process of thinking about one's wishes. Like most plans though, end of life plans rarely go as expected. Plans are better understood as a tool, to facilitate people's needs at the end of life and should be used as such.

We need to think of better tools for enabling planning discussions that do not rely on a written, complete plan. Flexible approaches to planning need to be embraced, acknowledging the complexity and variables that come to bear on the end of life phase.

## Professional medical home care is essential for supporting families

In order for families to be able to support a dying person, efficient, continuous medical care is needed. Being able to hold space for families to spend time with their loved one is critical and requires medical and emotional support.

The effect of a family member dying reverberates for a long time after they die. The effects caring for a dying person has on family and carers can be extensive. Dying patients were also keenly aware of what the impact of their dying and the associated care requirements might be on family and affected where they hoped to die - many chose hospital as a consequence of not wishing to strain or traumatise their family. As such, the emotional impact of end of life and its care on family must be factored into decision-making.

Recognising that planning end of life and where death takes place is not just about the patient is therefore critical. Acknowledging the fact and creating support structures to facilitate families after a bereavement is an essential component to end of life care planning, policy and procedures.

This point tacks onto the need for education, managing expectations for end of life so that dying becomes a less traumatic experience for all those involved.

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