

Introduction

This booklet is for those of us who are beginning to realise that we are in the end game of life. We are starting to recognise that we are not immortal after all and wondering, perhaps fearfully, how it will all end. It is particularly for those of us who do not yet have a diagnosis of a life-limiting illness - except for the fact that life itself is limited, even without an 'illness'. I am among that number, having past the milestone of three score years and ten.

Is there anything we can do to increase the chance of a dignified and comfortable death and thus reduce the risk of complicated grief for those left behind? What mechanisms exist to achieve that and what evidence is there that they are successful? Since the timing and nature of our death is unpredictable (even with a terminal diagnosis), what is the point of fretting about it and trying to second guess the outcome?

I will attempt to address these questions in the following pages and hope that, if you choose to read to the end, you will have an improved chance to not only achieving a graceful exit, but also living the rest of your allotted span in the knowledge that you have done your best and can enjoy what time is left to the full. There is a time to live and a time to die. When that time comes, you will have put systems in place to ensure, to the best of your ability, that you die in the place and in the manner that you prefer, not only for yourself but also for those who care about you.

Background

I am a retired doctor (GP and ophthalmologist) and bereavement support volunteer for Cruse Bereavement Support (www.cruse.org.uk). I have experienced several major bereavements personally, as well as being involved directly and indirectly with hundreds of deaths as a GP and supported many bereaved clients for Cruse over the past seven years

At the start of the recent pandemic, I set up and coordinated a campaign for those who would prefer to die at home with severe Covid-19, which we called 'In My Own Bed Please'. If you are interested to know more about the campaign, visit our website - www.inmyownbedplease.com.

Since then we have developed an Advance Care Plan (ACP) support service, in collaboration with Chiltern Compass – our local mortality awareness group (www.chilterncompass.org.uk). The Covid-19 pandemic demonstrated to us the importance of an ACP when faced with a likely terminal illness but with no time to think about preferences either for life sustaining treatment options or matters around the management of death.

A pilot was carried out with members of Chiltern u3a, who were invited to write ACPs after a couple of presentations during lockdown. The success of that pilot encouraged us to develop the programme using an adjustable template. We hope that, over time, the service will prove to be useful.

Considering your own death

Sooner or later the majority of us will have to accept that we will not live for ever. Those who don't will be those who die too young, too confused or without any warning. A tiny minority will remain in denial to their final breath.

Only 10% of people die without a firm diagnosis (Office for National Statistics (ONS) data) and around 25% will have insufficient time between diagnosis and death to prepare a plan (personal communication from the Goldline Palliative Care Service in Airedale). As we have experienced recently, during a pandemic, a much higher proportion may die without the opportunity to prepare. Under normal circumstances, of the 90% of people with a diagnosis prior to death, around 30% will have cancer, 30% another chronic illness and 30% severe frailty due to old age (ONS data)

Most of us instinctively shy away from considering our mortality. However this reluctance to face up to reality seems to wane as we get older and 'death' begins to stare at us from a little way off. What evidence is there that those of us who choose to talk about and prepare for our death live a happier or more fulfilling life after doing so? Could it be that becoming engaged with preparation for death could make us depressed or anxious? Could we even become so demoralised that life loses its sense of hope and purpose such that it is no longer worth living? Might it damage relations with partners or other family members?

To find out if this was the case I asked my colleagues in Cruse whether spending their time helping people deal with the fallout of death had made them depressed or demoralised. The result was reassuring. None of the respondents considered that discussing death made them feel depressed or demoralised.

They all concluded that discussing death, both for themselves and their clients, was beneficial for mental wellbeing. Obviously they had the benefit of helping people but even so, it is remarkable that, even though they were dealing with the worst aspects of death, none of them felt they had suffered as a result.

In La Crosse, Wisconsin, where at death 96% have an ACP, people reported an improvement in mental health and well-being after contemplating and planning for their own deaths (www.respectmydecision.com). More research in this area would be helpful, but so far, everything points to a positive outcome for quality of life after mortality acceptance combined with planning ahead.

If consciously considering our own death reduces a subconscious anxiety and fear, then it would make sense that people should express a sense of relief and a feeling that a burden has been lifted when they have completed an ACP, with all the necessary preparation and discussion involved.

What may be important is to have experienced support available whilst exploring the ramifications of advance care planning. Making a plan may bring up thoughts of bereavements from the past and unprocessed grief may need to be attended to. Also some will require help with the associated anticipatory grief that they will experience both with their own loss of a future and the effect of their death on those around them.

The definition of an Advance (no'd') Care Plan.

An Advance Care Plan has two parts - an Advance Decision to Refuse Treatment (ADRT) and an Advance Statement of Wishes and Preferences (ASWP).

The ADRT is essentially a list of life-sustaining treatments which the author of the plan does not wish to have and the circumstances in which those refusals apply should they lose capacity. As long as the author has capacity (see next chapter for definition) at the time of writing, and the ADRT is signed, dated and witnessed, it is a legal document (as designated in the Mental Capacity Act 2005) which must be respected by health care professionals (HCPs) involved in any end-of-life care. It must also clearly state that the decisions apply even if life is at risk.

The ASWP is a list of the ways the author would prefer their care to be handled should they lack the capacity to express those preferences at the time decisions need to be made. This might include where to be cared for and by whom for example. Unlike the ADRT, this part of the plan is advisory only but is, nonetheless, very helpful to HCPs when faced with care decisions relating to an unconscious or confused patient.

Some organisations include other death-related arrangements such as wills, Lasting Powers of Attorney, funeral plans and digital legacy under the heading of ACP. Although these are important considerations in themselves, for this booklet I consider them to be outside the remit of the ACP in which 'care' is the operative word.

The definition of capacity and its significance

Capacity is defined in the Mental Capacity Act (2005) and states that a person is unable to make a decision if they cannot –

- Understand the information relevant to the decision
- Retain that information
- Use it or weigh it up as part of making the decision

Examples of people who may lack capacity include those with –

- Dementia
- A severe learning disability
- A brain injury
- A mental health illness
- A stroke
- Unconsciousness for any reason

People may have capacity to make some decisions and not others - for example a decision about what to eat compared with a complex financial matter. Also capacity may come and go.

Evidence of effectiveness

How can we be sure that writing an ACP will be effective in achieving a graceful exit?

The answer to that question is that we can't be sure, however several studies have demonstrated that having an ACP in place improves the chances of dying where and how we would wish (www.acpdecisions.org). It must be said that the majority of studies have been in patients dying of a known illness when the ACP was made after diagnosis. In places such as La Crosse, Wisconsin, where having an ACP is the case for 90% of over 65s, the same applies, however.

What we do not have is statistics relating to those who die of a short illness with and without an ACP in place. As the interval between writing an ACP in the absence of a diagnosis, and the author's death could be very long, the data is going to be hard to come by. What might be possible to analyse, once more people have written an ACP, is how often a non-specific ACP has to be modified in the light of a life-limiting diagnosis.

Bereavement and ACP

There is substantial evidence that the incidence of complicated grief is reduced as a result of the deceased having had an ACP. Complicated grief is when the normal process of grieving is interrupted by unresolved thoughts, feelings or experiences about the dead person or the circumstances around their death. It is a major reason for the bereaved to seek support.

Personal experience and that of my colleagues in Cruse is that a 'poor' death is a common cause of complicated grief. Unnecessary CPR in the very elderly or people dying alone in hospital are common examples. An ACP can prevent these harrowing experiences which may sometimes even lead to Post-Traumatic Stress Disorder.

Much of my time as a doctor was spent in preventing disease rather than curing it. Now I see my role as an ACP advocate and supporter as preventing complicated grief. Grief is inevitable, but complicated grief is not. Complicated grief has repercussions way beyond the individual suffering from it. It extends to the whole family, the workplace, social interactions, unrelated health issues and sometimes preventable death.

Making sure it works and is available when required

Making a plan which covers all eventualities is not possible, but even if circumstances urgently arise which do not fit in exactly with it, the general tenor will allow the HCPs to make a more informed decisions than would be possible otherwise.

It's easy to make generalisations about refusals and wishes that ignore some scenarios – e.g.

- 'I don't wish to go to hospital' - with a broken hip?
- 'I don't wish to receive CPR' - with a sudden change in rhythm?
- 'I don't want to be ventilated' - even with Guillain-Barre' syndrome (a temporary paralysis after a viral illness)?
- 'I don't want antibiotics' - even for a urine infection?

It is important to establish that your wishes are feasible – e.g.

- Your partner and/or relatives are prepared and able to help care for you at home
- You have space for a hospital bed in your house
- There is a hospice nearby that will admit you for end-of-life care
- Your GP can access the care team to be able to die at home
- Your local hospital is not so busy that it cannot admit you

It may help to work through your plan with an ACP counsellor to ensure the best chance of it being effective.

It is essential that your plan is accessible to all HCPs involved in your EOL care at all times. In some areas it can be put on a data base accessible to all HCPs but not in all. Make sure paramedics/first-attenders can find it in an emergency. They are advised to look in the fridge, so put a guide to its whereabouts in a labelled pot placed prominently in there.

It is advisable to make several copies and give one to your GP to go onto your Summary Care Record and have at least two at home - all properly signed witnesses and dated. Only take one into hospital as it may well get lost and you will then have to start again.

Each area will have a preferred ACP format and you might be encouraged by your HCP to use that in order to improve accessibility and HCP recognition. However our plan can easily be adapted to these formats and often can be included, all of a piece, in the local version.

The ‘In my own bed please’ ACP template

There are several organisations in the UK which offer guidance and various levels of support and formats (e.g. www.compassionindying.org.uk). After discussion within the IMOBP team and with friends and relatives, we found that there was a strong preference for a completed template that could be altered rather than an empty form or an algorithm using a series of questions.

We set about devising our own ACPs and then came together regularly until we had arrived at a version that was closest to all our individual plans. The template is available on our website – www.inmyownbedplease.com - on the page ‘ACP support’. It can be downloaded and then adjusted to suit your particular needs. There is also a blank version if you prefer to start with that. The ACP template is appended at the back of the booklet.

We all started off with long detailed plans that would have been impossible to absorb in an emergency situation, so we have whittled it down to the bare minimum, keeping it to one page for the ADRT and another for the ASWP.

It is essential to leave in the statement that ‘the refusals apply even if life is at risk as a result’; otherwise the ACP will not have legal validity.

We would appreciate if those using our service could send us their completed plans. This allows us to check that they don’t contain any contradictions, covers most eventualities and are valid.

For anyone struggling to write a plan using the template, we offer one-to-one support either by email, phone or zoom – to access, email contact@inmyownbedplease.com or if necessary in person.

Revising your ACP

Once you have written a plan, it is a good idea to reconsider it every year or two, or if you should receive a diagnosis that is either long-term or life-limiting.

As we go through life, our priorities and responsibilities change and as a result so will our ACP. Those of us in the latter part of our lives will find it easier to let go and may choose to avoid life-extending interventions with serious side-effects and limited benefit. Those of you who are younger, with responsibilities and ambitions to achieve more out of life in the future, will mostly likely want to pull out all the stops in the event of life threatening illness or accident. As we move gradually from one to the other we must adapt our plan accordingly so that it truly reflects our wishes at the time.

One thing to be considered is whether we can predict how we will feel about our EOL care when the time comes and if, at that moment we feel differently, should we then express that change of heart or let the plan stand on the basis that when we made the plan we may have been thinking more rationally and not influenced by fear or anxiety.

On the one hand, it is reassuring that we can override the plan if we have capacity (indeed it only becomes valid when we lose capacity) but on the other hand, what is the point of writing and subsequently adjusting the plan if we cannot be sure that when we have to make the decisions about life-sustaining treatments, we have a change of heart?

I consider that, in the knowledge that we might and can have a change of mind at the last minute, it is still a worthwhile exercise and, having taken the trouble to make a plan, it will inform any decision we do make, even if it were to be a different one. Indeed that different decision, were the author of the plan to survive the life threatening event, could be written into it.

The plan is also available should we still have capacity but be feeling so weak or ill that we prefer to refer any HCP requiring direction to it, rather than go into our decisions and the reasoning behind them.

Lasting Power of Attorney and ACP

There are two types of lasting powers of attorney - one for finance and property and the other for health and welfare. They can only be arranged when you have capacity and give one or more people the power to make decisions about those matters on your behalf. In the case of health and welfare, those powers only come into play if you lose capacity. I will just address the latter.

If you choose to have more than one attorney you must decide whether they must act jointly or can act independently of each other. In the first instance no decision can be made unless all attorneys agreed. In the second, any one of them can make a decision. This allows for them not all being available at the appropriate time.

You have the option of including decisions about life-extending treatments or not. If you do include them and you have made an ACP which predates the LPA then the latter takes precedence and vice-versa. However there is a box on the form which allows you to express how you want your attorney to act and you can insert your ACP into that.

The advantage of having a valid LPA is that, if circumstances arise that aren't well covered by your ACP, then your attorney can make the decision on your behalf. The disadvantage is that you are handing over ultimate responsibility for life-extending decisions to someone who then has to cope with the emotional fallout if that decision turns out to result in unintended consequences and a poor death.

You might therefore prefer for the HCPs to take responsibility for any decisions not covered by your ACP in order to prevent the risk of guilty feelings interfering with the bereavement process for your attorney/s

Do not attempt cardio-pulmonary resuscitation (DNACPR)

A DNACPR instruction can be attached to your medical record by two methods.

The first is a medical decision (usually but not necessarily made in consultation with the patient or the patient's attorney for health and welfare) by the HCPs involved in your care on the grounds that it is not an appropriate intervention should the heart cease to function as an effective pump. This may be because the heart has failed due to an untreatable condition in another organ or organs - which means that either it would be unsuccessful or that in the unlikely event of success would result in a further failure very soon – or that the heart itself was malfunctioning in a way that could not be reversed by electrical or drug interventions. It is attached to the record to prevent a crash team arriving by default when the heart stops pumping and performing a traumatic and hopeless manoeuvre to everyone's disadvantage.

The second is as a result of an ADRT as part of a valid ACP or a decision to refuse treatment by a designated attorney for health and welfare.

It's important to be aware that if you mention DNACPR in your ACP but specify that it does not apply in all circumstances (eg if you collapse suddenly without a firm diagnosis) then your GP may erroneously attach a DNACPR to your record, which would then apply in all circumstances. It's worth checking your Summary Care Record to make sure that hasn't happened - (it happened to me!).

Improving End-of-Life support

It's all very well making a list of preferences, but what if the services to support them are not available? For example – you may prefer to die at home, but if you live alone, or the other occupants of your house are unwilling or unable to help care for you in the last days or weeks of your life, local community health and social services may not have the resources to take that on.

In theory, data from ACPs could have an effect on government policy relating to access to palliative care at end of life. If enough people wrote an ACP and it became evident that there was an unmet need for say more palliative care in the community or more hospice places to cater for all those who would wish to die in a hospice, then there would be an incentive for those services to be enhanced. The stumbling block is access to the data. It would need to be collected from every planner (as is the case for example in Spain).

There is another more dubious motive for ACPs possibly influencing government policy and that is one of cost. In Wisconsin, the high take-up of ACPs has resulted in significant cost savings. Although this is a somewhat unpalatable, it might incentivise government to take ACP more seriously, to the benefit of all.

IMOBP has been particularly concerned about access to emergency palliative care, which was a problem during the pandemic. Patients suffer an average of four emergency hospital admissions during the last year of life partly due to poor access to urgent care at home,

combined with a lack of ACPs (data from Marie Curie). Alongside Chiltern Compass, we have visited two palliative care services in the UK that have solved this problem - in Pembrokeshire and Airedale – both in their own different ways. Examples of excellent practice such as these can act as incentives to other areas to find their own local solutions to this problem. What was once the role of the on-call local GP has to be taken on by other agencies now that GPs no longer have out-of-hours responsibilities.

Having the conversation.

In order to find out what is feasible and acceptable for your family and friends, you need to have a conversation about what you would prefer and what they can manage – especially if you would like to die at home. This is bound to be upsetting but it needs to happen in order for the plan to be viable and for them to be prepared.

At first they might react with expressions of denial or false reassurance that you are not going to die any time soon. You need to gently explain that you are making a plan so you can put your and their minds at rest, so that you can live your life fully without the nagging worry about what might happen.

When they understand that this plan is for both you and them – to make your death easy for them too as well as in the aftermath - they will usually come round to your way of thinking and discuss what can be done to make your wishes come true.

Sometimes it helps to have a third party present at the discussion. It could be a palliative care nurse or an ACP supporter. IMOBP is able to offer such support virtually and if necessary face-to-face.

Once it's out in the open then you will be able to discuss the other relevant issues such as LPAs, your funeral arrangements etc.

Although it is not necessary to discuss your ACP with your GP, or get them to sign it – it does carry more weight with hospital staff if your GP has confirmed that they have discussed it with you and that you were of sound mind when you made and signed the plan. It also makes your GP aware of what you do and don't want to happen when you are dying and whether these requests are manageable within the resources available in your community. It could even result in a change of practice at community level.

ACP as an act of love

Over the past three years, since first recognising the significance of ACP and the power that it has in determining outcomes around death and dying, I have come to regard it as an act of kindness, generosity and even love. It changes both death and life for all the people involved.

In the first instance it is an act of love to oneself as it increases the likelihood of a calm and dignified end, more relaxed last years of life in the knowledge that the grief of those bereaved by your death is likely to be less painful.

Secondly, for those who care about you, you have reduced the stress around your death by telling them what you do and don't want, as well as making a good death more likely, resulting in less chance of complicated grief for them. At worst, a bad death can result in life changing damage to mental health, including PTSD and even suicide.

Thirdly, for the HCPs and non-medical carers looking after you, you have removed the need for them to second guess your wishes or revert to default procedures which they feel obliged to carry out. It makes their life less stressful and exhausting.

Fourthly it's an act of love to the whole of society. If you choose to die out of hospital and with minimal interventions, you are freeing manpower and resources for the benefit of others.

Assisted Dying and ACP

Whatever your views may be about assisted dying - as far as including it in an ACP is concerned - a wish to have assistance to die under certain circumstances is not likely to be possible in the foreseeable future in the UK. In most countries, where assisted dying is legally permitted at present (with the exception of Holland and Spain), the person being assisted to die must have capacity up to the moment of the administration of the drugs. That means an ACP cannot apply, as it only comes into force once you have lost capacity.

Unintended Consequences

How can we be sure that our plan won't have unintended consequences that impact adversely on friends and family? How can we balance our preferences with theirs and how far can we expect them to comply with those wishes should they require them to act in ways that may be hard, distasteful or disruptive to their daily lives and their other dependants? These are tricky areas and need to be addressed with each individual who may become involved in your care.

Complicated grief is often caused by guilt – often unreasonable guilt – about things which happened around the death which were unexpected, unprepared for or unavoidable. If you plan requests a particular care from a person or group of people who are not paid carers and they are unable to provide that care at the time it is needed, then you are setting them up for a difficult bereavement.

When working through this often irrational guilt with clients in complicated grief, it becomes apparent that it could usually have been avoided by having an in depth conversation ahead of time about what is actually on offer and/or realistic as far as unpaid care is concerned.

On the other hand, if your plan rules out any unpaid care from friends and family in order to protect them for inconvenience or upset, you may be depriving them of a role they wish to perform out of love for you and thus precipitate guilt because they weren't given the opportunity to provide it. Caring for someone you love can be very rewarding. It is both life-enhancing and an immunisation against complicated grief, when it goes well.

Conclusion

I hope this booklet, summarising the benefits of planning for your death, has proved worth reading.

There are many calls on our time and writing an ACP will often get pushed down and down the list. It may take a recent bereavement or a new diagnosis to trigger you into action, but from my own experience, I can assure that it is beneficial both for you, and those around you, to have brought fears and anxieties around death and dying into the open and to have done something to allay them.

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