

COMPASSION IN DYING

SUPPORTING YOUR CHOICES
AT THE END OF LIFE

What does co-ordinated, person-centred care at end of life look like?

Reviewing the National Voices Co-ordinated Care Narrative

Summary

In 2013 National Voices developed an important new tool for health and social care commissioners: the *Co-ordinated Care Narrative*. It aims to help commissioners understand the meaning and importance of 'co-ordinated care' to people who use health and social care services. It sets out values and principles that service users believe should underpin the organisation of their care and support.

But what exactly does co-ordinated *end of life care* entail? Compassion in Dying wanted to know whether people using care and support services at the very end of life see things the same way as people using services to cope with long term conditions. We examined research interviews with people with terminal illness and with carers, and compared themes in these interviews with the values and principles set out in National Voices 'Narrative'. There is much common ground, but we also found some important differences in emphasis.

The National Voices 'Narrative' consists of seven sections. In the full version of this report we discuss the differences we found when we compared our research data with the vision of co-ordinated care set out in each of those sections. We also argue the case for adding an eighth section. Here we highlight, section by section, some of the key issues for consideration.

1. Service user perspective.

Beliefs about how dying people *should* be cared for inform people's expectations of services. What constitutes 'a good death', and what can service providers reasonably expect of family and friend carers, who are crucial partners in end of life care? We ask whether a 'Narrative' for end of life care should define it as *holistic* as well as *co-ordinated* and *person-centred*.

2. My goals and outcomes.

Time is of the essence at end of life. Carers need timely training and support to provide care. Assessments of need must be completed quickly and result in real help. Many agree that a 'good' death means time spent with people close to you, relief of pain, preservation of dignity, and caring human contact. But coping with death is also intensely personal and requires providers to be responsive to individual preference.

3. Care planning.

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Care planning that helps people to foresee, understand, and make decisions about what is likely to happen is essential if people are to feel they remain in control. For people who die at home, family carers are as central to care planning as the dying person, but often feel marginalised. Care planning should prevent crises, not merely predict them.

4. Communication.

Because the underlying system is so highly fragmented, carers frequently call for a single contact point. But what they want is *action* not just information. When carers are under pressure they want someone who is more a pro-active case administrator and problem solve, than mere point of contact.

5. Information.

Having clear information at the right time is vital if dying people and their carers are to feel in control. Without it they experience distress, do not get the help to which they are entitled, carers are less able to care, and a crisis in care becomes more likely. Many interviewees did not understand terms common in end of life care – for example ‘palliative’ and ‘hospice’ – so that treatment or care options were unclear to them.

6. Benefits, budgets and entitlement to funding.

Section 6 of the National Voices ‘Narrative’ focuses on decision-making about care and support, and budgeting for care needs. Our data suggest that for dying people and their families, of financial concerns arise from a lack of timely information about entitlement to support; carers’ reluctance to seek assistance until they are desperate; end of life benefits, by definition, bringing home an unpleasant truth; and the injustice of a ‘postcode lottery’ in care provision meaning that very little assistance may be available.

7. Transitions and inter-agency care.

In end of life care, transitions between care providers often happen at particularly emotional points in patients’ and carers’ lives. Effective co-ordination would avert practical problems and reduce distress for terminally ill patients and their carers when responsibilities are shared between agencies. Good practice in some providers (for example, GP practices and out of hours agencies ‘flagging’ terminally ill people) show simple steps can make a difference.

8. Quality of care and support, and training for carers. The current version of the ‘Narrative’ does not have a section setting out expectations of the type or standard of support that should be available. However, interviewees spoke at length about the absence of nursing and care support, and the variable quality of care. We suggest an end of life care narrative should set out the support needed for people to die at home. If end of life care is to be *person-centred*, dying people and their carers have to be able to trust it to meet basic needs, which include urgent care, particularly pain relief, available 24/7 to people dying at home; nursing staff with the skill to manage, and train carers to manage,

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basic nursing care such as prevention of pressure ulcers; and staff with sufficient skill to deal with people with cognitive impairment.

9. Recommendations. In the final section of the report we reflect on key findings and the type of “I” statements they suggest should be included in a revised narrative.

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What does co-ordinated, person-centred care at end of life look like?

Reviewing the National Voices Co-ordinated Care Narrative

Introduction

In 2013 National Voices - the umbrella organisation for health charities – developed an important new tool for health and social care commissioners. It is called the *Co-ordinated Care Narrative*. The aim of the ‘Narrative’ is to help commissioners understand the meaning and importance of ‘co-ordinated care’ to people who use health and social care services. The National Voices ‘Narrative’ sets out the values and principles that service users expect to underpin the organisation of care and support.

Compassion in Dying knows that people who are dying want co-ordinated care. But what exactly does co-ordinated end of life care entail? We wanted to find out whether the aspirations and needs of people using services at the end of life were in any way different from the aspirations and needs of people using services to cope with long term conditions. We have therefore examined research interviews with people with terminal illness and with family and friends who cared for a dying person, and compared themes that emerge from these interviews with the values and principles set out in National Voices ‘Narrative’. There is much common ground, but we also found some important differences in emphasis.

Background

There has been growing demand in recent years for commissioners and managers in health and social care to provide ‘better integrated’ services for people living with a range of long term health conditions.

But there has been confusion about what ‘integrated’ services mean in practice. After lengthy discussion in the NHS ‘Future Forum’ about what ‘integrated care’ looked like, NHS England asked National Voices develop a ‘Narrative’ describing integrated care. The aim of the ‘Narrative’ is to ‘tell the story’ of what truly integrated care *should* be like, from the perspective of health and social care service users. National Voices developed the ‘Narrative’ through consultation with its members. The ‘Narrative’ is therefore based on peoples’ experiences of living with a long-term condition, receiving good, well-organised support and poor, fragmented support. Setting out what people want – but may not yet be getting – it is an aspirational document. It was formally adopted by NHS England in 2013 as a significant aid to commissioning person-centred care.

The purpose of the original ‘Narrative’ and the values it expresses

The original National Voices ‘Narrative’ was derived from the experiences of service users and carers, and through widespread consultation with the charities represented by

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National Voices. So why might the 'Narrative' need to be reviewed for its suitability for commissioning end of life care?

The original 'Narrative' was shaped largely by the concerns and aspirations of people actively living with long-term conditions. So first, we need to understand what those concerns and aspirations are. Next, we need to ask whether people have the same concerns and aspirations when they are dying. So we start here by briefly considering how the 'Narrative' represents the concerns of people living with long term conditions.

The call for 'better integration of services' resonates strongly with people who want to live a full and active life while contending with long-term illness or disability. People with long term conditions do not want to be viewed just as someone with a limiting condition, and nor do they want to spend precious time and energy trying to get what they need from fragmented, disorganised, unresponsive services. Rather, they want to be respected as individuals pursuing valued goals, in command of their own lives, and capable of managing their condition with thoughtfully co-ordinated support.

From the perspective of a person with a long-term condition, better integration means feeling in control of your life, your condition, and your support services.

To achieve this requires health and social care organisations to rethink how they provide support. It means a move *away* from health and social care providers independently defining what their clients need, telling them what they will get, and expecting them to work around what is on offer. It means a move *towards* health and social care agencies forging partnerships with each other, and with service users. The aim of these partnerships would be to ensure that people with long term conditions could access high quality support of the sort *they* know they need, when and however *they* need it.

The 'Narrative' is intended to help this rethinking by providing a clear description of the experience that people want to have when they need support. Part of the rethink is in the language. 'Integrated care' is the term that provider organisations use to refer to inter-agency planning and commissioning. 'Co-ordinated care' is the experience that people with long-term conditions are after. How co-ordinated care is planned and commissioned, and who provides it, is of secondary interest to users.

So the original National Voices 'Narrative' expresses the values, needs and aspirations of people getting on with life, living independently, and overcoming limitations associated with their condition. In our research, we have asked whether people have other important values, needs and aspirations when they are getting on with the business of dying.

Our method of inquiry

For our review of the 'Narrative' we have drawn on a set of video interviews initially carried out for the award-winning health experience website www.healthtalkonline.org. Researchers at the University of Oxford create content for www.healthtalkonline.org by

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carrying out rigorous, open-ended research interviews with people who volunteer to talk about their experiences of health and illness. We have had access to data from two studies, one of experiences of living with terminal illness and one of experiences of caring for dying family and friends. For this report we have drawn mainly on the second of these, because here people talked about the very final stages of life and the death itself. This study consists of 40 qualitative research interviews with carers, some of whom were currently caring and others of whom had been bereaved. Most of these research interviews were carried out in 2010-2011.

We re-analysed the interview transcripts to see what they could tell us about the importance of co-ordinated care to people, and their experience of existing care provision. We started by carefully reading the transcripts, paying close attention to how interviewees told their stories, and noticing the words they used to recount their feelings and experiences.

We identified themes within each interview, and then looked at how themes were shared across several interviews. Because we are interested in what people *want* from service providers but may not be *getting*, we noted how people expressed what was important to them, their examples of good practice, and their descriptions of poor practice. Some of the themes to emerge were common to a large proportion of the interviews, whilst others related to specific experiences (e.g. those of minority ethnic groups).

In the next stage, we compared the themes from the interviews with the statements in the existing 'Narrative'. Our themes included user and carer experiences of discharge from hospital care, hospital re-admissions, admission to hospice or residential care, and death at home. We asked whether the 'Narrative' statements of aspiration accommodated the values and experiences expressed in our themes.

Finally, our findings were discussed with service users and professional representatives on the National Council for Palliative Care 'People's Panel'. Their insights were invaluable, and have been incorporated into the body of the report.

Structure and content of the report

In this report we summarise the key similarities and differences that emerged through comparing www.healthtalkonline.org data with the 'Narrative'. We have therefore used the existing structure and headings of the National Voices 'Narrative'. At the beginning of each section of the report, we have reproduced the existing 'Narrative' to allow for comparison.

This report concentrates on the commonest themes to emerge from the interviews. However, we also refer to themes that are particularly important to small numbers of people affected by certain aspects of care.

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To conclude this introduction, we present an excerpt from one of the interviews. It neatly summarises the problem to which 'integrated care' is the proposed solution. It also demonstrates very clearly how the stories that interviewees tell convey rich emotional meanings as well as factual information. We have wanted to convey those emotions in this report, without, we hope, allowing the distress and frustration they convey to unbalance our findings.

The interviewee is a former nurse who cared for her husband as he was dying from MND.

It was quite difficult knowing who was responsible for what, [for example] who was responsible for putting a ramp outside the house, so that we could get in and out of the house, up our one step that we have outside. Because we had a social services OT, we had a hospital OT and I think, at some point...a community OT. And actually, does it matter who it is that's responsible? It really doesn't when you're the person who is the carer or you're the person with the disease. All you want is your ramp outside your front door, to be able to get in and out of the house...And those discussions that you occasionally are witness to in your own home! "Oh, no. That's not my responsibility. That's social services." Or, "No, that's not *my* responsibility." Actually, you know what, that's irrelevant. And those conversations shouldn't take place in front of somebody who's the carer or the person with the disease. Because you just need the thing *put* there.

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1. Definition - Service user perspective

The current National Voices 'Narrative':

I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me.

The 'Narrative' starts with a statement from the perspective of the user of services. It expresses a desire to be in control of care and support, with access to a range of services that help people to achieve their own aims.

The following interview excerpt illustrates how issues of control and co-ordination are as central to care at end of life as they are to living with other conditions. This interviewee is a husband who cared full time for his wife, who died of MND. This excerpt also points to how in end of life care, a carer may be as much the primary user of services as is the dying person.

The co-ordination between community services is poor, and who to talk to about community service is poor. The need is for a central co-ordinating clearing point. I need oxygen, I need to get some more tablets, I need something to lift the settee up so she can sit down. I need knives and forks with big handles on them. I need some incontinence pads. I want one telephone number, one point of contact - and even if they are not the people responsible for doing or providing that service they should be the ones that know who is...I saw my job as taking care of Teresa's needs, being her representative, being her mouthpiece as well as her partner and everything else. I spent far too long as a medical secretary ringing people who didn't know what I was talking about... Too many phone calls, e-mails whatever trying to find who was the right person, who owned the particular problem.

What gets in the way of being in control?

Taking control, being in control and staying in control are all the more difficult in the face of some key features of end of life care. These features present challenges to both dying people and their carers. Our data show that they include:

- strong psychological reactions to terminal prognoses (e.g. disorientation, anger, depression). These may make it difficult to look ahead, and indeed sometimes create conflict around the need to plan for the future;
- normative expectations about how dying people and their carers should behave. For example, dying people may be 'let off' for inconsiderate behaviours while carers feel obliged to be uncomplaining and altruistic. Such expectations can be a source of manipulation, anger, guilt, depression in care relationships;
- mounting health complications and diminishing independence, generating increasing need for scarce nursing, social or informal care;
- anticipating and managing deterioration and changing care needs;
- shortage of time (even where a person already has a disabling condition, the pace of deterioration at end of life can leave little time to make new arrangements);

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- the urgency of need for out-of-hours services to alleviate distress (e.g. pain control, breathing equipment);
- cognitive impairment arising either from illness or from medication, which complicates decision making with professional and informal carers;
- loss of bodily functions associated with dignity and self-control (e.g. continence), a source of distress to both the dying person and those around them;
- growing reliance on informal carers, who also need to be in control; and
- carer knowledge and confidence to manage the final phase of dying.

'Triadic' care relationships

Several of the challenging features we have listed involve a 'triadic' relationship between care agencies, a dying person, and carers. This complex relationship raises a number of questions. Are services being provided to the primary 'patient' or to the carer? Which of the two has priority (e.g. a burnt-out carer or a patient refusing respite care)? Who should be in control of what?

'Triadic' care relationships are not unique to end of life care; to a greater or lesser extent they exist whenever patients or service users have concerned friends or family looking out for them. But they do become a more prominent feature of care relationships in certain circumstances. Family care for people with advanced dementia is an obvious example; and it is possible that the needs of informal carers are more of an issue in end of life care than other long-term conditions.

The manner of a person's death has significant long-term impact on those who care for them at the end. Our data consist of interviews with carers varying in age from 20 – 70. But many carers are older people with compromised health, whose own death is not a distant prospect. Carer exhaustion and ill health, grief, and anxiety about one's own death can all be made worse by a person for whom one cares dying poorly supported, suffering indignity, or experiencing pain. The impact of death on those left behind is something that dying people themselves frequently talk about. In the study for www.healthtalkonline.org of people living with terminal illness, several interviewees talked of not wanting to burden their families with their end of life care needs, or not wanting to leave them with unhappy memories of death. They took this into consideration in care planning, with, for example, people choosing not to die at home so as to avoid 'contaminating' the family home with death.

Value assumptions about end of life care

As well as taking experiential data into account, we also need to reflect on the value assumptions we might make when proposing changes to the initial National Voices 'Narrative'. We noted in our introduction that the original 'Narrative' encapsulates and expresses a distinct perspective on what being a service user *should* mean. The 'Narrative' is not value neutral. In the 'Narrative', being a person with a long-term condition means being an active subject with life goals, not a passive object of care interventions.

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So too, beliefs about what being a dying person or caring for a dying person *should* mean will also, inevitably, inform a modified narrative. What constitutes 'a good death'? What is it *reasonable* to expect of carers? And what *ought* we to expect of health and social care provision?

The discussion in this section invites the question whether a modified Narrative should define the aims of end of life care as being *holistic* as well as *co-ordinated* and *person-centred*.

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2. My goals and outcomes

The current National Voices 'Narrative'

All my needs as a person are assessed.

My carer/family have their needs recognised and are given support to care for me.

I am supported to understand my choices and to set and achieve my goals.

Taken together, my care and support help me live the life I want to the best of my ability.

This section of the 'Narrative' focuses on the need to co-ordinate support that helps people reach their self-defined goals. To some extent it overlaps with later sections, so we concentrate here on needs assessment, practical support, and the goal of a 'good death'. We introduce our comment on these aspects of the 'Narrative' with a daughter's account of caring for her mother, who died from pancreatic cancer.

We had a District Nurse that would only come once a week to really just assess, I felt, to assess the situation with my mum, not to really care for her... We had to fight to get a carer to come twice a day. So she'd come for an hour in the morning and an hour in the evening to prepare my mum for bed. But in between that, which is a long period of time, it was really for my father or for me to take care of my mum. And that was a lot of heavy lifting in and out of bed. We couldn't wash my mother... I tried to sort of wash her hair over a bowl of water from her bed. But, you know, things like that were just impossible - to give her the most basic, simple things that you want to be able to give somebody that only has a few more months left to live... I felt that a lot of the time was taken up fighting to get proper care for my mum... to even get the doctor to come out and see her when she had a symptom that we couldn't deal with... All those things when we should have been able to just spend that time, cherish those times and just spend it with my mum, you know, doing the nice things you want to do for her, rather than all that energy going into fighting to just get things for her so that she could function on the most basic day to day basis... You weren't being offered anything that could really impact and help her, or help us make things easier for her...

Assessment of need

Several interviewees spoke of assessments of need coming too late to be of value. In some cases rapid deterioration in health resulted in rapidly changing need, so that agencies and systems were constantly one step behind. However, the end of life experience of people who were already living with a condition for which support was well organised (as was the case for some people with MND for example) could be different from those with more abrupt onset of illness. For some people already in the social care system there were fewer obstacles to organising appropriate support. They and their carers already had some familiarity with care agencies, knew of condition support groups where they could access informal knowledge, knew more about the terminal phase of their illness, and were more aware of the resources they could ask for.

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Provision of tangible support to meet basic care needs

There was considerable frustration that assessments of need were done, but did not result in any real help. One of the most striking aspects of our interview data is the variability in practical support available to carers. In some areas carers reported receiving no help whatever with actual care. Health professionals, Macmillan and district nurses visited when requested but practical help with day-to-day caring appeared not to be available. Where social services were well resourced and well organised, support was rapidly forthcoming and some interviewees even commented on over-provision.

However *no* carer interviewees – whether in poorly resourced or well-resourced areas - reported receiving training to enable them to carry out the nursing duties they assumed. There was a mix of frustration that they were left to get on with caring with no guidance (for instance, about managing incontinence); and at the same time not trusted to do vital things they could have done with training (such as administer pain relief).

The 'goal' of a 'good' death

Most would concur that a 'good' death entails relief of pain, preservation of dignity, and caring human contact. But what makes a good death is also a very personal judgment, as the following excerpt about caring for a husband dying from COPD makes apparent.

I think one of the hardest things that happened was, district nurses, they wasn't very helpful, and I didn't realise that I was losing control...[T]he district nurses said I had to have a hospital bed in the room. So not only did we have all these machines but we had this hospital bed come in. I was sleeping in the front room on a blow up bed - and that was finishing Terry off because we always had each other...when they brought this hospital bed in he said to me..."I feel it's over," he said, "if we haven't got each other in bed of a night..." I said to this [Macmillan] nurse and I broke down and I said, "He feels it's the end because at least we could comfort each other. I'd go to bed early just so that I can hold him, show him how much I loved him, and he felt it was all taken away." And she said to me, "But you don't have to have that. You don't have to do this. You can tell them you don't want that." And I didn't realise I could do that. I thought, you know, they're telling me I've got to do the best for Terry and I thought, "Okay." Like, "You know best." But she said, "No." That I knew best and I thought, and it was a turning point, and I thought, "Yeah, you're right. I know what's best for him" And we got our bed back...

Many interviewees discussed the difficulty of making dignified arrangements for washing and toileting, particularly when a dying person was immobile. Several commented that care staff were not permitted for health and safety reasons to lift and turn patients, so this was of necessity done by untrained carers. One interviewee drew attention to the lack of provision for minority ethnic women, who are mortified to receive intimate care from male strangers. This is part of a far wider problem. The preservation of dignity is an enormous challenge at end of life as normal bodily functions start to fail. Death at home permits greater privacy, and shields people from public indignity. But it requires appropriate aids to

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be provided, and for modifications to homes that may be unsuitable venues for caring for very ill people.

The importance of contact with intimates at the end of life was a persistent theme in the data. The 'Narrative' focuses on care in the community but 51% of deaths still take place in hospital, frequently after an exhausting period of care at home. Hospitals are ill equipped to support end of life contact. There are few facilities available for the family of those dying in hospital, for instance keeping vigil overnight. (Hospices were often spoken of as having this better organised.) Additionally, it can be very difficult for family carers to hand over caring to professional staff, particularly when they see care needs unmet in under-staffed wards. Many carers commented that they could – and *should* – have been allowed to be more involved in caring for family admitted to hospital.

We refer to pain relief in Section 8.

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3. Care planning

The current National Voices 'Narrative'

I work with my team to agree a care and support plan.
I know what is in my care and support plan.
I know what to do if things change or go wrong.
I have as much control of planning my care and support as I want.
I can decide the kind of support I need and how to receive it.
My care plan is clearly entered on my record.
I have regular reviews of my care and treatment, and of my care and support plan.
I have regular, comprehensive reviews of my medicines.
When something is planned, it happens.
I can plan ahead and stay in control in emergencies.
I have systems in place to get help at an early stage to avoid a crisis.

We have already referred in Sections 1 & 2 to some of the key experiences of end of life care that affect care planning. Our data on carer experience are not inconsistent with the original 'Narrative' statements, but the 'Narrative' focuses on enabling the person with the health condition to be in control. In our data, as dying people became increasingly dependent on informal care, the locus of control was either shared with or shifted towards their carer. The "I" in the 'Narrative' gradually progresses towards "I, with my carer" or "I, the carer". This calls for some tact and sensitivity on the part of agencies, so that neither dying people nor their carers are disempowered in care planning.

The next excerpt recounts the experience one of several carers who faced the challenge of care planning when a dying person, understandably, tries to put an optimistic gloss on their illness. When her 84-year-old mother was discharged from hospital with metastasised breast cancer, the interviewee cared for her until she finally felt totally overwhelmed. Her mother died soon after she managed to get her admitted to hospice.

I mean I was having to clean her. I was having to dress her. Try and get her down the stairs, I've got no lift. Everyone else, you know, all the men had gone off to work so having to literally, struggle with my arms under her to help bring her downstairs. Trying to get her to eat. Trying to take her pills. Was just an absolute nightmare...I just assumed that they would arrange for somebody to come and help but it doesn't work like that...The Macmillan nurse at the hospital gave me the telephone number of the palliative Macmillan nurse but I didn't know what palliative was...That palliative Macmillan nurse rang and made an appointment, but what she used to do was ring up and my mum would say, "Oh, can you come at three o'clock?" Because she knew I'd be at work and what she'd do is put her face on, you know, put a bit of eye shadow on, bit of lipstick, so that when the Macmillan nurse came my mum looked good. And I had to literally beg the Macmillan nurse to make an unannounced visit...[After it] she said, "Oh, your mum is quite poorly isn't she?" I said, "Yes, she is. That's what I've been trying to say to you. I am struggling trying to get her to eat and do everything, as well as go to work as well"...The next day nobody called me...That morning my mum was so poorly. And I just thought, "I can't do this any more." That's when I rang the hospice direct.

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Care planning means help to anticipate things that novice carers don't know about

In our data, carers repeatedly spoke about how they had not known about support services to which they were entitled until very late in their caring journey (on some occasions, too late to be of use). To be in control when planning care and support requires good, clear information – about what is available, about what other people have found useful, about what might happen in future – and so on.

Our data indicates care planning processes need to:

- be timely;
- make carers aware of what they are taking on when they undertake end of life care;
- take into account the carer's perspective and knowledge of the situation when planning care with a dying person (for example, paying attention to their concerns when they say their loved one is putting on a good show);
- take into account the likelihood of future mental incapacity;
- draw attention to decision preference tools such as Advance Decisions & Lasting Powers of Attorney;
- anticipate changing needs, activating support and mobilising resources before a crisis occurs;
- anticipate the sorts of treatment choices that might arise (such as administration of IV fluids) and provide understandable advice on these;
- in the case of controversial treatment choices such as Voluntarily Stopping Eating and Drinking, ensure clinical support is forthcoming;
- encourage carers to use available support before reaching crisis point;
- help carers to understand the dying process, and to feel in control of the decision to either transfer a dying person to a care service or manage the final stages at home.

It is a common criticism of care planning and support that professionals seem to wait for a crisis to arrive before taking any action. Here an interviewee reflects on how she had a superficial understanding of the likely stages in her mother's decline – having read up on it - but she had no help from professionals, who had experienced it many times before, to anticipate what it would mean for caring.

I think we probably needed support earlier on because I think the support waits until something goes wrong...[T]hat was all going to happen, and I was reading it was always going to happen, [but] where it suddenly kicked in she was in agony. It's quite hard to mobilise people at the time.

We close with a quotation from a woman caring for her husband who had slowly progressing MND. She had struggled for years with very little assistance – or sleep - and was finally told that she was entitled to ask for some help at night.

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And I didn't know this, that I could request somebody to come and help me at night. It was only that one of the evening nurses, the twilight nurses, when they come to check the syringe drivers and she said to me she said, "You can request for help at night." Because I wasn't sleeping...during September, October he had spent a lot of time in hospital and I had been staying with him in hospital and there was no bed. I was sleeping on one of those chairs, hospital chairs...I was very tired and even when he came home he wasn't well. He was really sick at that time...and I was getting up a lot at night and I was very tired. So one of the twilight nurses, she said, "You know, you can ask for help at night." I didn't know about this and she said, "Yeah, you need to just request it through your district nurses." And I felt that they could have done that for me. So if one of the evening nurses hadn't mentioned it, I wouldn't have known that this help is available. So that's when I felt disappointed, you know. They kept saying to me, "Oh, you look tired. Oh, you look..." But they didn't give me a solution, which they could have done, which I'm sure they knew about, but they didn't...

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4. Communication

The current National Voices 'Narrative'

I tell my story once.
I am listened to about what works for me, in my life.
I am always kept informed about what the next steps will be.
The professionals involved with my care talk to each other. We all work as a team.
I always know who is coordinating my care.
I have one first point of contact. They understand both me and my condition(s). I can go to them with questions at any time.

The *communication* theme in the 'Narrative' focuses on the need for regular, co-ordinated and accurate communication between agencies, professionals, and service users. (The succeeding section of the 'Narrative' deals with *information*, which we have taken to mean the *content* of communications between parties.)

In practice, communication and information concerns significantly overlap. We have already emphasised that timeliness is critical in end of life care, and it is as important to communication as it is elsewhere. Interviewees commonly reported spending hours on the phone, passed from one department or agency to another in their quest for information, with no one prepared to take responsibility for communicating their concerns to anyone else - or for solving their problem.

Communication as information management

The following extract, which encapsulates the views of many, is part of an interview with a carer whose wife died from pancreatic cancer.

What would be ideal is that as soon as you were put in this situation... someone could actually sit down with you straightaway and say, "Right this is the picture. You've got these people here and they're all talking to each other all the time. And everyone knows what's going on, and this is the person that you need to talk to about any queries you've got."...[T]hen you'd get the sense of knowing who to turn to and where to turn, and you'd have the sense of that they all know what's going on. They're all very good independently, but I don't think they work well together. We would have visits from an emergency out-of-hours doctor for example, who didn't have any notes on Karen, and there's no reason for that with electronic communication...And the whole thing about us relating, communicating with the specialist team when probably we should have been talking to...the community team more. They didn't know what each other was doing...They were all sort of available in the background, but we didn't know how it all worked... To be honest the various parties didn't seem to be very well versed themselves in what goes on. You know the GP, the community palliative care team, and the oncologists, they're not actually in that much communication with each other. And the [local hospice]. They're all working independently sort of. The GP can communicate with all of them. And looking back we should've made more use of the GP early on. But we didn't understand that.

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Communication as navigation through the system

There is already strong support in the palliative care community for the practice of a named liaison person (or liaison team, to allow for a 24/7 response). Named liaisons are also a feature of other conditions (such as the lung care and 'neuro-nurses' mentioned by some interviewees). However the point was well made by the NCPC People Panel that a named liaison is necessary because the underlying system is so highly fragmented, and so poorly co-ordinated. On this view, the named liaison person is an attempt to patch together a broken machine.

Importantly, our data suggest that what dying people and carers want from a liaison role is not just communication with them, but *action*. Interviewees often cited Macmillan and district nurses as a key point of contact, but their experiences were mixed. If what interviewees wanted was *information* - for example about who to speak to, or what benefits to apply for - they were reasonably satisfied. But a significant number of interviewees wanted more tangible support. There was disappointment and frustration that what seemed to be on offer was well-meaning advice. They wanted compassionate, responsive support - maybe making the phone calls, helping fill out benefit claims, ordering the oxygen, sorting out the ramp - in short, someone to help solve the problems and share the burden. When carers are under pressure, they want someone who is more an effective case administrator than a mere point of contact.

Communication across the 'care triad'

It was a feature of some interviews that carers reported being excluded from decision-making, particularly when care was transferred from home to hospital. There remains considerable confusion about the role of relatives in treatment decisions. Setting aside those who have Power of Attorney for health and welfare, there is widespread conviction among relatives that they have more of a role than the law provides. Professional approaches vary considerably: our interviewees perceived them to be on range from consultative and inclusionary to peremptory and exclusionary. The inquiry into the Liverpool Care Pathway was prompted by anxieties about under-treatment. In this data-set however, some carers reported active treatment continuing for longer than they thought the dying person would want because their carers' views were sidelined.

Communication across discontinuity in care

We conclude this section noting a view common among carers, that in a fragmented and uncoordinated system they are sometimes the sole reliable source of communication and information about the person they care for. It is therefore vital to the dying person that the carer's role is respected.

But other people recognised that I was actually part of Teresa's support and treatment care team, and treated me as such. And usually the times they found out that I could be the most valuable was at the times when they suddenly found things, or something had gone wrong. Because I actually represented continuity. I was the one that was there all the time. I'd heard what every doctor had

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said. I'd heard what every physiotherapist had said. And all the other professionals that had interfaced, what their views were. I had seen where the breakdowns in communication had occurred. I had seen where the notes had gone missing for a time, or somebody had said something and not put it in the notes. Because I was maintaining my own notes...[I knew that] from the GP to the community people to the four or five hospitals that we were dealing with, there were sometimes going to be delays in information being communicated between centres and within centres between different layers. And time was important. So the fact is, I was walking around with a short cut for Teresa's benefit, and all I needed was people to talk to me and be receptive.

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5. Information

The current National Voices 'Narrative'

I have the information, and support to use it, that I need to make decisions and choices about my care and support.

I have information, and support to use it, that helps me manage my condition(s).

I can see my health and care records at any time. I can decide who to share them with. I can correct any mistakes in the information.

Information is given to me at the right times. It is appropriate to my condition and circumstances. It is provided in a way that I can understand.

I am told about the other services that are available to someone in my circumstances, including support organisations.

I am not left alone to make sense of information. I can meet/phone/email a professional when I need to ask more questions or discuss the options.

Having the right information at the right time is absolutely necessary – although it is not in itself sufficient – for dying people and their carers to feel in control. Lacking clear information, dying people and their carers experience confusion and distress; they do not get the help to which they are entitled; the carer is less able to care; and a crisis in care becomes more likely. But unwelcome information can also cause distress. Professionals sometimes seek refuge in euphemism or technicality (several interviewees commented they had had no idea what 'palliative' meant), leaving patients and carers unclear about what they have heard. Seeking and misunderstanding information were such consistent themes that we include several examples to illustrate the difficulties.

Information about prognosis and options for care

We start with several linked excerpts, beginning with a daughter's description of learning that her mother – who suffered from Alzheimer's – now also had terminal cancer.

The consultant is doing his rounds and he comes to my mother and, first of all, he tries to usher me out of the enclosure and I said, "No, Mum's got Alzheimer's. You will need to talk to me." And he said, "Well, there's no point [doing a biopsy], I'm 99% certain it's moved to the liver." I didn't even know she had cancer, but it had already metastasised. He then looked at me and said, "It's palliative care only." And walked off. She was there for a further two weeks while we tried to find out what palliative care was, get someone to come and assess her and see where she had to go next. Nobody would give me a time frame. Nobody would tell me how bad it was. I didn't know what was going on...

Eventually, the interviewee came to the conclusion that the only option was continue to look after her mother at home until she died. Her first task was to gather information.

I did a lot of research...I looked up the Macmillan website first. I thought that's a good source of information about the illness itself and how one can cope with it. My GP, first port of call, he's been the doctor for us as a family since 1987 so he's known us personally for years and I completely trust him and it seemed sensible to go straight there and they have an enormous amount of information available. Because of my mum's dementia I was already a member of the Carer's Centre. That was

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another place I went to...It's piecemeal, it's all over the place, but there's an enormous amount [of information] out there...

In the final excerpt, she reflects on how – despite her own research - she had needed better information about options for care following her mother's diagnosis. Like many, she had avoided hospice care thinking that hospice was just a place for people to die.

I didn't know what to expect when we went to [the hospice]. As with most hospices, you hear the word hospice and you think, "She's going to go there and die." It isn't true but it's how our minds conjure things up... So I think from the moment of diagnosis the most useful thing would be to have things explained. "This is what you can expect. This is why we're not doing that. If your mother is going to come home, these are the resources that are available." That sort of thing from the get go would be useful. You may not take it all in but at least you'll know that someone's tried and you may have information written down or packs that you'll come back to later.

Other interviewees recounted experiences quite different from the stark delivery of bad news described above. Some clinical staff are reluctant to spell out to family that their loved one is terminally ill. In the next excerpt a woman tells how she found out her husband was rapidly dying from an aggressive cancer.

[The consultant] did, eventually, ring me and he said, "There is a worrying shadow on the x-ray, a worrying shadow on the lung and there is something nasty going on in the body." ...It sounded threatening but it wasn't telling me in very clear language what it was that they were getting at...So I rang [her husband's] counsellor, and I said... "I don't actually know what they mean." And he said, "I think what they mean to tell you is that he has cancer. That's what they're trying to tell you. Something nasty going on in the body must mean that they were looking for cancer."

Information about the dying process

Very few carers start out knowing what caring for a dying person will entail, or knowing anything about the dying process. The next interviewee cared for her mother until she died from lung cancer. This carer had felt well supported, particularly by district nurses.

The Marie Curie website and the Macmillan's site, I did find both of them useful. The Marie Curie one had a sort of "what to expect list", and that was really spot on I have to say. When Mum stopped wanting to eat and stopped wanting to drink, I'd read about it and knew what to expect. And that helped otherwise I think that would have worried me quite a lot if I hadn't been expecting it...I think you have to be quite proactive [getting information] yourself. You have to know what to ask for. The other thing is - of course, people will tell you things - but it's a question of, if they say this only once, you're not necessarily going to click, "Oh, actually. I do need that." I made lots of lists and the district nurse encouraged me to, so I didn't feel I was being bossy or anything...

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Information or training?

Our final excerpt points out that those caring for people who are dying have learning needs that go beyond simple information. In the absence of anyone else to do it, carers need proper training to carry out nursing tasks.

And the fact that, you know, nobody had any other information to sort of give you. Or you didn't even know what other symptoms to look out for...I think about a month before my mother did pass away, like I say, she just, she just got weaker and weaker. She had got bed [bound], so you had to deal with other things like bedsores. Because she couldn't move so much, you had to keep sort of turning her. I had to treat her bedsores, because even when the District Nurse would come they wouldn't have much time, they'd just do it quickly. So I had to almost like teach myself to sort of do those things....

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6. Benefits, budgets and entitlement to funding

The current National Voices 'Narrative'

I am as involved in discussions and decisions about my care, support and treatment as I want to be.
My family or carer is also involved in these decisions as much as I want them to be.
I have help to make informed choices if I need and want it.
I know the amount of money available to me for care and support needs, and I can determine how this is used (whether it's my own money, direct payment, or a 'personal budget' from the council or NHS).
I am able to get skilled advice to understand costs and make the best use of my budget.
I can get access to the money quickly without over-complicated procedures.

The 'Narrative' treats decision making, budgeting and funding under the same heading, which presumably reflects the close association between these elements when planning and purchasing care for long term conditions. We are not certain that this is the best way to group the issues in end of life care. For example, we found it necessary to discuss decision making in the sections on care planning, communication and information.

For dying people and their families, our data suggest that the major financial concerns are not really to do with making decisions. Rather, they are more to do with awareness of entitlement and the injustice of a 'postcode lottery' in social care provision.

The need for pro-active advice about entitlement

We start with a comment about 'deserving' financial support that is part of a broader set of concerns about accepting help at all, that carers commonly express. Many interviewees talked about feeling that they ought to be able to cope alone, that their circumstances did not warrant assistance, or that there were others who needed help more than they did. These comments may reflect a psychological need to maintain a sense of efficacy, autonomy, and independence. Whatever the source, they affect some people's willingness to ask about financial entitlements.

People did say, "Get a carer's allowance." And I did eventually do that. So I think I had it for about two weeks in the end, by the time I sort of thought, "Oh, well, maybe that would help out." Yes, because I'd stopped working and, you know, but again it's thinking, "Well, do I deserve that?" That was sort of thing, you know, we were spending a lot more money on care. That was one of the issues... But Mum had all the attendance allowance benefits and things and that did help to pay for it all.

It is a recurrent feature of both of our data sets (that is, living with terminal illness as well as caring for a dying person) that people report professionals hesitating to tell them that they are entitled to specific end of life care benefits. This is presumably because it highlights the unwelcome expectation that they have no more than 6 months to live.

To begin with I don't think we did [understand the prognosis] but they tread very carefully, I think, with a terminal illness because they don't want to deal with it or to say it... We wouldn't have known about the end of life benefit if my sister hadn't've worked in the DSS. She knew that if it was

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terminal, you'd get paid... [M]y sister's quite practical. The doctor said, "Do you realise the implications of that." She said, "Yeah." [The doctor] said, "Oh, good." So you know, I doubt if we'd have been told...It was purely the palliative [care team] that were able to give us information

These data were gathered prior to the widespread implementation of personal budgets to purchase social care. Only one interviewee commented on the experience of using direct payments. Despite being a local government officer with a good understanding of the system, he found managing direct payments unduly burdensome alongside providing care to his wife who was dying from MND.

So we opted for the direct payment system to try and employ somebody ourselves. Unfortunately what you have to do under the system is you actually have to set yourself effectively as a small business and do the PAYE and everything for the people you employ, the carers that you employ, an anti-fraud measure that the government has introduced. But it does make it a hell of a lot more difficult. There's a partner organisation in the county which will do it for you for a fee, so we opted for that because there was no way that I was going to sit down - I was going to say at the end of the day, but there wasn't an end of the day - and start working out PAYE and learning how to do that. So we opted for that. But we still had to do a lot of accounting, keeping hours, keeping records of annual leave that was entitled and all this sort of thing. So it was, it was actually quite a burden to do that. But we felt that because social services would use an agency and we would probably get a load of different staff of variable calibres we'd try to find somebody ourselves. And that was very difficult. It was very difficult to find anyone really and certainly it was very difficult to find somebody who we could trust.

The recent expansion of personal budgets and direct payments may mean that there is now better advice and guidance about care costs, which is sorely needed. Many of the carers in our data had used their own money to purchase basic care, either through social services or from an agency. Some carers were surprised to discover that it would have been cheaper to employ agency staff directly, because agencies charge a premium when providing care via local authorities.

The long term financial effects of caring for a dying person

Finally, providing care for family at home can have a significant impact on the carer's financial position long after the person they care for has died. This is unlikely to be a disadvantage that commissioners can offset in the current financial climate. But it is an important part of the of real cost of end of life care. It disproportionately disadvantages older women who are more likely to become carers, to give up full time work to do so, and be too old to return to work afterwards. The following interviewee cared for both her parents, and then subsequently cared for her husband who died from COPD.

With mum I didn't claim [carers allowance]. With dad, I claimed it...Thing was, once Terry ... couldn't work no longer, we had to claim benefits. So I had to stop claiming carer's for my dad and start claiming carer's for Terry. So I wrote a letter and they, they sort of, it was a book, at that time, and they just sort of just changed the book from my dad to Terry. Although I was still looking after

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both, you can't claim for both...So I got carer's allowance for all that time and the biggest shock was when Terry had passed away - and it's still going on now, a year after - is that obviously, I notified everybody and all the benefits stopped. Well, what savings we did have we spent like because I didn't work no more...If it wasn't for my children, I don't know what I'd have done to be honest...[N]o one prepares you for after like and you don't even consider about after because you're too busy worrying about the day but a year down the line ...I'm stressed out because of the benefits system now.

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7. Transitions and inter-agency care

The current National Voices 'Narrative'

When I use a new service, my care plan is known in advance and respected.

When I move between services or settings, there is a plan in place for what happens next.

I know in advance where I am going, what I will be provided with, and who will be my main point of professional contact.

I am given information about any medicines I take with me – their purpose, how to take them, potential side effects.

If I still need contact with previous services/professionals, this is made possible.

If I move across geographical boundaries I do not lose me entitlements to care and support.

Our data highlight two significant types of transition in end of life care. The first is a *primarily* psychological transition into 'the land of dying', when people and those who care for them realise they are now on a path that will end in death. Transition into 'the land of the dying' is a challenging emotional time, invoking responses such as anger and denial. Unfortunately, people making this transition *also* find themselves having to make care choices and build new relationships with care organisations. For example, irregular visits to hospital are replaced by growing reliance on community based care services. The second type of transition is a *primarily* organisational transition. This occurs when a dying person or their carer seeks care from different services, for example going in and out of hospital or hospice, calling an out of hours service instead of their own GP, or changing their social care agency. Unfortunately, bungled organisational transitions can generate considerable emotional anguish as people desperately seek care in distressing situations.

Transition into the 'land of the dying'

At this doubly difficult time, people are coming to terms with a bleak prognosis while grappling with decisions about future care. They need help to understand care options they may have chosen not to think about in the past, and may not want to think about now.

I really wish that we had accessed the hospice much earlier on... Sarah was offered that, but because of the difficulty she had in coming to terms with the fact that that this was a terminal illness she was very, very reluctant... Even while Sarah was still having the active treatment I would have somehow or other tried to work it that we maybe tried to get her in for respite or something ...[T]here was a lot of stuff that Sarah could have got involved in that might have helped her process the things that she was going through... really beneficial for her but also would have opened up more support for myself and the family for the situation that that we found ourselves in... I don't think I realised how different [hospice] would be... [G]oing up to the hospital, the focus is just different... they found it very difficult to say to Sarah "this is what's happening to you"... The hospital aren't interested in your situation at home... they'd say, "Oh, come back next week and we'll do another MRI scan." They had no interest in the fact that she couldn't get out of bed at home... When you're caring for someone that's what it's all about. It's whether or not they're feeling well enough to sit up. Are they able enough to get out of bed? Can they eat?

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Transitions between agencies

Towards the end of life many of those with terminal illness – and indeed many older people with multiple health conditions - will be admitted to hospital with some frequency. Several carers described how - in the face of poor information transfer across organisational boundaries – they had to take charge, as in the following extract.

There were two hospitals that she did have emergency admissions to, and we made detailed notes that were clear about what her treatment was, who her consultant was, what was happening, what had happened. And those were in the house, so that she was able to take that with her...My father is much more unable to communicate this information, so we created sheets that he could give to everybody, if we weren't there. This is what's happening. This is what needs to happen. These are the phone numbers; these are the people where her notes are. And in the hospitals where we knew she was most likely to have an A&E admission, again my sister is a social work professional, we did lots of intervening to make sure that case notes were held in a sort of co-ordinated fashion. That they were on systems that were accessible in A&E. We learnt about the systems so if any of us were there we could say, "This is the way you get her notes out."

Even when a person is already in 'the land of dying', being discharged from hospital to care at home, or from in-patient hospice care to care at home, can be a difficult transition. It may signal the point at which the carer suddenly feels that they bear all the responsibility for care; or it can signal a distressing entry into the end stage of the dying process. The next interviewee decided to bring his wife home to die after a period of hospice care.

So it, for me, it was the time factor, the extraordinary speed with which it all took place...When there was agreement that Pat should come out from the hospice to our home, it all happened in a day, in an afternoon in fact, and I had no idea...Anything that you wanted while in the hospice was there. I mean towels, blankets, pillows, all kinds of things were available, but I wasn't aware of what things I needed to have available at home. And so, on reflection...I could have been given a list of facilities like - you need plenty of towels, you need plenty of blankets, you need plenty of sheets because things are going to get soiled and so on. And so that's the kind of organisation I think is needed. This suddenness with which somebody you care for and somebody you want to help so much is delivered to you, if you like, and you have no real awareness of the enormity of it and the basic things that you need. An example, for instance, when the first carers came I was told..."You need bowls..."...You're not on your own in terms of being without help, you're on your own in terms of the mind process, and that can be, again I use the word, daunting really.

Rather differently, transition across services may mean different primary care providers attending the dying person at home. Carers reported that some services were extremely well organised, with dying people 'flagged' for special treatment. The experience recounted below, however, was one of several examples of failure to co-ordinate action across providers. The interviewee cared for her husband, who died from MND.

I rang the GP at about three o'clock in the morning because George was on diazepam and I thought actually, I need to give him another dose of diazepam to see if I can just get him to relax a bit. That really was all I wanted, permission just to be able to give him another dose of diazepam

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and to know that I wasn't going to kill him if I gave it to him. So I rang the out of hours GP. The triage doctor, who answered the phone, insisted that I had to take him to the out of hours GP centre, which is about a mile away. It would have taken me an hour to get George dressed and ready and into our van and I knew he wasn't well enough to do that...I kept saying to the doctor, "I can't bring him. I cannot bring him. He's not well enough. He needs to be seen here. He's terminally ill." And I must have said it three or four times to this GP... In the end, I put the phone down because I just didn't know what to do. I was absolutely at my wit's end. I just felt so out of control. The whole thing was out of control and it was the first time really, that I felt utterly and completely out of my depth...So I rang [the hospice] and I said, "I don't want to take him to A&E. The GP is being absolutely useless. Can he come into you?" And they said, "No, he's never been in as an inpatient so we can't admit him. You'll have to phone the out of hours GP back..."[An out of hours GP finally visited and wanted to admit him to A&E. I refused]...As she was leaving I said to her, "Can I give him some more diazepam?" And her response was, "It'll do no harm I suppose." And that was all I needed, actually, because that gave me permission just to give him some more diazepam.

8. Availability and quality of care and support

The current version of the 'Narrative' does not have a section setting out expectations of the type or standard of support that should be available. This may reflect that many people with long term conditions will expect to purchase their own support services using direct budgets, and are therefore directly responsible for defining the type of support they want and assuring the quality of care they receive.

In our data however, carers spoke at length about the lack of nursing and personal care support available, and their anxieties about the quality of care on offer. Carers are all too aware that in some areas well organised support is provided from the beginning of the care journey, whilst in others little or no support is offered even when carers and the dying person feel they are in dire circumstances. This is perceived as a real injustice.

All of this poses the question whether - if it is to be of value to local commissioners in a national system - an end of life care narrative should state people's expectations of the support that should be available. The argument for including an additional section in the narrative is that if end of life care is to be meaningfully described as *person-centred*, it has to be of sufficient quality and reliability that dying people and their carers can trust it to meet their basic needs.

The need for urgent home care, including urgent pain relief

We have already seen that one of the basic needs is for urgent care to be available 24/7, often for relief of pain. Several interviewees spoke of difficulties around getting hold of morphine-based medication, which some doctors were reluctant to carry and some small rural pharmacies did not supply. Other times, as with the following example, pain was simply not well managed. This interviewee was first introduced in Section 3. She cared for her 84-year-old mother, who died in hospice of widely metastasised breast cancer.

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And so then my mum got a bit worse. The GP came out again and said she had to keep the leg up. So we found a table that we thought was about the right height and then she was having medication for that...I think it might be thrombosis. She was on medication for the cancer, just a tablet and also painkillers, which was co-codamol, which she could only take in liquid form. But that made her really, really badly constipated, which then gave her more pain. And I'm trying to work out how I can stop my mum from being in pain because I'm not a doctor. I'm not a nurse. Who do you ring? What do you do? So I rang the Macmillan nurse because that's who I thought and she said, "Okay. We'll try and get something done." And they did send a nurse round on a Friday afternoon at two o'clock...She said she'd come back on the Monday...I knew my mum was in pain...I knew from her face that she was in pain and they didn't really do much, to be quite honest, whatever this nurse was doing...And because of the pain my mum was in, and because she couldn't go to the toilet, and she said her mouth was sore, she couldn't eat.

The need for quality support and respite services

It is widely recognised in research on caring that carers will not use poor quality services, which contributes to carer 'burn-out'. Where there is no option but to rely on care services of poor quality, both the cared-for person and their carer suffer. Our interviewees recounted experiences of agency staff such as twilight carers not arriving on time - or at all - so that a dying person was left without food and drink or basic personal care. They reported low skill levels and unprofessional behaviour from both social care assistants and (less frequently but more worryingly) district nurses. There is a scarcity of care staff with the skill to deal with people with cognitive impairments, such as dementia. Getting continuity of care – particularly important for dementia sufferers who are easily confused and distressed by the appearance of strangers – appears close to impossible. Finally, if people are to use services such as respite care, commissioned provision has to be of a quality they can trust.

The next extract is from an interview with a carer we also met in Section 3. She was caring for her husband who had MND, and freely admitted that she was exhausted. Here, she talks of the importance of having continuity among the carers supporting her husband and how, after one experience of respite care, she would not entrust her husband to it again.

We are trying to build up continuity with the same nurses...I can understand that we can't have the same person every time because that person is also, you know, committed somewhere else and they go on leave and things like that. But...continuity does help because you build up a rapport...He was so unhappy in the nursing home when I went away for four days, he was so unhappy, and I don't blame him. Things didn't work out. It's not worth having that respite. I feel I'm better off here, you know, coping rather than going away...Because his needs are so specific. And because he can't speak the other person can't understand him, and he can't demand...say if he's wet himself, they just leave him there, you know. When they've got time they will come, whereas at home, he gets seen to straight away. That was the difference. They will wash him when they've got time and...equipment wasn't up to scratch. You know, they didn't have a commode large enough...they didn't have a hoist to get him out of bed...so it wasn't a good experience for him."

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The need to provide services that carers do not think they deserve

A well-known feature of caring, clearly visible in our data, is carers' reluctance to seek support at the outset. Convincing yourself that you are able to cope may be an important strategy, enabling carers to manage the challenge of caring while still feeling in control. But does a vicious circle operate, with carers determined to cope and health and social care agencies waiting for a crisis before they step in to help?

I think, I think it would have been helpful for people to actually - I think if you're dealing with carers, it's sort of getting them to feel that they deserve things I think is important. Because I sort had the attitude of "Oh, well I can manage, you know, we're doing all right." But actually, it might have been better if I'd had the Marie Curie nurse earlier and it's actually, people's input, just the exchanges you have gives you ideas you haven't thought of. And, you know...it helps you feel that you've done everything, that you've not, you know, overlooked something.

The need to commission personalised training for carers at end of life

We have referred in earlier sections to the need for training for carers if people are to receive good care at end of life. Some of the problems to which carers referred – preventing pressure ulcers for example – would be the focus of patient safety activity in healthcare settings. We have also noted that carers are not entrusted with vital tasks they could be taught, such as giving injections. Perversely, this both deprives the dying person of prompt relief and also creates unnecessary dependence on professional caregivers.

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9. Recommendations

The primary purpose of this research report is to serve as a commentary on the National Voices 'Narrative', identifying areas where it might benefit from revision.

A revised 'Narrative' is likely to mirror the original narrative, which (as we have seen) consists of themed groups of "I" statements. These "I" statements issue from the perspective of service users, and they describe the *experience* of care processes and outcomes that users of services desire.

The aim of these "I" statements is to guide commissioners in their thinking about service design. The "Narrative" describes what service users want the *results* of commissioning to look and feel like. It does not constrain commissioners by saying what type or shape of service should be commissioned. Instead, it gives licence to invent new solutions by focusing on the user experience that commissioned services should *accomplish*. There will be many different ways to meet service users' needs, and plenty of scope for commissioners to learn from each other's innovations and from diversity in provision.

In this section, we reflect on some key areas of need that should be expressed in the "I" statements.

1. A proactive, holistic approach. The "I" statements should reflect service users' needs for proactive, holistic approaches to care. Service users need care services to be designed in such a way that professionals will anticipate and actively manage deterioration in a patient's condition. They need professionals to do this in partnership with the patient and their carers. Additionally, dying people and their carers need services designed, as far as possible, to take account of their psychological, social and spiritual needs as well as their physical needs. At present, this is not consistently the experience of people dying at home or in hospital. It does seem to be more frequently achieved in care homes, and is by and large the experience of in-patient hospice care.

2. Identifying the 'service users'. The "I" statements should reflect how carers are themselves users of end of life care services. (They are also providers of care, and we deal with this in the next paragraph.) Carers are sometimes service users in *partnership* with the person for whom they care: for example, when the person for whom they care is highly dependent so that the carer is the person calling for professional help, and taking advice on what to do. At other times, carers need services in their own right: for example, advice, counselling or other emotional support. Identifying end of life carers as 'service users' with their own "I" perspective has significant implications. First, it raises questions about how to design services so that professionals and carers can work together as genuine partners in care; this in turn raises questions about the scope of carers' involvement in decision-making about care options for the dying person. Second, commissioning end of life care entails giving consideration to carers' needs for support for

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themselves. Attending to carers' needs is partly instrumental, because if carers fail to provide care then other services will have to step in and fill the gap.

3. Time and relationships at end of life. The "I" statements should reflect that time, and cherished relationships, are of great importance to people who are dying. Knowing that time is short makes the amount of time wasted on co-ordinating care services a potent source of frustration for both patients and carers. Dying people are also aware that caring, and the process of dying, can be a burden on their loved ones. Services that help to relieve that burden and support carers offer a psychological benefit to both parties.

4. Active liaison The "I" statements should emphasise the desire for effective liaison (and greatly improved information sharing) between the plethora of health and social care providers contributing to end of life care. There is widespread support for the concept of a named liaison person who supports patients and carers to understand their situation, access the full range of local services, and secure the resources to which they are entitled. The need for an active problem-solving approach has been clearly articulated. This goes beyond merely providing information, to being more of a 'concierge' style service. This means offering tangible support to carers and patients by giving information and guidance, anticipating future needs, helping them to consider unfamiliar possibilities, and giving practical help to secure resources or facilitate access to services. Service users recognise that people with different conditions would make different demands on this role, and also that overlap with existing provision (such as Marie Curie and Macmillan nursing services) should be avoided.

5. Active communication. The "I" statements should emphasise the desire for good communication between service users and providers, and between providers themselves. "I" statements should reflect that service users are conscious they themselves cannot anticipate the issues that are likely to arise for decision. Many want the option to consider advance care plans and statements, and to be helped to understand legal instruments such as powers of attorney and advance decisions to refuse treatment. "I" statements on communication *between providers* should reflect the need for services to respond rapidly and effectively when urgent care is required for people dying at home. Dying patients and carers should not constantly have to explain their circumstances and needs in order to secure an effective response. Opening the market to new "qualified providers" may create opportunities to improve services, but it is also likely to increase fragmentation and confusion. "I" statements should encourage commissioners to think carefully about how to overcome existing difficulties in communication between NHS providers, and improve communication in a future mixed economy of private / NHS / and not-for-profit providers.

6. Safety and dignity. The "I" statements should reflect that patients and carers both want end of life care at home to be safe and dignified. This this can be difficult to achieve when mobility is significantly impaired, and carers have limited knowledge and nursing skills. Preserving dignity in the face of loss of physical function, and providing basic

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nursing care, present significant challenges and may entail carers needing to rapidly develop new skills to deal with common issues, such as preventing pressure sores, lifting, washing, giving injections and so on.

7. Training and supporting carers as care providers. The “I” statements should reflect that carers are major providers of end of life care services, and are aware they often require training and support to fulfil this role. If carers are to be true care partners (that is, working in partnership with both the patient and the professional), they need to know what they are being asked to undertake, and probably need guidance or training (often both) to deliver care. Carers are highly motivated to give the best care they can to the person for whom they care and may derive real satisfaction from doing it well. The converse is they may suffer significant distress when they perceive they have failed.