

# RightCare scenario:

# The variation between standard and optimal pathways



Janet's story: Frailty

# The story of Janet's experience of a frailty care pathway, and how it could be so much better

In this scenario – using a fictional patient, Janet – we examine a frailty care pathway, comparing a sub-optimal but typical scenario against an ideal pathway. At each stage we have modelled the costs of care, both financial to the commissioner but also the impact on the person and their family's outcomes and experience.

This document is intended to help commissioners and providers understand the implications – both in terms of quality of life and costs – of shifting the care pathway of older people living with frailty from a reactive approach (primarily based on an acute response) to a proactive approach, e.g. providing an integrated primary care and community-based response, with support from the voluntary sector.

It shows how the RightCare methodology can help clinicians and commissioners improve the value and outcomes of the care pathway.

Two summary slide packs are also included as appendices.

#### Introduction

Around 10 per cent of people aged over 65 currently live with frailty, rising to between a quarter and a half of those aged over 85<sup>1</sup>. People living with frailty sometimes find themselves in receipt of poor quality care and experience repeated avoidable admissions to hospitals and delayed discharges – resulting in worse health and wellbeing outcomes, and higher costs to health and care services.

Typically their evolving frailty goes largely unnoticed until a crisis happens which necessitates urgent intervention. Even then, the response tends to focus on the shorter-term issue in a reactive way, without addressing the underlying problems.

Frailty is a distinctive state of health related to the ageing process, usually characterised by a complex mix of physical, mental health and social care needs. It is a condition where the body's in-built reserves are eroded, meaning people are vulnerable to sudden changes in their health triggered by seemingly small events, such as a minor infection or a change in medication. Whilst there is evidence that frailty may be modifiable, in the current system a person will typically present in crisis with non-specific manifestations of frailty such as delirium, sudden immobility or a fall.

However, frailty doesn't appear suddenly. It is a progressive condition that develops over five to ten years, which suggests that more could be done before a health crisis occurs. Older people living with frailty can be identified sooner and are usually known to local health and care professionals. As with any other long-term condition, when older people living with frailty are supported to live well independently and to

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<sup>&</sup>lt;sup>1</sup> Clegg A. et al, "Frailty in elderly people", Lancet, March 2013

manage their long-term condition(s), they are less likely to reach a crisis, require urgent care or experience poor outcomes.

### **Introducing Janet**



Janet is an 84-year-old retired teacher living with her 85-year-old husband Arthur in the family home they bought when they had their first child.

Since retiring 20 years ago, Janet had been active, going to the local market on Saturdays and playing bowls with her husband and friends every Sunday.

### Janet's journey

Janet's journey started typically when she began to find everyday tasks more difficult to complete and started to feel generally slower. She had already had one fall but had not requested or received any support to prevent further falls.

On a Friday evening, while using the bathroom, Janet felt dizzy and fell on the floor. Arthur, Janet's husband, came to help her but couldn't manage to get her back on her feet. He wasn't really sure how badly she was hurt and she had a nasty bruise on her right hip. He called 999 and when the paramedics arrived, they advised the couple that Janet would need to go to A&E, even though she wasn't keen and preferred to stay at home.

At 6.30pm on a Friday night, Janet was under the bright lights of her local hospital's emergency department. Around 8pm, the on-call A&E consultant arranged for her to get a hip X-ray, which didn't show any fracture. However, her blood and urine tests suggested she was mildly dehydrated and might have a urinary tract infection.

Having waited nearly four hours in the emergency department, Janet was then moved on to the acute medical unit where she was put on a drip and given antibiotics to treat her infection along with her usual medications.

On Saturday morning, Janet was seen by the on-call doctor for a medical check-up. But before anyone had a chance to fully assess her mobility, needs and preferences, she was moved to the first available bed on a general medical ward. She spent the rest of the weekend worrying and waiting for further updates on what might happen to her. There was no routine physiotherapy or occupational therapy over the

weekend, so she couldn't be referred to the home rehabilitation team until Monday. Arthur was unable to visit her over the weekend as his car was undergoing some repairs and he was left worrying at home.



By Monday morning, Janet had been either on a trolley or in bed with the cot sides up for three days and nights, because she was deemed to be at high risk of falls and a catheter had been inserted to monitor fluid output.

By then, her muscles had started to get weaker, particularly in her legs. She was seen that morning by the physiotherapist who got her out of bed with the aid of a walking frame. She didn't have any day clothes with her as she had been rushed in in an ambulance.

On Monday morning the ward doctors and occupational therapists decided to gather more information on Janet's medical history, usual abilities and needs. They asked for her GP records to be faxed in and also talked to Arthur, who was by then able to get to the hospital to see her on the ward. Arthur told the ward doctors that Janet had been getting more unsteady recently and that he often had to help her climb the stairs. She had suffered another fall and he also explained her memory wasn't as good as it used to be.

The ward team discovered that her blood pressure was dropping very low when she stood up; indicating that she had postural hypotension which often leads to falls and faints in older people. They decided to stop a couple of her heart medications to see if it could help solve this problem.

Janet was moved to a cardiology ward as the bed on the acute medical ward was needed for another acutely ill patient.

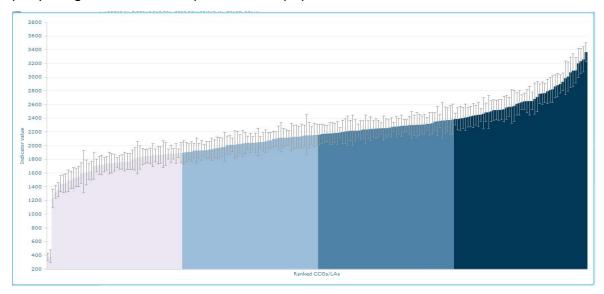
### Data analysis on frailty

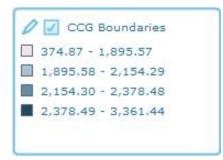
One of the key findings from the work on Janet's scenario is that more data needs to be captured in this area.

Therefore, we will use the most relevant datasets available to provide the best available proxy information.

#### The scale of the issues raised in this scenario

We know that there is a strong correlation between frailty, impaired mobility and falls<sup>2</sup>. Therefore, to understand the potential scale of frailty issues across England a good measure is the "Rate of emergency admissions for injuries due to falls in people aged 65 and over per 100,000 population"





In 2014/15 the average number of falls (that were serious enough to cause injury) per CCG was 2,154 per 100,000 population. The sum of all 209 CCGs' actual falls equates to 210,000 serious falls and these are just the ones that we know about – this scale is significant.

The role of CCGs is to understand the reasons why people become frail and to use that knowledge to commission care and support differently in the future.

Ref: The Commissioning for Value Tool 2016 http://ccgtools.england.nhs.uk/cfv2016/flash/atlas.html

## Back to the story...

On Wednesday, five days after her admission, Janet was able to stand with assistance and walk short distances. The physiotherapists came to see her and made a plan to refer her to ongoing rehabilitation in the local community hospital before going back home. The referral involved filling out and faxing a number of

<sup>&</sup>lt;sup>2</sup> ...significant correlations between avoidance of activities on the one hand, and physical performance, muscle strength, forward endpoint excursion of the centre of gravity, and previous falls on the other hand. Logistic regression analysis revealed that fear of falling and avoidance of activities in daily life were predictive of falls within a 1-year follow-up, (Fear-related avoidance of activities, falls and physical frailty. A prospective community-based cohort study KIM DELBAERE, GEERT CROMBEZ, GUY VANDERSTRAETEN, TINE WILLEMS, DIRK CAMBIER 2004)

Nowak and Hubbard, 2009. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2746842/ Also references that people living with frailty are 3.6x as likely to fall as non frail adults

forms to their referral 'hub'. However, there were no beds available in the community hospital, so she had to stay in the acute hospital.



By the following Monday – day ten of her admission – the cardiology ward needed more beds for people with serious heart issues so she was moved to a 'winter escalation' ward. After all these moves, Janet had become increasingly confused and agitated. She sustained another fall, and was found lying on the floor by the nurses. She sprained her wrist which made it difficult to hold her walking frame, and now required two nurses to move her out of bed.

Janet spent more and more time in bed with the cot sides up to protect her from another fall. By day 12 of her admission, the community hospital phoned back saying that she had 'no potential for rehabilitation' and should have a care package instead. She was therefore referred to social services with the aim of sending her home on Friday, over two weeks after her admission to hospital.

However, the care package could not be put in place until the following Tuesday, when she went home to receive a three-times-a-day care package. She still hadn't received a formal diagnosis for her progressive memory issues and falls, or a plan made to further investigate these issues in the community.

# 10 days in a hospital bed (acute or community) leads to the equivalent of 10 years ageing in the muscles of people over 80

Gill et al (2004) studied the association between bed rest and functional decline over 18 months. They found a relationship between the amount of time spent in bed rest and the magnitude of functional decline in instrumental activities of daily living, mobility, physical activity and social activity.

Kortebein P, Symons TB, Ferrando A, et al. Functional impact of 10 days of bed rest in healthy older adults. J Gerontol A Biol Sci Med Sci. 2008;63:1076-1081

Seven months after leaving the hospital, Janet suffered another serious fall and another stay in hospital; similar in many ways to her first acute experience.

Four weeks later, Janet's memory was getting worse, and Arthur was more and more anxious, worried and exhausted and this was the trigger for Janet to be admitted for respite to a local care home. As she was now living with severe frailty and required daily personal care, she was kept in the care home for just over a month. Arthur was left on his own in their family house, visiting Janet as often as he was able.

The care home support came to an end when Janet (who was now deteriorating quickly) had another serious fall. She was again taken to hospital and after one week of hospital care Janet was admitted to intensive care where she died ten days later.

Arthur was lonely and isolated at home and his eyesight was getting worse. A few months later, he was unable to reapply for a driving licence due to his poor vision and had to sell his car. His social interaction with the world became less and less frequent, as he feared leaving the house and had less reason to without Janet.

#### Questions for GPs and commissioners to consider

At the CCG population level, there are likely to be thousands of people living with frailty related issues many of whose frailty will not have been identified formally to the care system.

In the local population, who has overall responsibility for:

- Promoting frailty as a condition for which targeted interventions must be planned and delivered?
- Identifying individuals living with frailty?
- Planning care models to address key stages of frailty (pre/early, moderate or severe)?
- Identifying and reporting on measurable positive and negative frailty associated outcomes?
- Quality assurance and value for money of frailty care?
- Getting best value for money from the investment by caring agencies re frailty?
- How do we do the right thing for the patient and at the same time recognise that costs shift from health to social care?

The above questions are vital in understanding who manages which components of a whole system. Most importantly, it is impossible to effect optimal improvement if the system is not aware of the answers.

# What could have happened differently? Janet's optimal care pathway

#### Janet's journey starts four years earlier

This is the story of Janet, an 80-year-old retired teacher who was living with her 81-year-old husband Arthur in the family home they had bought when they had their first child back in 1950s. Since retiring 15 years ago, Janet had been quite active, going to the local market on Saturdays and playing bowls with her husband and friends every Sunday.

On a Friday afternoon, Janet and Arthur received a visit from the local Fire and Rescue Services. This was part of the firefighters' programme of 'Safe and Well' visits in the area, and had been booked through previous correspondence with them. The firefighters checked appliances and potential risks of fire. They also took this opportunity to check how Janet and Arthur were coping in the house and whether they had any particular needs. Arthur told them that Janet had started finding everyday tasks longer to do and was finding it harder to move around the house, let alone walk to the local shop.



The fire-fighters took this opportunity to assess Janet's walking speed through a gait speed test. The results showed that her walking speed was slower than normal (more than five seconds to cover four metres), and that she may be displaying early signs of frailty.

The firefighters provided Janet and Arthur with a leaflet, 'A Practical Guide to Healthy Ageing', which contained hints and tips on how to stay physically and mentally well and independent. They also recommended getting in touch with a local charity to find out about exercise classes, which could help her to remain mobile and fit. Janet and Arthur started a regular exercise class that improved their fitness and gave them an opportunity to meet new people and socialise. Using the information she had learned from the guide and her engagement with other people, doing the exercises and continuing her regular visits to her classes enabled Janet to maintain her wellbeing and independence for the next few years.



Five years later, Janet – now aged 85 – decided to visit her GP with her husband, as although she was well, she had been feeling weaker and had found it more difficult to cope at home.

The GP carried out a structured holistic assessment of Janet's medical, social and environmental needs. She noted that Janet was becoming frail and using the electronic frailty index, she was able to categorise her as living with moderate frailty. This was logged on the practice computer system and the multidisciplinary team were made aware of her increasing needs. The GP explained to Janet and Arthur that a few more assessments would need to be undertaken to better understand Janet's underlying needs and conditions.

Over the following two months, the multidisciplinary team carried out a falls risk assessment in Janet's own home, which also included an informed medication review by the local pharmacist targeted at falls risk reduction. Janet was also referred to the local Memory Service, where she was diagnosed with early-stage Alzheimer's disease. All her results were quickly sent back to her GP electronically.

When Janet returned to see her GP with Arthur, they discussed together the implications of her diagnosis, including her moderate frailty and early-stage Alzheimer's disease, and proceeded to agree together a personalised frailty and dementia care plan. This would identify her support needs, reflect her goals and aspirations and outline actions, including what to do in case of a serious fall. Janet's care plan included a routine of falls prevention exercises supported by a Physiotherapist; as well as regular attendance at a Memory Café run by the local charity to reduce the impact of her memory problems and to provide both Janet and Arthur with support. She also received a planned visit from social services to fix handrails in her bathroom as well as providing Janet with properly fitted slippers.

Two years later, on a Wednesday evening, Janet fell in the kitchen. Arthur helped her up and to be on the safe side, contacted the out-of-hours doctor for advice. The out-of-hours GP had access to Janet's personalised care plan and was aware of all the services already involved in Janet's care. Importantly he was aware of the decisions she had made earlier with her GP about her preferences for care in the event that she fell, and also that she had already received full assessment and interventions to reduce the risk of falling and injury as far as was possible.

He was able to contact the local case management team leader on duty who advised what should happen next and was able to ensure that her case management key worker was informed of events once back on duty. In discussion with Janet and

Arthur the case management team decided to refer to the local Community Geriatrician's rapid access clinic for a Comprehensive Geriatric Assessment.

The assessment showed that Janet's blood pressure was dropping very low when she stood up, indicating that she had postural hypotension, which often leads to falls and faints in older people. Some changes were made to her medication and all of her results were recorded in in her medical record and shared with the GP.

A few days later, Janet and Arthur reviewed her care plan with her key worker. She advised that Janet's frailty had increased and that a few more steps would need to be taken to minimise her risks of falling. The key worker provided Arthur with advice and information on how to cope at home with a view to alleviating his concerns and agreed to visit regularly to coordinate Janet's care.

# And older people tend to conceive their ability to live independently as a 'spectrum'.....



Losing independence entirely and becoming totally reliant on support

· Synonymous with entering into a care home or hospital for many older people

Becoming almost or totally *unable* to manage personal hygiene without (significant) support

· Viewed as a distinct 'step up' in terms of invasiveness of support



Becoming almost or totally *unable* to do the everyday tasks important to maintaining the status quo *without* (significant) support

. When coping mechanisms and adaptions are no longer sufficient to 'get by'



Being able to do everyday tasks to maintain the status quo with some minor adaptations or 'light touch' support

- Often through coping mechanisms older people develop themselves
- And in some circumstances, through informal help from others (e.g. relatives)



Being able to do everyday tasks that are critical to maintaining the status quo without any support from others

- · For older women, this is particularly about keeping up the routine at home
- · For men, this is often tied up with outdoor and social activities

Source: BritainThinks. Frailty: Language and Perceptions: A report prepared by BritainThinks on behalf of Age UK and the British Geriatrics Society June 2015. Available at: <a href="https://dementianews.wordpress.com/2015/07/28/the-power-of-language-weighing-the-pros-and-cons-of-the-term-frailty-nursing-times-age-uk-bgs-britainthinks/">https://dementianews.wordpress.com/2015/07/28/the-power-of-language-weighing-the-pros-and-cons-of-the-term-frailty-nursing-times-age-uk-bgs-britainthinks/</a>

A couple of years later, shortly after her 88th birthday, Janet suffered a fall while she was in the bathroom. It was Friday night, and she was getting ready to go to bed. Arthur came to help her but couldn't manage to get her back on her feet. As he wasn't really sure how badly she was hurt and she had a nasty bruise on her right

hip, he dialled 999 to call an ambulance. The ambulance trust were aware of Janet's needs and the services involved in her care due to shared protocols with primary care and community services to access her personalised care and support plan. They sent a paramedic to assess her injuries. The paramedic was concerned that she may have broken her hip, so she advised Janet and Arthur that she would need to be checked at the hospital. Janet was helped to put on her clothes and transported in an ambulance with her husband.

On arrival at the ambulatory care unit, Janet had an X-ray and then waited in her own clothes for the results. The doctors were able to review her personalised care and support plan and carry out an assessment to see if there had been any important new changes to her condition. Due to the complexity of her needs and the potential seriousness of her injuries, they decided that further investigation was needed and arranged her admission to the acute frailty unit for 72 hours. A consultant geriatrician led the unit, working with a ward-based multidisciplinary team and advanced nurse practitioners with expertise in older people. Janet's stay on the unit was clearly focused from the outset on rapid targeted assessment and future care planning to support discharge within 72 hours.

Although she was now in a bed, Janet was still in her own clothes and comforted by Arthur's presence who was allowed to stay on the ward. She was given intravenous fluids and antibiotics as she was found to be mildly dehydrated and to have a urinary tract infection. Once a hip fracture had been excluded she was supported to get out of bed and move around as much as possible, with an expected discharge before the end of the weekend. By that point the team had already alerted the GP surgery and case management team of Janet's admission to, and expected discharge from, the hospital and recorded the information in her personal records.

On the Saturday morning, the specialist team completed a Comprehensive Geriatric Assessment. As Janet's condition was now stable but showed deterioration in her mobility and associated increase in her frailty, the team discussed plans for discharge the following day with the couple. Because of her increased needs, plans were made for her to have support initially with two weeks of intermediate bed based care and then through on-going support at home. Together the team reviewed Janet's personalised care and support plan to take account of her changed medical, functional and environmental support needs, and enable her rehabilitation and independence.

The specialist team confirmed Janet's care plans to her local GP and that Janet would be going home (from intermediate care) in two weeks' time and the specialist team also arranged for her key worker from the case management team to visit her at home shortly after to check how the couple were coping at home. A key component of the acute frailty unit discharge arrangement was to agree and confirm the appointments. This management reassured the couple and provided confidence that they would be supported with adequate community care support.

The first six weeks following her discharge from intermediate care, Janet received weekly visits from the case management key worker and the community rehabilitation team. Her agreed care package also included visits from a social care support worker three times a day for the first three weeks – which were then reduced to two visits a day. It also involved monthly home based respite care for Arthur provided by a local charity.



The prompt provision of short-term rehabilitation services as well as long-term support from social care services helped to keep Janet's condition stable, while maintaining her independence. She was able to continue to live in her own home with support from her husband, who would make time for himself too through respite breaks.

### The 'bills' and how they compare

What is the cost of Janet's journey to the NHS and the wider social and economic impacts?

Initially we created the two pen portrait journeys above at a high level. See Table 1 below:

Table 1
Standard pathway

Year 1	Year 2	Year 3	Year 4	Year 5	Year 6	Year 7	Year 8	Year 9
			First fall aged 84	Another cycle – circa 20 days in acute care				
			Month in acute setting	Deteriorat ion (10 days in intensive)				
			Care could be improved	Dies in hospital aged 85				

#### **Optimal pathway**

Year 1	Year 2	Year 3	Year 4	Year 5	Year 6	Year 7	Year 8	Year 9
Early community engagement and education	Charity support including exercise groups	Self help	Self help	Primary care analysis aged 85	Self help	First fall aged 87	Second fall aged 88 – just a few days in acute setting	Dies at home aged 89
				Appropriate care and support				

Then we performed detailed analysis through mapping the lifecycle of the pathways. Through this process we were able to identify the cost drivers that would be incurred in primary, hospital and residential care, using NHS reference costs and, where there is a hospital stay, average cost per bed day<sup>3</sup>. We have included the wider social impacts and economic impacts but we have not attempted to cost financially outside of the health remit.

Tables 2a & 2b below summarise the financial costs for both pathways.

Table 2a

Analysis by Cost Category	Standard	Optimal
Prevention and Public Health	£0	£2,239
Detection	£0	£20
Primary Care Management	£176	£59
Urgent and Emergency Care	£699	£233
Non-elective Admissions	£28,838	£0
Intermediate Care	£2,735	£4,979
Community Care	£2,766	£11,856
Miscellaneous	£60	£0
Grand total	£ 35,274	£ 19,386

This is the cost to the local health economy rather than the commissioner (which would be tariff based)

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<sup>&</sup>lt;sup>3</sup> An overnight stay in hospital varies according to location and the type of services needed. Data on NHS costs is not collected by bed day but according to the treatment required. However a hospital stay is estimated to cost £400 per day Data.Gov.uk <a href="https://data.gov.uk/data-request/nhs-hospital-stay">https://data.gov.uk/data-request/nhs-hospital-stay</a>. Edbrooke and colleagues estimated the average cost per patient day in 11 ICUs was £1,000 www.ics.ac.uk/EasySiteWeb/GatewayLink.aspx?alId=441

The excel spreadsheet designed to cost these scenarios includes full details of cost data sources and is available upon request.

Table 2b

Analysis by Provider	Standard	Optimal	
Fire Service - Safe & well visits	£0	£60	
Community teams	£0	£903	
3rd Sector	£0	£4,400	
Primary Care	£176	£370	
Ambulance Service	£699	£233	
Rapid access assessment unit	£0	£314	
Acute	£28,830	£0	
Acute frailty unit	£0	£1,200	
Ambulatory Care unit	£0	£157	
Community Hospital	£0	£2,993	
Mental Health Provider	£0	£272	
Social Services	£2,842	£8,483	
Care Home	£2,727	£0	
Grand total	£ 35,274	£ 19,386	

This is the cost to the local health economy rather than the commissioner (which would be tariff based).

In the standard pathway Janet received no support during the early years of her frailty symptoms. No health costs arise at that point but the time-bomb is starting to tick loudly. Strategically, these years were the most important to Janet's long-term health. If preventative care had begun to impact here, then the later complications would have been delayed and/or been more manageable as highlighted in the optimal pathway.

Not only is Janet's (and her husband's) health and quality of life significantly better in the optimal scenario, but the costs to the health economy are reduced by 45% - even though Janet lives for an additional four years. The impact is significant on outcomes, quality and finance.

### Think change, Think RightCare

This optimal pathway was understood, tested and created using the proven RightCare approach.

NHS RightCare is a methodology that focuses relentlessly on increasing value in healthcare and tackling unwarranted variation. It is underpinned by intelligence and robust evidence, showing commissioners and local health economies 'where to look' i.e. where variation and low value exists. The approach then goes on to support health economies through 'what to change' and 'how to change'. The diagram showing all three key phases is shown below

RightCare offers facilitation and support to all CCGs and their health economies in implementing the RightCare approach and the developmental thinking, tools and data that enhance population healthcare improvement.

RightCare is a proven approach that delivers better outcomes and frees up funds for further innovation. Please explore our latest Commissioning for Value <u>publications</u> and for more details about our programme visit <u>www.england.nhs.uk/rightcare</u>

You can also contact the RightCare team at <a href="mailto:rightcare@nhs.net">rightcare@nhs.net</a>



For a toolkit for general practice in supporting older people with frailty and achieving the requirements of the Unplanned Admissions Enhanced Service please visit: <a href="http://www.nhsiq.nhs.uk/media/2630779/toolkit\_for\_general\_practice\_in\_supporting\_older\_people.pdf">http://www.nhsiq.nhs.uk/media/2630779/toolkit\_for\_general\_practice\_in\_supporting\_older\_people.pdf</a>

For more information about the Long Term Conditions work at NHS England please contact <a href="mailto:england.longtermconditions@nhs.net">england.longtermconditions@nhs.net</a>

Two slide packs to summarise this scenario – a full length pack and a three page summary – are included as appendices.

This information can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request. Please contact 0300 311 22 33 or email <a href="mailto:england.contactus@nhs.net">england.contactus@nhs.net</a>