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SUPPORTED SELF-MANAGEMENT FOR PEOPLE WITH FRAILTY

The first section of this supplement made the case to consider frailty from the perspective of a long-term condition. This and the next section explore what this means in terms of applying some of the well-developed models for the care of long-term conditions to people who are living with frailty. First, we examine how the highly evidence-based model of supported self-management might be applied to frailty.

Key points

- Supported self-management is an evidence-based, effective intervention for long-term conditions
- The aim is to collaboratively help individuals and their carers to develop the knowledge, skills and confidence to care for themselves and their condition effectively
- Supported self-management can be readily applied to people living with frailty
- An evidenced-based, supported self-management guide for people with frailty has been produced
- Loneliness in later life is a particular issue for older people and impacts adversely on physical and mental health. It is best addressed through a 'more than medicine' approach

It is a common mistake to consider that supported self-management largely equates to provision of information: leaflets, booklets, web links, etc. Important though these are, the research evidence suggests that providing information alone is a very weak intervention that is not associated with improved outcomes.

Consider, for a moment, the commonplace life decision of buying a new car. Some background reading might well take place (information gathering), but almost certainly supplemented with advice from trusted friends (peer support) and car dealers (professional advisors). Lots of competing issues would be weighed up— model, cost, size, style, colour, gadgets—but the final choice and decision would be yours, for only you can fully understand the sort of car that fits into your life. You would be unhappy if someone simply told you what car to have!

In this simple analogy you have become an expert, or more of an expert than you were, in car buying. That is, you have used information gathered from a wide range of sources, engaged with the problem and self-tutored yourself into a position in which you are comfortable about making a choice and decision.

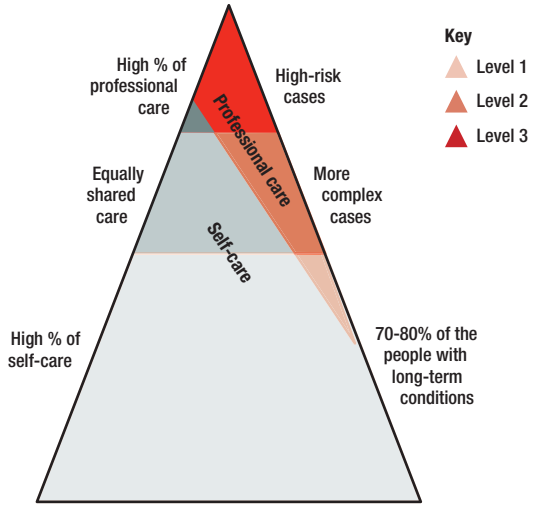
"Supported self-management may improve health outcomes, reduce hospital admission rates and be cost-effective"

It is this supported self-tutoring or self-education that lies at the heart of supported self-management for people with long-term conditions (LTCs). So supporting self-care and self-management for an LTCs requires more than simply giving patients information about their condition. It is about acknowledging their central role in the management of their own care and empowering them and their family and carers to handle their condition as effectively as possible.

In order to support self-care, healthcare professionals should:

- Ensure patients and carers have the skills and knowledge they need to understand how to best handle their condition, including how to deal with flare-ups, to adjust medicines, improve their lifestyles and access healthcare services
- Provide information that people are able to find easily and use meaningfully
- Enable and empower patients and their carers to manage their own condition more effectively; for example, by implementing self-monitoring or providing supporting prompts and reminders for patients to identify when they should be doing something and attending for care
- Provide a trusted and consistent person to contact
- Ensure support is available from a knowledgeable patient as well as broader peer networks and community support

Figure 1: Supported self-management and the long-term care pyramid



Supported self-management cuts across all three tiers of increasing case complexity, but is the dominant care response for people with Level 1 needs at the bottom of the pyramid:

- Level 1: aim to provide supported self-care. Collaboratively help individuals and their carers to develop the knowledge, skills and confidence to care for themselves and their condition effectively
- Level 2: aim to provide disease-specific care management. Provide people with a complex single need or multiple conditions with specialist services using multidisciplinary teams and disease-specific protocols and pathways
- Level 3: aim to provide case management. Identify the most vulnerable people, those with highly complex multiple long-term conditions, and use a case-management approach to anticipate, co-ordinate and join up health and social care

EVIDENCE BASE

A substantial, but complex evidence base for supported self-management is available. Over 200 systematic reviews have been identified and summarised in a 'review of reviews' by National Voices. The research relates to people living with LTC rather than frailty because, as described in Section 1 above, we are only just beginning to conceptualise frailty as an LTC. The evidence base for frailty is therefore necessarily indirect and must be extrapolated from the LTC research.

What emerges is strong evidence that supported self-management is associated with an increase in a person's knowledge about their condition and how to self-care, improved confidence and coping ability, improved health behaviours, and when to appropriately use healthcare—resulting in an overall improved experience of care. The evidence base is strongest for self-management by an educational process that is integrated into routine care with the active involvement and support of health professionals. Many types of educational materials such as booklets, leaflets and DVDs can be effective. There is suggestive, but not conclusive, evidence that supported self-management may improve health outcomes, reduce hospital admission rates and be cost-effective.

WHERE DOES SUPPORTED SELF-CARE FIT?

Over 15.4 million people in England live with one or more LTC such as arthritis, asthma, diabetes, heart disease and dementia. To this list we must now add people with frailty. The resources required to manage these conditions are enormous. Treatment associated with LTCs accounts for 70% of NHS health and care spend. This includes 77% of all inpatient bed days, 55% of all GP appointments and 68% of all outpatient and A&E appointments.

The NHS long-term conditions model considers the population of people with LTCs as a pyramid comprising three levels of decreasing size and increasing complexity of care (Figure 1). As far as frailty is concerned, it should now be apparent that supported self-management will have a role for all grades of frailty but is particularly relevant to people with early or mild frailty. From the prevalence rates for frailty recorded in Section 1 (page 02), this equates to about 200 people for a GP list of 2,000.

APPLYING SUPPORTED SELF-MANAGEMENT TO FRAILTY

As an initial step, NHS England and Age UK have co-produced *A practical guide to healthy ageing*, a supported self-management guide for people with frailty. It is designed to target people with mild frailty and was carefully constructed with the help of focus groups to ensure the content was meaningful and acceptable. The guide is based on three principles:

1. Language: older people are reluctant to use the word 'frail' as a self-descriptive term. More indirect language is used, such as 'slowing down', 'things taking longer' or 'less energy'. This is reflected in the guide. Indeed, the words 'frailty' or 'frail' are not used at all. The guide is couched in terms of promoting 'health and wellbeing' in later life.
2. Self-discovery and self-activation: the guide begins by suggesting people self-conduct the 4 metre walking speed test (see pages 10-11) on the basis that people are more likely to engage with the guide if they reason 'it is for me' because they find they are objectively walking slowly. The guide is then essentially a menu of items, only some of which will apply to a particular individual. Deciding 'what I need to do' is an important aspect of supported self-management, but obviously family and friends, and healthcare professionals will have a big role to play in the discovery process.

3. Independence: the guide focuses on maintaining and promoting independence as this is an issue that is both important and well understood by older people.

The evidence base for the topics in the guide is derived from a systematic review of 78 longitudinal observational studies that collectively identified 13 principal risk factors associated with functional decline in older people living at home. The majority of these risk factors are potentially modifiable. Take a look at the risk factors in Table 1.

Table 1: Potentially modifiable risk factors associated with functional decline in community-dwelling older people

- Alcohol excess
- Cognitive impairment
- Comorbidity
- Falls
- Functional impairment
- Hearing problems
- Mood problems
- Nutritional compromise
- Physical inactivity
- Polypharmacy
- Smoking
- Social isolation and loneliness
- Vision problems

Inspection of these risk factors probably has no surprises for you. They all seem to 'make sense'. Or perhaps social isolation and loneliness may be unexpected (see below). But the issue is that we currently have no system of care that addresses these important risk factors systematically. For example, many older people have undetected (but potentially treatable) mood, visual and hearing problems.

All the risk factors are likely to significantly aggravate the frailty process and will impact adversely on quality of life. They will reduce the person's resilience and make them more vulnerable to health and social care crises. The supported self-management guide incorporates these triggers for functional decline and provides signposting to additional information along with 'red flags' that direct them to their GP or practice nurse.

Are there any issues you think are not covered by the 13 risk factors? Table 2 lists the section headings for the guide. You can see that foot problems, safe homes, vaccinations, keeping warm, preparing for winter and bladder problems have also been included on the basis that these are important in relation to maintaining independence. Experience suggests that one issue, loneliness, is less well understood by healthcare professionals, and will therefore be discussed in more detail.

Table 2: Topics covered in the NHS England and Age UK guide *A practical guide to healthy ageing*

- Look after your feet
- Look after your eyes
- Make your home safe
- Keep active
- Medicines review
- Hearing tests
- Preventing falls
- Vaccinations
- Keeping warm
- Getting ready for winter
- Bladder problems
- Mental wellbeing

SOCIAL ISOLATION AND LONELINESS

It is only recently that the pernicious nature of loneliness in later life has been fully appreciated. Loneliness has a strong association with depression and it appears to have a significant impact on physical health, being linked detrimentally to higher blood pressure, worse sleep, immune stress responses and worse cognition over time (Table 3). In a systematic review of 148 studies involving 308,849 people, Holt-Lunstad *et al.* found that loneliness is associated with a 50% increase in mortality.

Table 3: Loneliness and/or social isolation in people with frailty

- Loneliness and/or social isolation are associated with marked negative outcomes in later life
- 59% of adults aged > 52 years who report poor health say they feel lonely some of the time or often compared with 21% who say they are in excellent health
- Lacking social connections is a comparable risk factor for early death to smoking 15 cigarettes a day, and is worse for us than well-known risk factors such as obesity or physical inactivity
- Social isolation is one of the top five causes of admission to care homes
- People who are socially isolated visit their GP more often, have higher use of medication and a higher incidence of falls

It is therefore good practice to routinely (and sensitively) ask older people about their felt experience of loneliness. Remember loneliness is not a 'present/not present' phenomenon: it comes and goes. And it is paradoxically particularly common in care home residents. A useful initial enquiry is: "Do you sometimes feel a bit lonely?" If the response is "Yes", then you can begin to gently explore how often the person feels lonely and how intrusive they find it.

It is recognised that health and social care professionals often feel uncomfortable when addressing loneliness. It seems to go beyond our training and expertise. 'More than medicine' is a newly introduced term that conveys the explicit acknowledgement that social as well as medical aspects need to be addressed for people with LTCs and frailty, and that different services are required to meet their wider social, physical and mental wellbeing goals. Such services offer an alternative to traditional health and social care services, instead looking at mobilising communities and networks to support people on their terms.

Examples of 'more than medicine' support options include:

- Physical activity: *eg* community gardening projects
- Healthy eating/cooking: *eg* cookery club in a community centre
- Arts for health: *eg* 'knit and natter' groups
- Befriending: *eg* local volunteer-led befriending scheme
- Welfare rights/benefits: *eg* local Citizens Advice Bureau or advocacy centre
- Volunteering opportunities: *eg* volunteering at community hub

The alternative provision is not intended to replace traditional planned medical care, but to complement it by developing an infrastructure to reliably and consistently deliver social models of support to enable people to live better. Working in this way requires healthcare professionals to forge strong links with local non-traditional providers (*eg* charities, voluntary and community organisations, and social enterprises). Increasingly, such services are being specifically commissioned by clinical commissioning groups (CCGs), usually in partnership with local councils. A good example is the Leeds Neighbourhood Networks.

SUPPORTED SELF-MANAGEMENT AND PRIMARY CARE

It will now be apparent that the primary care practitioner has a key role in providing supported self-management for people living with frailty. Five tasks can be identified:

1. Understand frailty—hence, read this supplement! But also integrate into your work the Older People's Narrative produced by National Voices (Table 4). This narrative provides a useful framework for what you should be aiming to achieve.
2. Identify people with frailty. Consider setting up the walking speed test (pages 10-11) in your practice and making it a routine procedure while the person is waiting for their appointment, or consider incorporating it into the Flu Clinic.
3. Discuss frailty (using terms such as 'slowing down', 'more of a struggle', 'things taking longer', etc) during consultations.
4. Disseminate the NHS England/Age UK supported self-management guide *A practical guide to healthy ageing*.
5. Be prepared to respond to queries arising from the guide. This will mean becoming familiar with local services required for the guide, including 'more than medicine' approaches.

CONCLUSION

The 'more than medicine' approach will demand a change in focus in primary care, but it can be used to offer supportive self-management to the majority of our patients who live with frailty (*ie* those comprising the base of the NHS chronic disease pyramid). The next Section considers the role of care and support planning for people with frailty and more complex needs.

Table 4: The Older People's Narrative from National Voices

Independence	• I am supported to be independent • I can do activities that are important to me • I am recognised for what I can do rather than making assumptions about what I cannot • My family are recognised as being key to my independence and quality of life
Community interactions	• I can maintain social contact as much as I want
Decision making	• I can make my own decisions, with advice and support from family, friends or professionals if I want it
Care and support	• 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 • I can build relationships with people who support me

more information

- *A practical guide to healthy ageing* (a supported self-management guide): **www.england.nhs.uk/resources/resources-for-ccgs/out-frwrk/dom-2/healthy-ageing/**
- Leeds Neighbourhood Networks: **www.leeds.gov.uk/residents/Pages/Support-organisations-and-neighbourhood-network-schemes.aspx**
- National Voices: **www.nationalvoices.org.uk**
- NHS Improving Quality Long Term Conditions webinars series: **www.nhsiq.nhs.uk/ltcwebinars**
- NHS Improving Quality Long Term Conditions monthly bulletin: **www.nhsiq.nhs.uk/ltcbulletin**

Further reading

- National Voices. Supporting self-management: **www.nationalvoices.org.uk/supporting-self-management**
- Stuck AE, Wathert JM, Nikolaus T, *et al*. Risk factors for functional status decline in community living elderly people: a systematic review. *Social Sci Med* 1999;**48**:445-69
- Holt-Lunstad J, Smith TB, Layton JB. Social relationships and mortality risk: a meta-analytic review. *PLoS Med* 2010;**7**:e1000316