The Initiation of Advance Care Planning in Community Care Settings

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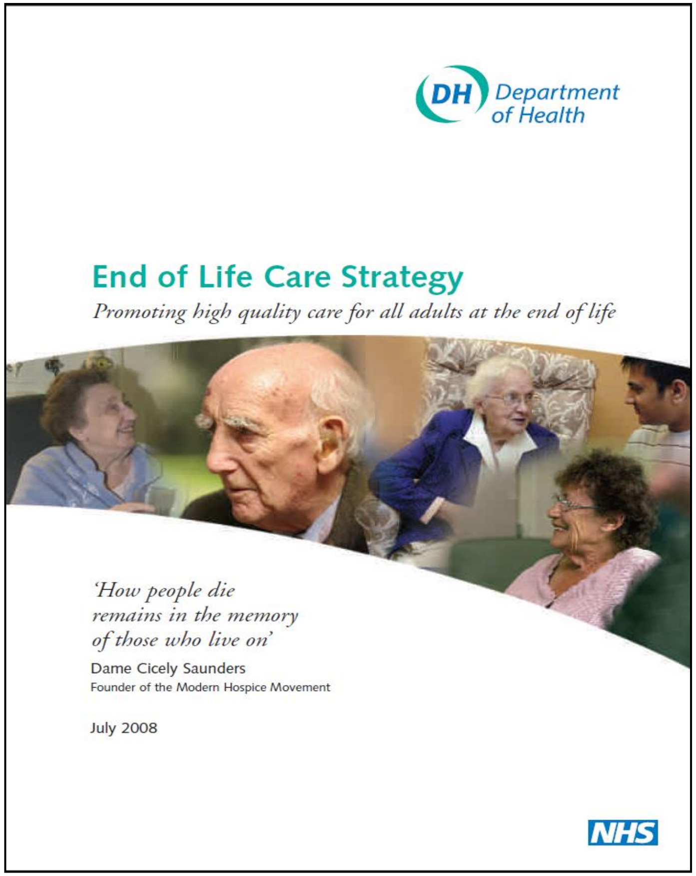
End of Life Care

Challenges:

1. Supporting patients through an extended period of decline and frailty before death.
2. Recognising the point of transition between active and comfort/palliative care.
3. Managing the social and economic costs of caring for increasing numbers of frail elderly people.
4. Changing the way we experience, organise, provide and pay for care.
5. Encouraging everyone to talk about death and dying

End of Life Care Strategy



DH Department of Health

End of Life Care Strategy

Promoting high quality care for all adults at the end of life

'How people die remains in the memory of those who live on'

Dame Cicely Saunders
Founder of the Modern Hospice Movement

July 2008

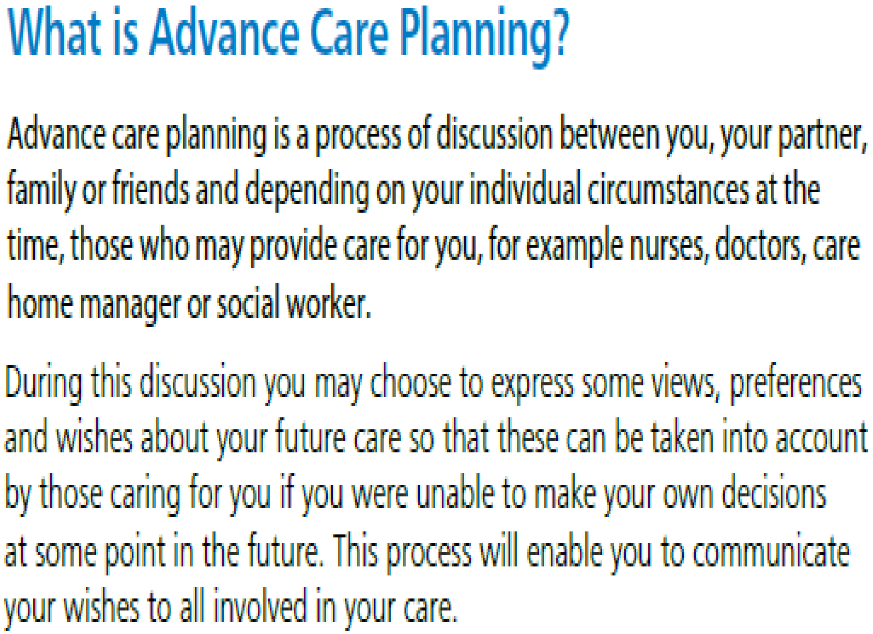
NHS

"the lack of *open discussion* between health and social care staff and those approaching the end of life and those who care for them, as one of the key *barriers* to the delivery of good end of life care"

Advance Care Planning

Planning for your future care

A GUIDE



What is Advance Care Planning?

Advance care planning is a process of discussion between you, your partner, family or friends and depending on your individual circumstances at the time, those who may provide care for you, for example nurses, doctors, care home manager or social worker.

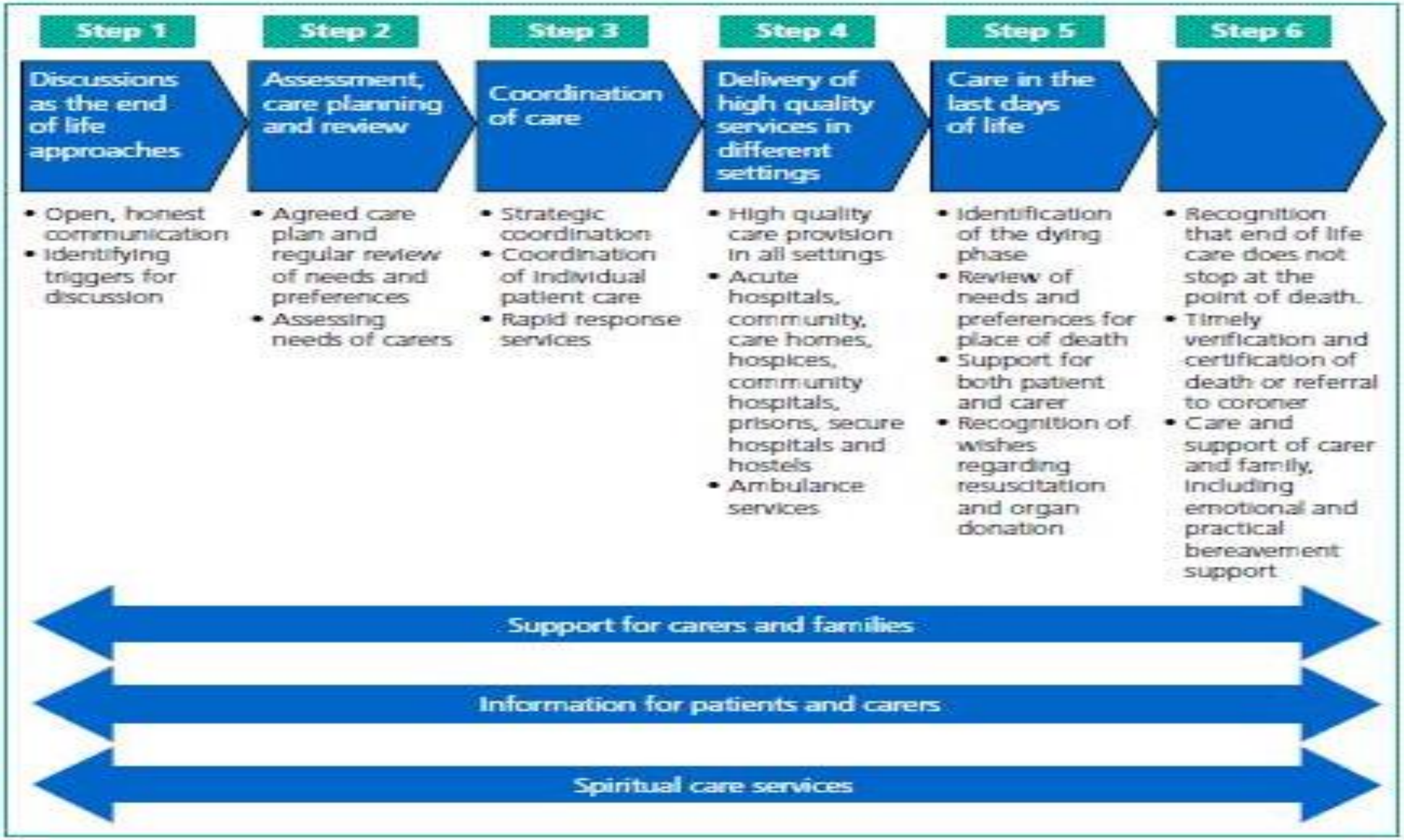
During this discussion you may choose to express some views, preferences and wishes about your future care so that these can be taken into account by those caring for you if you were unable to make your own decisions at some point in the future. This process will enable you to communicate your wishes to all involved in your care.

Aspects of Advance Care Planning

- Opening the conversation
- Exploring your options
- Identifying your wishes and preferences
- Refusing specific treatment, if you wish to
- Identifying who you would like to be consulted on your behalf
- Appointing someone to make decisions for you using a Lasting Power of Attorney
- Letting people know your wishes

Planning for your future care, 2014

The end of life care pathway



Step 1
Discussions as the end of life approaches
- Open, honest communication
- Identifying triggers for discussion

Step 2
Assessment, care planning and review
- Agreed care plan and regular review of needs and preferences
- Assessing needs of carers

Step 3
Coordination of care
- Strategic coordination
- Coordination of individual patient care
- Rapid response services

Step 4
Delivery of high quality services in different settings
- High quality care provision in all settings
- Acute hospitals, community, care homes, hospices, community hospitals, prisons, secure hospitals and hostels
- Ambulance services

Step 5
Care in the last days of life
- Identification of the dying phase
- Review of needs and preferences for place of death
- Support for both patient and carer
- Recognition of wishes regarding resuscitation and organ donation

Step 6
- Recognition that end of life care does not stop at the point of death.
- Timely verification and certification of death or referral to coroner
- Care and support of carer and family, including emotional and practical bereavement support

Support for carers and families

Information for patients and carers

Spiritual care services

The Black Box

- Communicating with patients, families and carers about ACP and the transition into palliative care at EOL is difficult
- Little known about
    - how conversations about preferred priorities for care and death are initiated and facilitated
    - Patient and carer experiences and preferences
- Lack of research to establish how decisions are communicated and implemented over time and at points of crises

"Care and communication between health professionals and patients affected by severe or chronic illness in community care settings"

Aims:

To investigate

- how patients, informal carers and health professionals negotiate the initiation of Advance Care Planning (ACP)

- the outcomes of ACP discussions in terms of how closely expressed preferences for EOLC are realised

Study configuration

Professional Perspective Interviews:

- semi- structured interviews with HCPs providing EOLC

Longitudinal patient-centred case studies:

- semi- structured interviews with patients judged to be in their last six months of life and their nominated informal and professional carers.
- six month follow up
- review of medical records

Professional Perspective Interviews

Professional	Number interviewed
GPs	12
Community /district nurses	5
Community Matrons	6
Heart Failure specialist nurses	6
Specialist palliative care nurses	3
Specialist nurses (specific conditions)	3
Allied Health Professionals (AHP)	2
Total:	**37**

Patient Case Studies

Patients (n=21)		Family Carers (n=13)			Healthcare Professionals (n=14)	
Male 12	**Age range** 62-91	**Male** 3	**Female** 10	**None** 8	(General Practitioner) GP	5
					Palliative Care Nurse (PCN)	3
					Allied Health Professional (AHP)	3
					Community Matron (CM)	2
Female 9	**Age range** 38-92	Spouse		10	Consultant in Palliative Medicine (CPM)	1
		Son/daughter		2	**Total**	**14**
		Sibling		1	None	7

Cases with documented EOLC planning

ACP element	Cases (n=20)
Any element documented	17 (85%)
GSF register	15 (75%)
DNACPR	11 (55%)
PPOC/PPOD	11 (55%)
Anticipatory Medications	7 (35%)
Fast Track	5 (25%)
DS1500	5 (25%)
ADRT	1 (5%)

Recorded time on GSF register

Case	**Time on GSF**
Mrs. Tomlinson	1 month until death
Mr. Brown	2 months until death
Mrs. Jones	2 months until death
Mrs. Winters	2 months until death
Mr. Corley	6 months until death
Mr. Andrews	10 months until death
Mr. Farley	14 months until death
Mr. Williamson	26 months until death
Mr. Barlow	6 months ongoing
Mrs. Harrison	12 months ongoing
Mr. Roper	14 months ongoing
Mr. Arthur	16 months ongoing
Mr. Jenkins	18 months ongoing
Mrs. Elder	22 months ongoing
Mrs. Barker	33 months ongoing

Professional Perspectives

- ACP linked to better outcomes at EOL
  - Death at home
  - Increased sense of control

- Little knowledge or use of EOLC PW and resources

- ACP not common
  - Reduced to documentable items and specific targets:
    - DNAR; PPOD; avoiding Hospital admission
  - Usually one-off event vs process

The benefits of ACP

No pain and no transferring from home in an ambulance to hospital, no cannula, no arterial bloods which they hate because it's so painful, the arterial blood gasses. And her husband was very, very pleased that this happened: she died in her own bed in her own house without suffering. *NC102*

Whereas if they've had time to discuss an advanced care plan, I'm not suggesting that they're not fearful and that you haven't got issues to deal with on the way, or things that might not have been addressed. But I think they have a greater control, I think they have taken a little bit of control about what's happening to them.

CM4

Barriers to ACP

- Discussions are difficult
- Prognostic uncertainty undermines value of planning
- Patients don’t (want to) realise they are dying
- Patients don’t want to engage in discussion
- Preferences cannot be guaranteed/risk of false expectations
- Preferences/plans subject to change

Difficulties of prognostication

But with long term conditions, you can look at someone and think, ‘Well, actually, I don’t think you’re going to be here in six months’, and two years later, they’re still bumping along. So it’s far more difficult to predict.
CM101

I’ve just spoken to a family now and they were told that their father had got three months, at the most, absolutely, at the most. So the family had put every bit of energy they’ve ever got to look after their dad in what they thought was the last three months. This guy’s now been going for nine months. They’re absolutely exhausted. They’ve sort of put everything in but now, they don’t feel that they can say to him, ‘We’re all exhausted, we need you to have some respite.’ *CC101FG*

Patient resistance

Just thinking about it. I mean this is not scientific at all, but perhaps about 30% of people want to pursue, 30% don't and 30% will partially engage. That's just a feeling I've had thinking of the ones that I've been involved with over the last couple of years. GP12

It was quite difficult with her [patient] because she does know that she's not so good and things are probably going to get worse but she really doesn't want to… Actually she said that 'Yes, I do have worries and concerns but I really don't want to talk about them at the moment.' And you sort of leave it at that. The sort of the first step has been made really and that may always be the case she may never want to say anything else. But I think giving that opportunity and getting it out in the open seems to be the main thing. GP2

Changing plans

I had a patient a few years ago who was absolutely adamant he was going to die at home. And the family supported him with it and he ended up unfortunately being admitted to hospital. … throughout all his care, he'd said, 'I want to be at home. I want to be at home.' But in the cold light of day it was, 'Actually, no, we [family] can't deal with this, let's have him in hospital.' And he agreed. You know, it wasn't against his will… CC101FG

And if somebody's saying to me that they want to die in the hospice, whilst acknowledging that is their preferred place, I would also say, given limitations, we can't always guarantee, and try and put that across so they're aware what other options would be. But, I think, sometimes, it's taken out of their hands if they go in with an acute episode of something and then don't recover from it or deteriorate. PCN4

Initiating ACP

- waiting for patient to take initiative (not common)

- searching for cues
  - a ‘window of opportunity’

- reactive rather than pre-emptive

- stepped, incremental approach

- vague language and euphemisms

Who initiates the discussion?

And this time, only three weeks ago, she said she, if it happens again, she's not going to go in [to Hospital]. She agreed to it and husband was fine with it, her family all right and we get the DNR form signed. And yeah, then she died at home, that's what she wanted. NC102

Some GPs, because we go to all the GSF meetings, and I was at one last week, and it was brought up, and the doctor said, 'I can't do that. I can't have that [ACP] discussion, can you?' And asked one of the district nurses if they could and she said, 'No, I can't.' But I have to say, as a community nurse, I often had those discussions with a patient, very often because I was best placed person, I've been visiting …

CC101FG

Cues

And you can tell, when you're talking to somebody, whether they're going to be receptive or not or whether it's the right time. And often, it's the patient that will make a comment. You know, if they say 'I don't want to go back into hospital', then you can say, 'Well, where would you like us to look after you if you start to get more poorly?' Or, you know, something happens, what would you want? *CC101FG*

Sometimes you have to just put the picture there, 'Well, you know, this is what the consultant said and this is where we're at and this has been happening. What do you think's happening now?' Personally, I try for them to see what's happening and take their cues. But sometimes, you can't do that, sometimes you have to be a bit more proactive, and even then, they're not always receptive.

B402HP

Vague language

So sometimes when patients say, ‘Oh, I want to try and stay at home,’ they don’t always mean they want to die at home. And often, if you pin people down a bit more, they might say, ‘Well, I want to stay at home as long as possible or, want to stay at home as long as I can cope or as long as my carers are coping.’ So there’s often a lot of, sort of provisos along with that really.
H303HP

I’m sure I used euphemisms rather than ...We had a discussion that, you know, ‘If you were to become unconscious or you’re slipping away, whether you’d want, if the ambulance came, to resuscitate you?’ *GP14*

Documentation

People often see all the procedures, along a pathway and actually they miss the end product that they're looking for. So, you can tick all the boxes but actually, you've missed the spirit of the thing.

GP4

It helps you focus on what stages that you think the patient's at and in theory, then what we should be thinking about at those different stages? I'm loathe to call it a tick-box exercise because it's not …I think it just reminds people.

PCN2

Targets

There's no pressure in that respect in the driver of keeping them out of hospital. I've not got the pressure, but obviously they wanted to reduce hospital admissions.... I don't know what kind of point system it's got, but if you'd filled an advanced care plan, preferred priorities of care in, it counted as one of their QOF points …So each one that you'd done, obviously, it looked better, and they did aim that everyone that was palliative had one of those in place. DN4

Well we've had that priorities of care plan …Last year it just came out and I don't know if it was a CQUIN target and one month we had to record how many people we'd given those out to. And whether they filled them in or not was irrelevant; it was just whether we'd offered that piece of paperwork. So we did it once, and then never really heard anything about that again. …it was basically a quality marker of how well you're doing. …and there's money attached to those. So it's not really a target, but if you don't meet that money gets taken from the organisation. DN5

‘Persuasion’

And I think relatives panic. If you saw your loved one not breathing……If you see your loved one struggling for breath, knowing everything that’s in place, ***you’ve been told, ‘Do not call 999’,*** *what you going to do? Of course you’re going to, and* ***that’s why we try and, you know, go on and on about it*** *just because, we know it happens, reality is, Who wouldn’t?…* *CC101FG*

So, I have a patient at the moment that’s, ***we’re just managing to turn him around*** *to see that actually, no, he does want to be at home. …. It was all about communication, he now doesn’t want to go to hospital so we’re going to be able to keep him home successfully* ***and save all that money,*** *that unnecessary thousands and thousands of pounds.* *D103N*

The patient perspective

- Uncertain, pragmatic, complex and shifting
- Desire for limited information
  - Wanting to know, but not too much
- Living in the moment: one day at a time
- Denial as a positive strategy
  - getting on with life
- Not wanting to be a burden
- Preference for informality and trust
- Deference to professional expertise

Patient responses to future planning

I've done my funeral, it's all in place. It's all done. Right down to the lining in the coffin, I've chose everything for my funeral. …I didn't want my husband to think and worry 'What would she have wanted? Would she have liked this, would she have wanted that?' So, we have discussed it, we have talked about it and I chose a funeral directors ... [my husband has] not got anything to worry about. (Mrs. Jones, Int1)

I don't think I think about the future. I think I just take it more or less a day at a time. …I can't think long term because I know, like I said to you, I know I'm not going to get better. How long I've got? I don't know. Because, how long is a piece of string? I mean, I don't think they, doctors, really know, do they? (Mrs. Avery, Int2)

Pragmatism and uncertainty

I would rather stay here [home] for as long as possible. If it gets to the point where I can't manage to go to the toilet by myself, I'll have to rethink that. And I think everyone's got their limits of what they're prepared to put up with, or dignity. There's all sorts of things that come into it, into play. But I'm not at that point at the moment.

Mr Brown (Int 1)

I said I would prefer if possible, at home. But I think they've stopped one of the services that the Macmillan nurses used to provide, where they come and stay with you. So I don't know whether that would still be allowed. But I don't want to go into hospital, I'd rather go to the hospice, if I, well, I won't have a choice, will I, really?

Mrs. Elder (Int2)

ACP and outcomes in EOLC

- 9 patients died during follow up
  - documented preferences
    - 5 home ; 2 home/hospice; 1 no preference; 1 not recorded
- 6 patients died at home
    - 3 via fast track from hospital
    - 1 avoided resuscitation because DNR in place
- 1 in hospice: patient and family accepted
- 1 in care home: patient and family accepted
- 1 in hospice: patient and family conflicted

Parallel Planning

- Professional
- Personal
- Advance Care Planning

Conclusion 1

- ACP is not routine.
  - Professionals find it difficult to discuss
    - Search for a window of opportunity
    - Tend to use euphemism and vague language
  - Reactive and prompted by events
  - Happens close to the end of life

- Patient preferences are inclined to be uncertain, pragmatic, complex and shifting in response to unfolding uncertainty and complexity.

- Patients and families struggle to balance conflicting interests of obligation and imposition. The language of ‘choice’ ‘empowerment’ and ‘autonomy’ has little salience for patients’ lived experience.

Conclusion 2

- Patients vary widely in response and receptiveness to ACP.
- Planning is undermined by uncertainty and changing circumstance.
- The study findings reveal the real world difficulties that patients, carers and professionals confront in establishing the best thing to do in challenging and difficult circumstances.
- Risk that overly prescriptive guidelines and targets regarding ACP will limit rather than enable realisation of patient preferences.
- ‘Choice’ may become ‘obligation’

Conclusion 3

What is ACP?

- to support the exercise of patient choice and precedent autonomy
- to improve the patient and family experience of death and dying
- to reduce the number of hospital admissions and associated costs of end of life care
- to facilitate professional planning and management of EOLC
- to help patients and families anticipate and come to terms with the reality of death and dying
- to encourage public awareness of death and greater responsibility for managing care of dying patients
- a bureaucratic process of documentation and audit
- an incentivised strategy for changing professional practice

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