Older people with social care needs and multiple long-term conditions

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Contents

Recommendations .......................................................................................................................................................... 3

1.1 Identifying and assessing social care needs .................................................................................................................. 3

1.2 Care planning ............................................................................................................................................................................ 4

1.3 Supporting carers ..................................................................................................................................................................... 7

1.4 Integrating health and social care planning .......................................................................................................................... 8

1.5 Delivering care .......................................................................................................................................................................... 9

1.6 Preventing social isolation .................................................................................................................................................... 12

1.7 Training health and social care practitioners ........................................................................................................................ 13

Terms used in this guideline .................................................................................................................................................. 13

Older people with social care needs and multiple long-term conditions implementation: getting started.......................................................... 15

The challenge: empowering older people with social care needs and multiple long-term conditions and their carers to choose and manage their own support ........................................................................................................ 15

The challenge: empowering practitioners to deliver person-centred care ........................................................................................................ 16

The challenge: integrating different care and support options to enable person-centred care .............................................. 17

Need more help? ........................................................................................................................................................................ 18

Context .................................................................................................................................................................................... 19

Recommendations for research .............................................................................................................................................. 21

1 Older people’s experiences ...................................................................................................................................................... 21

2 Service delivery models ............................................................................................................................................................. 21

3 Supporting people in care homes to stay active ........................................................................................................................ 22

4 Developing a ‘risk positive’ approach in care homes ............................................................................................................... 22

5 Self-management ....................................................................................................................................................................... 23
Recommendations

People using services have the right to be involved in discussions and make informed decisions about their care, as described in your care.

Making decisions using NICE guidelines explains how we use words to show the strength of our recommendations, and has information about safeguarding, consent and prescribing medicines.

Making information accessible

Information provided to both people using services and their families and carers should be in a format that suits their needs and preferences. In particular, practitioners must identify, record and meet the information and communication needs of people who have hearing loss, sight loss or learning disabilities, as set out in NHS England’s Accessible Information Standard.

1.1 Identifying and assessing social care needs

1.1.1 Health and social care practitioners should consider referring older people with multiple long-term conditions to the local authority for a needs assessment as soon as it is identified that they may need social care and support.

1.1.2 Consider referral for a specialist clinical assessment by a geriatrician or old-age psychiatrist to guide social care planning for older people with social care needs and multiple long-term conditions:

- whose social care needs are likely to increase to the point where they are assessed as having a significant impact on the person's wellbeing
- who may need to go into a nursing or care home.

1.1.3 When planning and undertaking assessments for older people with social care needs and multiple long-term conditions, health and social care practitioners should:

- always involve the person and, if appropriate, their carer
- take into account the person's strengths, needs and preferences
- involve the relevant practitioners to address all of the person's needs, including their medical, psychological, emotional, social, personal, sexual, spiritual and cultural needs;
sight, hearing and communication needs; and accommodation and environmental care needs

- ensure that if a person and their carer cannot attend an assessment meeting, they have the opportunity to be involved in another way, for example in a separate meeting or through an advocate.

- give people information about the services available to them, their cost and how they can be paid for.

1.1.4 Recognise that many carers of older people with social care needs and multiple long-term conditions will also need support. If the person's carer has specific social care needs of their own, refer them to the local authority for a needs assessment in their own right.

1.1.5 Recognise that many older people with social care needs and multiple long-term conditions are also carers, but may not see themselves as such. Ask the person if they have caring responsibilities and, if so, ensure they are offered a carer's assessment.

**Telecare to support older people with social care needs and multiple long-term conditions**

1.1.6 The health or social care practitioner leading the assessment should discuss with the person any telecare options that may support them so that they can make informed choices about their usefulness to help them manage their conditions, as well as other potential benefits, risks and costs.

1.1.7 The lead practitioner should consider, in discussion with the person, whether a demonstration of telecare equipment would help them to make an informed decision about it.

### 1.2 Care planning

**Coordinating care**

1.2.1 Ensure that older people with social care needs and multiple long-term conditions have a single, named care coordinator who acts as their first point of contact. Working within local arrangements, the named care coordinator should:
1.2.2 Offer the person the opportunity to:

- be involved in planning their care and support
- have a summary of their life story included in their care plan
- prioritise the support they need, recognising that people want to do different things with their lives at different times, and that the way that people's long-term conditions affect them can change over time.

1.2.3 Ensure the person, their carers or advocate and the care practitioners jointly own the care plan, sign it to indicate they agree with it and are given a copy.

1.2.4 Review and update care plans regularly and at least annually to recognise the changing needs associated with multiple long-term conditions. Record the results of the review in the care plan, along with any changes made.

Planning care collaboratively

1.2.5 Ensure care plans are tailored to each person, giving them choice and control and recognising the inter-related nature of multiple long-term conditions. Offer the person the opportunity to:

- address a range of needs including medical, psychological, emotional, social, personal, sexual, spiritual and cultural needs, sight, hearing and communication needs and environmental care needs
- address palliative and end-of-life needs
- identify health problems, including continence needs and chronic pain and skin integrity, if appropriate, and the support needed to minimise their impact
• identify the help they need to look after their own care and support, manage their conditions, take part in preferred activities, hobbies and interests, and make contact with relevant support services (see section 1.5)

• include leisure and social activities outside and inside the home, mobility and transport needs, adaptations to the home and any support needed to use them.

1.2.6 Discuss managing medicines with each person and their carer as part of care planning.

1.2.7 Write any requirements about managing medicines into the care plan including:

• the purpose of, and information on, medicines

• the importance of dosage and timing and implications of non-adherence

• details of who to contact in the case of any concerns.

For more information on managing medicines see the NICE guidelines on medicines optimisation and managing medicines in care homes.

1.2.8 Develop care plans in collaboration with GPs and representatives from other agencies that will be providing support to the person in the care planning process.

1.2.9 With the person's agreement, involve their carers or advocate in the planning process. Recognise that carers are important partners in supporting older people with social care needs and multiple long-term conditions.

1.2.10 Ensure older people with social care needs and multiple long-term conditions are supported to make use of personal budgets, continuing healthcare budgets, individual service funds and direct payments (where they wish to) by:

• giving them and their carers information about different funding mechanisms they could use to manage the budget available to them, and any impact these may have on their carer

• supporting them to try out different mechanisms for managing their budget

• offering information, advice and support to people who pay for or arrange their own care, as well as to those whose care is publicly funded
- offering information about benefits entitlement
- ensuring that carers’ needs are taken fully into account.

1.2.11 Ensure that care plans enable older people with social care needs and multiple long-term conditions to participate in different aspects of daily life, as appropriate, including:

- self-care
- taking medicines
- learning
- volunteering
- maintaining a home
- financial management
- employment
- socialising with friends
- hobbies and interests.

1.2.12 Ensure that care plans include ordinary activities outside the home (whether that is a care home or the person's own home), for example shopping or visiting public spaces. Include activities that:

- reduce isolation because this can be particularly acute for older people with social care needs and multiple long-term conditions (see section 1.6)
- build people's confidence by involving them in their wider community, as well as with family and friends.

1.3 Supporting carers

1.3.1 In line with the Care Act 2014 local authorities must offer carers an individual assessment of their needs. Ensure this assessment:

- recognises the complex nature of multiple long-term conditions and their impact on people's wellbeing
• takes into account carers' views about services that could help them maintain their caring role and live the life they choose

• involves cross-checking any assumptions the person has made about the support their carer will provide.

1.3.2 Check what impact the carer's assessment is likely to have on the person's care plan.

1.3.3 Support carers to explore the possible benefits of personal budgets and direct payments, and how they might be used for themselves and for the person they care for. Offer the carer help to administer their budget so that their ability to support the person's care or their own health problems are not undermined by anxiety about managing the process.

1.3.4 Consider helping carers access support services and interventions, such as carer breaks.

1.4 Integrating health and social care planning

1.4.1 Build into service specifications and contracts the need:

• to direct older people with social care needs and multiple long-term conditions to different services as needed

• for seamless referrals between practitioners, including the appropriate sharing of information

• to make links with appropriate professionals, for example geriatricians in acute care settings.

1.4.2 Ensure there is community-based multidisciplinary support for older people with social care needs and multiple long-term conditions, recognising the progressive nature of many conditions. The health and social care practitioners involved in the team might include, for example, a community pharmacist, physiotherapist or occupational therapist, a mental health social worker or psychiatrist, and a community-based services liaison worker.

1.4.3 Health and social care practitioners should inform the named care coordinator if the person has needs that they cannot meet.
1.4.4 Named care coordinators should record any needs the person has that health and social care practitioners cannot meet. Discuss and agree a plan of action to address these needs with the person and their carer.

1.5 Delivering care

Providing support and information

1.5.1 Health and social care providers should ensure that care is person-centred and that the person is supported in a way that is respectful and promotes dignity and trust.

1.5.2 Named care coordinators should review people's information needs regularly, recognising that people with existing conditions may not take in information when they receive a new diagnosis.

1.5.3 Consider continuing to offer information and support to people and their carers even if they have declined it previously, recognising that long-term conditions can be changeable or progressive, and people's information needs may change.

1.5.4 Inform people about, and direct them to, advocacy services.

1.5.5 Health and social care practitioners should offer older people with social care needs and multiple long-term conditions:

- opportunities to interact with other people with similar conditions
- help to access one-to-one or group support, social media and other activities, such as dementia cafés, walking groups and specialist support groups, exercise and dance.

Supporting self-management

See also section 1.7.

1.5.6 Health and social care practitioners should review recorded information about medicines and therapies regularly and follow up any issues related to managing medicines. This includes making sure information on changes to medicines is made available to relevant agencies.
1.5.7 Social care practitioners should contact the person's healthcare practitioners with any concerns about prescribed medicines.

1.5.8 Social care practitioners should tell the named care coordinator if any prescribed medicines are affecting the person's wellbeing. This could include known side effects or reluctance to take medicines.

1.5.9 Health and social care providers should recognise incontinence as a symptom and ensure people have access to diagnosis and treatment. This should include meeting with a specialist continence nurse.

1.5.10 Health and social care providers should give people information and advice about continence. Make a range of continence products available, paying full attention to people's dignity and treating them with respect.

1.5.11 Health and social care providers should give people information about services that can help them manage their lives. This should be given:

- at the first point of contact and when new problems or issues arise
- in different formats which should be accessible, including through interpreters (see making information accessible).

**Ensuring continuity of care and links with specialist services**

1.5.12 Named care coordinators should take responsibility for:

- giving people and their carers information about what to do and who to contact in times of crisis, at any time of day or night
- ensuring an effective response in times of crisis
- ensuring there is continuity of care with familiar workers, so that wherever possible, personal care and support is carried out by workers known to the person and their family and carers
- engaging local community health and social care services, including those in the voluntary sector
• ensuring people and their carers have information about their particular conditions, and how to manage them
• knowing where to access specialist knowledge and support, about particular health conditions
• involving carers and advocates.

**Care in care homes**

These recommendations for care home providers are about ensuring that care and support addresses the specific needs of older people with social care needs and multiple long-term conditions in care homes.

1.5.13 Identify ways to address particular nutritional and hydration requirements.

1.5.14 Ensure people have a choice of things to eat and drink and varied snacks throughout the day, including outside regular meal times.

1.5.15 Ensure the care home environment and layout are used in a way that encourages social interaction, activity and peer support, as well as providing privacy and personal space.

1.5.16 Ensure people are physically comfortable, for example by allowing them control over the heating in their rooms.

1.5.17 Encourage social contact and provide opportunities for education, entertainment and meaningful occupation by:

• making it easier for people to communicate and interact with others, for example by reducing background noise, providing face-to-face contact with other people, using accessible signage and lighting
• using a range of technologies such as IT platforms and Wi-Fi, hearing loops and TV listeners
• involving the wider community in the life of the care home through befriending schemes and intergenerational projects
• offering opportunities for movement.
1.5.18 Build links with local communities, including voluntary and community sector organisations that can support older people with social care needs and multiple long-term conditions, and encourage interaction between residents and local people of all ages and backgrounds.

1.5.19 Make publicly available information about:

- tariffs for self-funded and publicly-funded care
- what residents are entitled to and whether this could change if their funding status or ability to pay changes.

Make available a statement for each person using services about what their funding pays for.

1.6 Preventing social isolation

1.6.1 All practitioners should recognise that social isolation can be a particular problem for older people with social care needs and multiple long-term conditions.

1.6.2 Health and social care practitioners should support older people with social care needs and multiple long-term conditions to maintain links with their friends, family and community, and identify if people are lonely or isolated.

1.6.3 Named care coordinators and advocates should provide information to help people who are going to live in a care home to choose the right care home for them, for example one where they have friends or links with the community already.

1.6.4 Health and social care practitioners should give people advice and information about social activities and opportunities that can help them maintain their social contacts, and build new contacts if they wish to.

1.6.5 Consider contracting with voluntary and community sector enterprises and services to help older people with social care needs and multiple long-term conditions to remain active in their home and engaged in their community, including when people are in care homes.
1.6.6 Voluntary and community sector providers should consider collaborating with local authorities to develop new ways to help people to remain active and engaged in their communities, including when people are in care homes.

1.7 Training health and social care practitioners

1.7.1 Those responsible for contracting and providing care services should ensure health and social care practitioners caring for older people with social care needs and multiple long-term conditions are assessed as having the necessary training and competencies in managing medicines.

1.7.2 Ensure health and social care practitioners are able to recognise, consider the impact of, and respond to:

- common conditions, such as dementia, hearing and sight loss, and
- common care needs, such as nutrition, hydration, chronic pain, falls and skin integrity, and
- common support needs, such as dealing with bereavement and end-of-life, and
- deterioration in someone's health or circumstances.

1.7.3 Make provision for more specialist support to be available to people who need it – for example, in response to complex long-term health conditions – either by training practitioners directly involved in supporting people, or by ensuring partnerships are in place with specialist organisations.

Terms used in this guideline

Local authority needs assessment

The process by which a local authority works with a person to identify their needs and the outcomes they would like to achieve to maintain or improve their wellbeing. The local authority's aim is to determine how it should respond to meet the person's needs.

Multiple long-term conditions

In this guideline, a long-term condition is defined as one that generally lasts a year or longer and impacts on a person's life. Examples include arthritis, asthma, cancer, dementia, diabetes, heart
disease, mental health conditions and stroke. Multiple means a person is living with more than 1 condition. The impact and symptoms of these conditions can fluctuate, and people may or may not need to take medication for their conditions.

Named care coordinator

The named care coordinator is one of the people from among the group of workers providing care and support designated to take a coordinating role. This could be, for example, a social worker, practitioner working for a voluntary or community sector organisation, or lead nurse.

Social care needs

In this guideline, a person with social care needs is defined as someone needing personal care and other practical assistance because of their age, illness, disability, dependence on alcohol or drugs, or any other similar circumstances. This is based on the definition of social care in section 65 of the Health and Social Care Act 2012.

You can also see this guideline in the NICE pathway on social care for older people with multiple long-term conditions.

To find out what NICE has said on topics related to this guideline, see our web pages on older people, multiple long-term conditions and care homes.

[1] This is in addition to the statutory requirements placed on local authorities in relation to advocacy provision, set out in the Care Act 2014.

[2] In line with the Care Act 2014.

[3] This recommendation is adapted from NICE's guideline on home care.

[4] See the NICE quality standard on mental wellbeing of older people in care homes. For recommendations about delivering care at home, see the NICE guideline on home care.

[5] This recommendation is adapted from NICE's guideline on home care.
Older people with social care needs and multiple long-term conditions
implementation: getting started

This section highlights 3 areas of the older people with social care needs and multiple long-term conditions guideline that could have a big impact on practice and be challenging to implement, along with the reasons why change is happening in these areas (given in the box at the start of each area). We identified these with the help of stakeholders and Guideline Committee members (see section 9.4 of the manual). The section also gives information on resources to help with implementation.

The challenge: empowering older people with social care needs and multiple long-term conditions and their carers to choose and manage their own support

See recommendations 1.1.3, 1.2.5 and 1.2.10.

A person-centred assessment, focused on ensuring a person has choice and control over their care and support, can:

- result in a care and support plan that better meets the person's needs, helps them to maintain their independence for longer and may delay the need for higher levels of care
- contribute to the person's sense of wellbeing and improve their quality of life, which is consistent with the principles of the Care Act 2014 and the desire of older people to live a 'normal' life as described in published research.

Changing perceptions

As a result of pressures within the social care system, managers and practitioners often prioritise meeting older people's essential personal care needs over their wish to live a 'normal' life. This approach needs to change to reflect a much wider understanding of the role and contribution of social care.

To do this, social care managers and practitioners could:

- Work in partnership with focus groups, care providers or existing local forums to review their provision of information and advice, and ensure it covers all aspects needed to enable people to choose and manage their own care and support. The Care Act Statutory Guidance provides some helpful points to consider. The SCIE guide on co-production in social care provides some
helpful pointers and practice examples about reviewing services in partnership with those who use them.

- Draw on information and examples, such as those found in SCIE’s Prevention Library or as part of the Campaign to End Loneliness, to develop an awareness and understanding of the impact of social isolation. They should also consider the contribution that person-centred assessment and support planning can make to reduce social isolation, including through access-to-peer support.

- Work with older people locally who are already using personal budgets, continuing healthcare budgets, individual service funds and direct payments, to review the support they need.

The challenge: empowering practitioners to deliver person-centred care

See recommendations 1.2.5, 1.5.1 and 1.7.1–3.

Knowledgeable, confident and well-supported practitioners can deliver:

- more effective person-centred care and support that promotes independence, choice and control for older people with multiple long-term conditions using health and social care services

- coordinated care that is more cost-effective and better meets the wishes of older people as highlighted in the National Voices publication 'I'm still me – a narrative for co-ordinated support for older people.'

Skills and knowledge development

To support older people with social care needs and multiple long-term conditions, health and social care practitioners need to have skills and knowledge about a range of conditions, care needs, support options and legislation. Managers also need to understand their role in supporting this.

To do this, managers could:

- Use this guideline and local forums to review the knowledge, skills and qualifications practitioners need to provide person-centred care and support to older people with social care needs and multiple long-term conditions, and to identify any gaps.
- Use resources (such as the SCIE guide to effective supervision in a variety of settings) that highlight the importance of supervision, coaching, training and development plans, and regularly review progress and performance in partnership with practitioners.

- Use the Care Quality Commission's provider handbook for community community adult social care services (Appendix B: Characteristics of each rating level) to understand the characteristics of a well-led service and review the current approach using this as a benchmark.

- Use resources such as those developed by Skills for Care to review and identify the personal support managers need, including from their peers, to provide effective and supportive management and leadership.

The challenge: integrating different care and support options to enable person-centred care

See recommendations 1.2.1, 1.4.1 and 1.4.2.

Joined-up care and support helps to deliver better experiences and outcomes for older people with social care needs and multiple long-term conditions and their carers, who are known to value coordinated care with good links to the wider health and social care system. It also saves time and money across the health and social care system through avoiding duplication.

Working across boundaries

Traditionally, health and social care services that support older people with social care needs and multiple long-term conditions focus on managing separate health conditions, and the system is complex to navigate. Systems and structures may need to change to help professionals to work across service boundaries and specialisms.

To do this, managers and commissioners could:

- Establish named care coordinators locally and ensure they have the authority to provide continuity of support and amend care and support plans as needed. Share information about their role and responsibilities widely to make sure it is fully understood.

- Provide care coordinators with the necessary training and support based on a clear understanding of their role, and the skills and knowledge they need.
• Review local relationships across health, social care and the voluntary sector and identify where more support is needed to work across service boundaries and professions. Resources such as The How to... guides produced to support the Better Care Fund can help with this.

Need more help?

Further resources are available from NICE that may help to support implementation.

• NICE produces indicators annually for use in the Quality and Outcomes Framework (QOF) for the UK. The process for this and the NICE menu can be found here.

• Uptake data about guideline recommendations and quality standard measures are available on the NICE website.
Context

A long-term condition is one that generally lasts a year or longer and impacts on a person's life. Examples include arthritis, asthma, cancer, dementia, diabetes, heart disease, mental health conditions and stroke. Long-term conditions may also be known as 'chronic conditions'.

The prevalence of long-term conditions is strongly linked to ageing and the number of people with multiple (more than 1) long-term conditions in England is projected to rise to 2.9 million by 2018 (Long term conditions compendium of information third edition Department of Health). Prevention, delaying onset and slowing the progression of long-term conditions are all important outcomes for older people. Other important outcomes include quality of life and positive experience related to independence, choice, dignity and control.

Despite recent policy focusing on integrated health and social care services, some people are still being treated as a collection of conditions or symptoms, rather than as a whole person (The mandate: a mandate from the government to the NHS Commissioning Board: April 2013 to March 2015, Department of Health). People with multiple long-term conditions want joined-up, coordinated services but often find they are hard to access and fragmented (Integrated care and support: our shared commitment, Department of Health). Poor mental health can be associated with both social isolation and poor physical health, and can go unnoticed. The issue of delivering integrated support to people with long-term conditions who live in nursing and care homes has also been neglected (A quest for quality in care homes, British Geriatrics Society; Health care in care homes Care Quality Commission).

The Department of Health asked NICE to develop an evidence-based guideline to help address these issues (see the scope). The guideline was developed by a Guideline Committee following a detailed review of the evidence. The guideline focuses on older people with social care needs and multiple long-term conditions and their carers. The guideline does not cover younger adults (although many of the recommendations may also be relevant to younger adults). This is because the largest group of people affected by multiple long-term conditions is older people and because older people can experience inequalities in terms of resource allocation which is in the context of decreasing resources available to them overall (Older people's vision for long-term care Joseph Rowntree Foundation, What is social care, and how can health services better integrate with it? British Medical Association).

This guideline considers how person-centred social care and support for older people with social care needs and multiple long-term conditions should be planned and delivered. It addresses how those responsible for commissioning, managing and providing care for people with social care
needs and multiple long-term conditions should work together to deliver safe, high-quality services that promote independence, choice and control. It is relevant to all older people with social care needs and multiple long-term conditions, including those living in their own homes, in specialist settings or in care homes.

This guideline has been developed in the context of a complex and rapidly evolving landscape of guidance and legislation, most notably the Care Act 2014. While the Care Act and other legislation describe what organisations must do, this guideline is focused on 'what works' in terms of how to fulfil those duties, and deliver support to older people with social care needs and multiple long-term conditions.

The guideline will complement a range of NICE guidelines on topics such as dementia, diabetes, hypertension, mental wellbeing and older adults, and Parkinson’s disease.
Recommendations for research

The Guideline Committee has made the following research recommendations in response to gaps and uncertainties in the evidence identified from the evidence reviews. The Guideline Committee selected the key research recommendations that they think will have the greatest impact on people's care and support.

1 Older people's experiences

What is the lived experience of older people with social care needs and multiple long-term conditions?

Why this is important

While there was some evidence on the experiences of older people with social care needs and multiple long-term conditions, there were gaps in relation to people's lived experience of how such conditions impact on their life in their own words. Research could be qualitative, ethnographic or could use cross-sectional surveys using open-ended questions to gather views and experiences, in particular on:

- the experiences of older people in the UK living with multiple long-term conditions and how their conditions affect them over time and at different stages of their life
- how a person's multiple long-term conditions interact with each other and how this affects the person over time
- the priorities, meanings and preferences of older people living with multiple long-term conditions.

2 Service delivery models

Which models of service delivery are effective and cost-effective for older people with social care needs and multiple long-term conditions?

Why this is important

There was a lack of evidence about different models of support provision for older people with social care needs and multiple long-term conditions. There is a need for robust evaluations of different approaches to service delivery comparing, for example:
models led by different practitioners

different team structures

the components and configurations of models

barriers and facilitators to the implementation of models.

Outcomes could include social care- and health-related quality of life, satisfaction, carer's health, number of unpaid care hours provided and health and social care resource use. Outcomes and service use should be measured over 1 or 2 years to enable assessment of the health and economic impact of different models of service delivery in the short and longer term.

3 Supporting people in care homes to stay active

What is the most effective and cost-effective way of supporting older people with social care needs and multiple long-term conditions in care homes to live as independently as possible?

Why this is important

There is a need for robust evaluation of different interventions for supporting older people with social care needs and multiple long-term conditions in care homes. The Committee thought it particularly important to ensure that future studies evaluate how people living in care homes can best be supported to participate in social and leisure activities. This is important given that views data, Committee members' experiences and expert witness testimonies indicated that people living in care homes can feel particularly isolated and unable to take part in activities of their choice.

A range of study designs could be used, including randomised controlled trials, quantitative and qualitative evaluations of different packages of social and leisure activities, and their impact on social care- and health-related quality of life, satisfaction and participation in and experience of meaningful social and leisure activities.

4 Developing a 'risk positive' approach in care homes

What is the effectiveness and acceptability of different strategies to enable positive risk-taking in care homes?
**Why this is important**

The Committee noted that people take informed risks as part of normal everyday life, but for older people who need support, their ability to take these risks can be limited. Helping older people exercise choice and control, therefore, relies on a 'risk positive' approach. The Committee identified a gap in the literature about what works well in care homes in this respect. Studies are needed to explore different types of approaches to managing risk in care homes, for example looking at:

- organisational, operational and individual-level approaches to risk-taking in care homes
- the views and experiences of people using care home services and their carers
- barriers and facilitators to risk-positive approaches in care homes.

**5 Self-management**

What is the impact of different early intervention-focused approaches to self-management on outcomes for older people with social care needs and multiple long-term conditions?

**Why this is important**

The Guideline Committee highlighted a lack of evidence on the impact of different approaches to self-management, particularly those aimed at helping older people with social care needs and multiple long-term conditions to continue living independently for as long as possible. They highlighted the need to understand better the type of interventions and strategies available, and then to evaluate their effectiveness in terms of the impacts on outcomes for older people and their carers.

Future research should compare different approaches to self-management and their impact on social care-related quality of life and wellbeing in addition to physical health, acceptability and accessibility. It should also look at the views, experiences and potential impact on carers.

Accreditation

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www.nice.org.uk/accreditation