

I'm still me

*...a narrative for
coordinated support
for older people*



Preface

We all like categories. They help us make sense of the world and feel more comfortable. And so we have ‘young people’; ‘middle aged people’ and ‘older people’. These familiar categories automatically entreat us to consider differences. Yet an extra moment’s thought might redirect us to a view that any differences are actually smaller than the similarities of shared humanity between the groups.

An older person is not an alien species – simply our (former) selves grown older. Older people value today what they valued yesterday – that is: independence; life roles; connections with family, friends and communities; fun; challenges; etc., etc. What needs to be recognised is not the ‘oldness’ of a person, but their individuality.

It is this individuality that can so easily become submerged and hidden from view in the pressure caldron that characterises our contemporary health and social care system.

This Older People’s Narrative serves to remind us of vital core values to which we all might lay claim – but restated through the eyes of an older person. In a sense, it is a shame that there is a need to restate these values. But we are where we are.

Professionals and service providers need explicitly to reconnect with these core statements. The narrative is designed to lift the individual within the older person label into clearer focus – not an alien being, but simply a human being who has lived longer.

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Introduction

The set of narrative statements published in this document describes the way older people want high quality coordinated care to support them. This document is intended to be used as an extension to the **Narrative for person centred coordinated care**¹ published by National Voices and Think Local Act Personal, in May 2013. Together they will help commissioners and providers to work together with older people, to design care and support that will be successful in achieving the outcomes that matter most to them.

Why older people? Why now?

Our population is ageing by five hours a day². The number of people in the UK over the age of 85 is set to double in the next 20 years and treble in the next 30³. As a consequence older populations will form a growing proportion of our society.

75% of 75 year olds have more than one long-term condition, rising to 82% of 85 year olds⁴. The majority of older people may therefore have multiple physical and mental health needs which require input from across primary care, secondary care settings and social care.

For older people living with frailty or complex needs, health and quality of life is vulnerable to sudden changes. A 'trigger event' such as a fall, or a change in circumstances like the loss of a carer, can result in a rapid deterioration in health and significant loss of independence. It may also lead to sharp increases in the costs of care. With better care planning and more tailored support, many such episodes could be avoided, or the need could at least be anticipated and better managed.

Therefore, it is becoming a priority for health and social care systems to look at how they respond to the needs of older people. In particular, how they identify people who are at risk of such crises and how they then ensure that proactive strategies are in place. This enables services to intervene early and support

people to avoid distressing emergencies, which typically carry with them a substantial human and financial cost.

Why additional statements were needed

The *Narrative for person centred coordinated care* has provided a single, common cross-system definition of the goals for care integration. It was consciously designed to be 'generic' and equally relevant to all groups of people who need to use multiple health and care services over time. This generic approach, however, might exclude some factors in the care of older people that are very significant to them, but do not always apply to other groups. National Voices, UCLPartners and Age UK, working with other partners and with older people themselves, set out to examine whether this was true.

We looked particularly at older people who might be vulnerable to sudden deterioration in their health, possibly including crisis or hospital admission. They might be described by professionals as 'frail' – but, as we discuss later, this is a term that older people themselves reject.

Similar pieces of work with other groups of service users – such as people using mental health services – resulted in quite extensive new sets of I statements giving their particular perspectives on their care and support.⁵ With older people, there was a different need.

Although we found that the domains and statements in the existing Narrative were relevant to them, the older people we spoke to were less concerned about the specific shape or type of service provision, and more concerned about the outcomes that matter in relation to living their lives.

This new Narrative seeks to articulate these outcomes, and we urge commissioners and providers to consider adopting these statements alongside the generic Narrative as the goals of care for older people, particularly those with complex needs.



INDEPENDENCE

“I can go to bed when I want, get up when I want. I can think for myself. I don’t rely on other people, as long as I’ve got my mobility.”

¹ National Voices & Think Local Act Personal (2013) A Narrative for Person-Centred Coordinated Care. <http://www.england.nhs.uk/wp-content/uploads/2013/05/nv-narrative-cc.pdf>

² Kirkwood (2006) Too Fast By Mistake. *Nature* 444:1015-1016

³ Office of National Statistics (2013) National Population 2012-based Statistical Bulletin. London: ONS. http://www.ons.gov.uk/ons/dcp171778_334975.pdf

⁴ Mercer (2011) The Scottish School of Primary Care’s Multimorbidity Research Programme. <http://www.slideserve.com/ryann/multimorbidity-in-scotland>

⁵ National Voices & Think Local Act Personal (2014) No Assumptions: A Narrative for Personalised, coordinated care and support in Mental Health. <http://www.england.nhs.uk/wp-content/uploads/2014/08/no-assumps-mh.pdf>

The I statements

Community interactions

- I can maintain social contact as much as I want

Care and support

- I can build relationships with people who support me
- 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
- Taken together, my care and support help me live the life I want to the best of my ability

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Independence

- I am recognised for what I can do rather than assumptions being made about what I cannot
- I am supported to be independent
- I can do activities that are important to me
- Where appropriate, my family are recognised as being key to my independence and quality of life

Decision making

- I can make my own decisions, with advice and support from family, friends or professionals if I want it

Research methods

In order to develop a specific narrative for older people, reflecting the different perspectives and preferences of that population group, we needed to invest time listening to them, asking them 'What matters most to you?' and reflecting on the key themes that emerged.

The research, carried out between May 2013 and March 2014, included:

- 1 A literature review** of existing research and materials to understand core themes and provide a foundation for interviews to build on. Published and grey literature was included that contained the search terms: older people, frailty, frail, vulnerable, [and] person-centred, outcomes, care needs.
- 2 An online survey** and two **focus groups** to gather the perspectives of health professionals, system leaders, carers and older individuals, both reflecting on the existing Narrative for coordinated care and suggesting additional themes and statements that are relevant for older people. 43 people participated in the focus groups and 28 responded to the online survey.
- 3 Ethnographic research** conducted by IPSOS Mori on behalf of Age UK to explore the experience of living with frailty⁶. The researchers spent around 30 hours with five households, seeing the impact of living with frailty and some of the ways older people adapted to live with changing needs.
- 4 1:1 interviews** with older people exploring the things that are most important in their lives; their experiences of accessing services and support; and attitudes to terminology such as 'frail', 'old', 'elderly', 'older'.

74 semi-structured interviews were conducted with participants aged over 75 years, each lasting on average 25 minutes. Interviewees were recruited from Age UK day centres (51%), hospital wards (42%), house-bound GP patients (4%) and Age UK befriending services (3%). Purposive sampling was used to ensure that the cohort was varied in terms of: functional ability, level of support received, cognitive ability, age, cultural and ethnic groups, social classes, urban and rural settings and living arrangements.

Interview research cohort:

- Average age of 84
- Ethnicity of participants fell mid-way between figures for London and England as a whole (White British: 80%, Indian: 7%, Black: 6%, Other: 7%)
- 63% lived alone (including in sheltered housing), 18% lived with family, 8% lived with a partner and 4% had other arrangements (7% unknown)
- 42% owned their accommodation, 31% rented, 3% other (24% unknown)
- 28% were independently mobile, 68% were independent with a walking aid, and 4% were not mobile.
- 47% had formal support packages in place. 23% had no form of support (formal or informal) (30% unknown).

⁶IPSOS/MORI (2014) Understanding the lives of older people living with frailty: A qualitative investigation. IPSOS/MORI for Age UK <http://www.ageuk.org.uk/frailty>

What matters most to older people: key themes

Independence:

Independence was described by the majority of the older people we spoke to as one of the most important things to them. For most this meant being able to 'do what I want, when I want' and 'getting out and about'.

Support from either family and friends or formal carers to maintain a level of independence, particularly when mobility was limited, was not seen to impact perceived independence. In both the interviews and ethnographic work, people who were supported and able to adapt to changing health needs were able to enjoy a better quality of life. Their perceptions of their own health and perceptions of their independence did not necessarily correlate, suggesting that older people do not want to be defined or limited by their diagnoses.

There can be a tension between independence and safety. Whilst several studies in the literature review spoke about independence and safety, they did not delve into the meaning of these and many studies appeared to be very 'problem focused' rather than looking at the people with frailty themselves as individuals.

Being able to do activities that were important to them, also helped to maintain a sense of achievement and identity. For example, many interviewees described great pride in doing the washing-up or housework and disappointment when these habitual tasks were taken over by carers. The workshop participants suggested that independence was about more than attending to the basic activities of daily living – but about being able to do activities which were meaningful to them and even having the opportunity to try new activities.

Community interactions:

Many of the older people we spoke to said that they did feel part of their community. But there was also a sense of people wanting to have control over the amount of social contact they had – some wanted much more social contact but others valued time alone.

Many described feelings of loneliness. Many said that they missed friends who had died and in some instances, there was resignation that they could no longer expect to have peer relationships. This was often associated with losing a partner.

Surprisingly, in the interview cohort there was a higher correlation of self-reported loneliness in those that lived with family than those who lived alone and therefore felt they needed to make the effort for social interaction. This highlights that having frequent social contact is not enough to prevent feelings of loneliness.

Decision making:

Individuals wanted to retain choice and control of decision making. However many also described the desire for clear guidance and support from professionals and family. In many instances family were the first port of call for both accessing support and for discussing decisions.



CARE AND SUPPORT

“I like the company of them coming into my home and I feel she’s part of it now... I wish she had more time.”

COMMUNITY INTERACTIONS

“I feel lonely when I get up in the morning. I hate mornings... you want to talk to somebody about something, or you thought of something in the night, or sometimes something happened, when you walk into the house and you want to tell somebody and there’s nobody here to tell.”





DECISION MAKING

“Well you’re not in control of your health because things happen to you...I think it’s important that you do make your own decisions but at the same time you have to listen to a professional, that’s what they’re there for.”

CARE AND SUPPORT

“I like to be known by my name and not that old woman.”

COMMUNITY INTERACTIONS

“I just have the television for company.”



COMMUNITY INTERACTIONS

“I miss social interactions. I don’t mean going out whatever, I mean having a good conversation.”

Care and support:

Both the workshop and the interview participants emphasised the social aspects of care in addition to the practical components. People often described their satisfaction or dissatisfaction with their care in terms of personal relationships rather than the actual care that was being delivered.

It is important to note that the older people we spoke to did not generally draw a distinction between health and social care support; they saw their support as one entity.

There appeared to be limited awareness or discussion of formal care plans and although some interviewees said that they had thought about the future, this was seldom with regards to advance care planning or end of life care. Most participants referenced the future with regards to plans in place for supporting family in their absence, funeral arrangements, or more generally as an inevitability over which they had no control, and therefore a desire to ‘take one day at a time’.

To summarise what was important in terms of care and support, the survey and workshop participants found the composite statements from the existing narrative very useful, hence these were carried into the care and support section of this narrative.

Terminology:

There were mixed views on the terms ‘old’ and ‘elderly’, but ‘frailty’ was almost universally rejected. Though there was some sense that it could be recognised in others, people did not see it as a way to describe themselves.

Development of the I statements

The I statements were initially drafted by the steering group around the above key themes that emerged from the literature review, the survey and the workshops – but with particular reference to what the older people we interviewed described as being most important to them.

The narrative was then reviewed, revised and verified through further discussions with older people. The group felt it was essential to ensure that the narrative reflected the views of older people and that the statements resonated with them.

Using the I statements

The research we conducted for this narrative illuminates the challenges of long-term conditions and frailty from the perspective of older people with care and support needs. This poses some key challenges for health and care services.

- **Perception of health:** An effective approach to supporting older people living with frailty is not simply about 'managing long-term conditions'. While older people recognise the constraints that their health conditions sometimes place on their lives, they have told us that they do not identify themselves by these conditions and that they are focused on living their lives – not on a preoccupation with their health. This implies that there will be limits to the success of strategies that seek to engage people only through their management of their health.
- **Use of care services:** People do not picture their lives in relation to their use of care services. Indeed, when asked about who would be their first point of contact for a health problem, very often people cite a family member (e.g. their spouse or child) as their principal adviser and the person who would make, or suggest making, contact with services. This implies both a need for mainstream services to establish proactive outreach; and a need to work closely with family members and informal carers in support of the person.
- **Independence:** Although older people want to be able to get support when they need it, they also want to remain as independent as possible. The value of care and support is that, as the I statement says, it 'help(s) me live the life I want to the best of my ability'. This can present a challenge in that rehabilitation services are often stretched and there can be a perception that it is quicker for staff to 'do something to' a person rather than encourage independence. There can also be a 'risk averse' attitude among both health and social care staff and older people's families, which results in people being discouraged from participating in activities of daily living where it is felt that there may be a perceived risk to their safety.
- **Social support:** The research has also highlighted the importance of social support – both as part of their community but also in relation to feeling that they have a personal and social relationship with the health and care professionals with whom they come into contact. This presents a challenge in terms of the time that health and social care staff have available.

INDEPENDENCE

"I'm independent because I'm living my own life in my own home and I love it. I'm ninety two and I can still do that. I call that independence."

COMMUNITY INTERACTIONS

“I’m extremely lonely. I miss my wife.”

DECISION MAKING

“I talk it over with my daughter... she’s one of those that as long as you want to be independent, she’ll let you be. If she thought something was radically wrong, she would do something.”

It is intended that these I statements will be used to encourage health and social care services to work together to focus on the outcomes that are important to older people in their population. We would encourage people working within health and social care services to reflect on the issues identified in the I statements.

For example:

- **Are we helping people to maintain independence?**
- **Are we enabling older people to build and maintain relationships with their professionals and practitioners?**
- **How to reach out to people in ways which are not solely dominated by ‘health management’ considerations?**
- **How to work with family and informal carers and supporters?**

Health and social care services should also reflect on whether they are measuring what is important to older people.

For example, maintaining independence and social interaction are recognised in social care but are less likely to be seen as outcomes by which mainstream health services and practitioners judge their success. This will have to change.



The 'frailty' challenge

As discussed in the introduction we have an ageing population, and across England local areas are prioritising care and support for older people. To help identify older people at risk of poor health outcomes, considerable effort is now put into better defining 'frailty', in the hope of managing it as a long-term health condition. The British Geriatrics Society (BGS), in association with Age UK and the Royal College of GPs (RCGP), has produced guidance on recognising and managing frailty outside of hospital.⁷

A key feature of frailty is that it describes a person at a higher risk of a sudden deterioration in their physical and mental health. This will include people who could otherwise be very stable and low users of health services. It will also include people who require high levels of support and may be at the end of their lives.

Recognising a spectrum of need that overlaps, rather than duplicates long-term conditions management is an important message. As a system, this means that having frailty in mind when identifying, assessing and planning care needs will be vital to achieving better outcomes for older people and preventing the need for crisis or emergency care.

A foundation of good practice will mean coordinating older people's support needs across all of the agencies and people involved in their care, including informal care and support as well as that provided by voluntary and community sector groups.

"I identify with getting older. I'm not frail."

Call for a national dialogue on frailty:

This research has focused on asking older people what matters most to them and it has reminded us that the older person's perception of what constitutes good health or frailty is often very different to the clinician's perspective.

Even patients with a number of health conditions, who we may describe as being frail, did not associate themselves as such, and wanted to be supported to be as independent as possible.

Significantly, older people have told us that they do not like the term 'frail' or 'frailty' and very few wished to describe themselves using these terms. In fact, this narrative was originally about 'frail' older people, but we soon dropped that word in the face of its rejection by the very people we were working with.

This presents us with a dilemma: How do we ensure that we identify frailty as a trigger so that people are referred appropriately within the health and social care system? And how do we do this in a way that is acceptable for older people and enables them to work in partnership with their professionals? Health commissioners, practitioners and services may be investing in frailty strategies that risk being rejected by the people with whom they are seeking to work in partnership.

We are therefore issuing a call for a new national conversation. We need to understand better how older people with health conditions and those whose job it is to commission and provide their care services, can find a common language and principles for working with each other.

It is vital that this conversation continues to be led by the views of older people.

⁷British Geriatrics Society (2014) *Fit for Frailty*. http://www.bgs.org.uk/campaigns/fff/fff_full.pdf

Case study

“nobody calls me frail.”



The challenge of defining frailty?

This is Ken. Ken may have been described as frail by clinicians. When we met him, he was 100 years old, had a number of co-morbidities and was close to the end of his life, passing away just a few weeks later..

However, he did not identify himself as being frail. He lived alone with only domestic assistance. He used an iPad and went to Pilates classes twice a week. He described his health as ‘pretty good’ and said that independence to him meant ‘doing things for others’

Picture courtesy of the Hemel Hempstead Gazette. Many thanks to Ken’s daughter for her kind permission to share his story .



UCLPartners is a leading academic health science partnership that supports the healthcare system serving over six million people in parts of London, Hertfordshire, Bedfordshire and Essex. Member organisations from higher education and the NHS have come together through UCLPartners to improve health outcomes and create wealth for the local population at scale and pace.

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National Voices
People shaping health
and social care

National Voices is the national coalition of health and social care charities in England. We work together to strengthen the voice of patients, service users, carers, their families and the voluntary organisations that work for them.

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Age UK is the country's largest charity dedicated to helping everyone make the most of later life. The over-60s is the fastest-growing group in society and there are more of us than ever before. At Age UK we provide services and support at a national and local level to inspire, enable and support older people. We stand up and speak for all those who have reached later life, and also protect the long-term interests of future generations.

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