NICE Collaborating Centre for Social Care

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

Consultation sessions with older people – main messages

1. The older people who were part of the 2 consultation sessions were broadly positive about this draft guideline. They felt that the right areas are covered and agreed with many of the recommendations. They didn't identify any major gaps.

2. All the participants welcomed the opportunity to take part in these sessions, and were pleased to be able to contribute their knowledge and experience. They felt it was a positive step to be invited to contribute directly.

3. All participants felt that there could be some confusion around the settings in which this guideline will apply. Care homes are the only setting mentioned directly, and everyone therefore assumed that the guideline was primarily about care homes. The absence of any reference to Extra Care Housing/supported housing or indeed considering housing options within assessments/care planning was also noted and identified as a gap.

4. The impact of dementia on the likely success/relevance of the recommendations was raised several times. Given that dementia will very often co-exist with other long-term conditions, participants felt it is important to consider how this may affect what practitioners need to do. Good links with the dementia guideline and quality standards will help.

5. Participants welcomed the recommendations around assessment, as they believe this to be a crucial stage that is often limited and fails to address all of the person's needs, particularly in regard to social isolation. Experiences suggested that it is not always person-centred, and is very dependent on the individual assessor. They would have liked to see some clarity and direction around the knowledge, skills and qualifications that assessors should have.

The NCCSC is a collaboration led by SCIE

6. The role of a single named care co-ordinator was welcomed, and participants felt that it has the potential to significantly improve the experience of older people with multiple long-term conditions. However, they also felt that it will require a huge shift in practice and, from their experiences, suggested that some of the recommendations on this issue raised further questions:

   - Given what is expected of individuals in such a role, who should they be?
   - How will the care co-ordinator ensure continuity of care? Is this actually within their power?
   - How will one person cover all aspects of the role and get access to all the information needed, including from health services?
   - Which organisation should they work for or be responsible to?

7. Participants were pleased to see the importance of social activities and engaging in the community reflected in the recommendations in several sections. However, they felt that in practice the recommendations will be extremely challenging for a number of reasons:

   - Funding cuts, particularly within local authorities and the voluntary sector
   - The impact of living with several conditions and complex care needs
   - The need for support and/or an escort to get out
   - The limitations posed by the rigid timings of care services
   - Transport, and particularly the lack of accessible transport for those with significant mobility problems
   - Personal financial limitations.

8. For many participants, preventing social isolation was the single most important area covered by the guideline. They emphasised the huge impact that loneliness and isolation does have, particularly when already living with several health conditions. They welcomed the recommendation around peer support, and stated that personal contact and conversation are even more important than activity and getting out.

9. Self-management was acknowledged to be an important issue, but participants felt that the recommendations are weak. They highlighted that the focus is primarily on professionals talking to one another, and struggled to see how this would support improved practice in this area.

10. All participants talked about the importance – and frequent absence - of person-centred care, but were not convinced that the recommendations in this guideline will be enough to change or improve practice in this area. They feel that it is hard to measure, and that the needs of the service will often come first. Financial constraints were also seen as a barrier to person centred care.

11. The older people involved in this consultation did not choose to discuss the recommendations around integration, but it was inevitably part of both sessions. There was a strong sense that the lack of integrated health and social care services will affect the successful implementation of this guideline, and participants felt that it will be a challenge for these recommendations to have a significant effect.

12. Although carers issues were not a focus of the discussions, the Broadstairs group felt the needs of the carer are often not adequately assessed, which places an additional burden on them. They also felt that the guideline must be absolutely clear in terms of differentiating between care staff and carers who are family and friends.

Consultation sessions with older people – full report

Introduction

During the development of the guideline *Older people with social care needs and multiple long-term conditions* some Guideline Committee (GC) members highlighted a need to strengthen the voice of older people within the guideline. Although groups representing this audience are registered as stakeholders, GC members were keen to hear direct from individuals as part of the consultation stage. In partnership with Age UK (Sutton) and Bradstow Court (an Extra Care Housing unit, part of the Housing and Care 21 group) the NCCSC undertook this piece of work.

Aims

To enhance the voice and contribution of older people within this guideline. Specifically, this piece of work was developed to:

- Gather views on the acceptability and relevance of the draft recommendations

- Provide the GC with some additional input from older people as they finalised the guideline following consultation.

Process

The scope and detail of this consultation was developed in partnership with Age UK (Sutton), Bradstow Court, and colleagues at NICE. To ensure the sessions were objective and impartial, Age UK (Sutton) planned and facilitated them. They have also quality assured this report.

Appendix E – Consultation with older people: Final report

Participants

a) Bradstow Court – an extra care housing unit in Broadstairs, Kent which also hosts an Age UK day service. Bradstow Court is part of the Housing and Care 21 group. Residents in this location are age 70-95, and have a range of health conditions. All receive care services to help them live independently. This is also the case for those attending the Age UK day service.

b) Sutton Age UK – One Voice for Age, a large group of older Sutton residents. Members are aged 55-100, 20% from BME groups. Some are Expert Patients, and some are carers. This group is often involved in consultations, and is particularly knowledgeable about health and social care, so were able to comment and contribute in considerable depth. The group is large, so participants for this exercise were drawn from those for whom the guideline will have most relevance.

Sutton Age UK also provided facilitators for the 3 sessions:

- Silvia Schehrer

- Maya Albert

- Hannah Murphy.

Method

Before the session

Everyone who agreed to take part in a session was provided with a copy of the draft guideline (short version) and a short leaflet to introduce the consultation exercise (see Supporting documents).

NCCSC staff sought advice from the Social Care Research Ethics Committee and were advised that as the piece of work was a consultation exercise, ethics approval was not required. A form for participants to sign to give their informed consent to take part in the consultation was developed in discussion with Age UK (Sutton) and informed consent gained from all participants.

Preliminary session

The draft guideline comprised 7 sections and 53 recommendations. It was therefore necessary to focus on a subset of these during the consultation sessions. In order to select the areas for discussion, Maya Albert (Involvement Officer at Age UK Sutton) organised and facilitated a preliminary meeting to enable some participants to discuss the main areas covered by the guideline and begin to identify the recommendations to explore further. At the consultation events in both Broadstairs and Sutton, participants focused on this selection of recommendations, determined by older people themselves. The preliminary meeting was held on 9th June 2015 and the following areas were selected:

Appendix E – Consultation with older people: Final report

- Identifying and assessing social care needs

- Care planning

- Care delivery

- Preventing social isolation.

For more detail on how and why these areas were selected, a report of the session can be found in the supporting documents.

<u>Main consultation sessions</u>

The consultation sessions were held on 16th June 2015 (Sutton) and 18th June 2015 (Broadstairs). In Sutton, 8 people were present and in Broadstairs there were 5. The change of date necessitated by the extension of purdah following the General Election reduced the size of the group in Broadstairs. The sessions lasted 2-3 hours. Both were facilitated by Silvia Schehrer, supported by Maya Albert (in Sutton) and Hannah Murphy (in Broadstairs) NCCSC staff attended to listen and take notes. All participants signed a consent form at the start of the session.

An outline of the structure followed for these sessions can be found in the supporting documents.

For the sections and recommendations discussed, participants were asked to think about and comment on the following:

- How far is this relevant to you and your situation?
- In what ways could it make a difference?
- Is there anything missing?
- How could it be improved?

Most of the Sutton participants also attended the preliminary session, and have significant experience and expertise in consultation exercises through their involvement in One Voice for Age. Their main session lasted for three hours, and they covered all four selected areas. In Broadstairs, the session was two hours long and participants focused primarily on identifying and assessing social care needs and preventing social isolation, with a particular focus on sharing their experiences of the health and social care system.

All participants had read the draft guideline (short version) prior to the consultation sessions. Discussion encompassed the broad principles of social care for this group and the wider impact of living with multiple long-term conditions and complex care needs, as well as the individual recommendations in each section.

Findings

The views expressed in the two sessions were consistent with one another, so are reported below as one set of findings. Where there were significant differences, it has been made clear which group the comments were made by. As mentioned earlier in this report, the group in Sutton were more experienced in this type of consultation activity and were able to cover more areas.

General comments on the guideline

Participants in both locations were unclear as to what settings the recommendations applied to. The absence of any recommendations relating to homecare services or mention of ECH/supported housing, together with the direct reference to care homes, led individuals to assume that the guideline primarily applied to people living in care homes. Participants were informed that a separate guideline for homecare is in development. They hope that good links will be made between the two.

The number of different roles referred to throughout the recommendations was felt to be confusing, particularly where a section of recommendations (e.g. Care Delivery) included reference to several different roles with similar titles, for example:

> *'What exactly is a 'social care practitioner?''*

Participants mentioned several times that the recommendations could be particularly challenging to achieve if a person was living with dementia, and even more so if they were living on their own.

Identifying and assessing social care needs

General comments:

Participants identified assessment as being the most crucial stage of any individual involvement with health or social care and the recommendations in this section were broadly welcomed:

'The initial assessment is so important – it's the basis for care planning and delivery'

Most experiences of assessment were not positive:

'They just went through a list…it's just ticking boxes on a list'

'It's terrible when the person comes in and really knows very little about you. You have to explain it all again….and sometime later – guess what – the person's changed again'

Appendix E – Consultation with older people: Final report

Participants felt that the need to explore different housing options is not reflected in the recommendations, and considered it to be an important area that should be discussed in detail at the assessment stage.

<u>Comments on specific recommendations:</u>

1.1.1   This recommendation needs to be followed regardless of the individual's financial position. Participants felt that this had not been the case to date in their experience, but hoped the Care Act would change this.

1.1.2   Specialist medical assessments can be helpful, but the wording suggests that they can be made by health and social care practitioners. Participants said that, in their experience, these referrals had to go via a GP and felt that this task would need to be shared more widely for the recommendation to work. These referrals would need to be easy to make, with no bottle-necks in the system, and to be delegated to other health professionals. They felt this recommendation to be particularly important, as the impact of deprivation on top of long-term conditions is resulting in people living with very complex needs. However, they would like to have seen more specific wording, focussed on how different health and social care professionals can ensure such referrals are made.

1.1.3   The detail in this recommendation about what should happen and who should be involved is helpful, and the point about providing information is felt to be particularly essential. However, the knowledge, skills and qualifications of the assessors are crucial and yet they have not been specified.

1.1.6   Participants welcomed the telecare recommendations. They consider telecare
1.1.7   to be a cost effective option, but in their experience it is not consistently considered in assessments:

> *'Telecare works...it seems very good'*

Care planning

<u>General comments:</u>

The idea of a single named care co-ordinator became one of the main focal points for discussion. Participants agreed that the existence of such a role could make a significant difference to the experience of people who have multiple long-term conditions and complex care needs. However, thinking about the recommendations in practice raised many questions:

> *'This is such a complex task and could be very demanding'*

Appendix E – Consultation with older people: Final report

Comments on specific recommendations:

1.2.1   Although participants welcomed the idea of a single, named care co-ordinator, they expressed concern about how feasible it will be to achieve. Their experiences of rapid turnover of staff made them question how continuity would be achieved in this role and how individual co-ordinators would gain easy access to all the information they required, particularly records relating to health and medicines. Participants felt it would also be important to be clear about who should do this role and what skills and knowledge they would need. They considered the most important areas to be a background in care and support, medical knowledge and understanding, someone who cares and has good insight. They wondered where such a person might be based and within what sort of an organisation. Who would select the care co-ordinator? Would the older person have a say? Some participants talked about Care Managers/practitioners that they have never met – they emphasised that the role of a care co-ordinator cannot be a desk job. For those living in an ECH unit or care home, it would be most effective if the named care co-ordinator was based on the premises but some expressed concern that this could result in increased care costs.

1.2.3   Owning and agreeing the care plan was felt to be an important principle, and one that doesn't necessarily happen currently:

'I didn't quite understand completely what I was entering into'

1.2.5   Participants expressed some concern about how one person would manage to effectively cover all the areas identified in this recommendation. They felt it would be a significant change from current experiences of care planning. They also suggested it would be important for named care co-ordinators to have guidance about their role in relation to someone living with dementia, and around how to draw on specialist knowledge and expertise.

1.2.6
1.2.7   Participants felt medicine management to be an important issue and welcomed the recommendations. They would have liked to see regular reviews mentioned, and again questioned how the recommendations will work for people living with dementia. Some participants shared experiences of needing to personally manage numerous complex doses of medication and to ensure they re-ordered their prescriptions in good time.

1.2.10 Participants felt that the support required to try out direct payments should be specified more clearly, including any external agencies that can help with this. Substantial support should be available, as using direct payments can be a 'minefield'.

1.2.12 Whilst participants welcomed the inclusion of activities outside the home in the recommendations, they highlighted the difficulties likely to be encountered in

resourcing such activities and the effect cuts are having on voluntary sector provision. Some shared their experiences of finding the challenges associated with getting out insurmountable – finding the transport, and escort and the money to cover any costs:

> *'I wouldn't know where to start, who to ask'*

Those participants living in Extra Care housing were particularly keen to do 'normal' things – such as a cup of tea in the local café, or shopping in the High Street – rather than 'big days out.' Links with the local community were felt to be important in helping address isolation.

They also stated clearly that although getting out of the home is important, in their experience personal contact and conversation is even more so:

> *'…just feeling like someone cares'*

Delivering care

Comments under this heading are primarily drawn from the session held in Sutton.

General comments:

In the draft version, this section opened with recommendations specifically for care homes. Participants felt this created some confusion as to which apply only to care homes and which go wider.

Comments on specific recommendations:

Providing support and information

1.5.5   Participants felt that this could be a particularly important recommendation, and suggested that peer support would also be a valuable tool to address the risk of isolation.

Supporting self-management

Participants felt that the recommendations in this section lacked a clear focus on supporting the individual to manage their own condition and situation. They pointed out that most of the recommendations appear to be about practitioners interacting with one another and struggled to see how this would support self-management.

> *'…not much about self-management in there, it's all about professionals'*

Participants also found the varying roles referred to in this section particularly confusing, and were unclear as to how the distinction between recommendations for practitioners and those for providers had been determined.

1.5.6 Participants felt that the wording of this recommendation does not reflect the real challenges of self-managing medication, nor does it recognise that for some it is a very private issue. They felt that it needed greater clarity around exactly who is responsible and how/when information is to be shared.

1.5.7 This recommendation would benefit from greater clarity around who needs to do what and who they should involve. Participants felt that the phrase 'the person's healthcare practitioners' was very vague and weren't sure who this would cover.

1.5.9 Participants questioned whether 'recognise' is the right word to use. They felt it suggests the need for some physical evidence, whereas people may actually keep incontinence well-hidden. They felt it isn't clear what to expect of providers in such situations, nor what training would be required.

1.5.10 Participants wondered whether it would be care workers (rather than providers) who should give information and advice about continence. They welcomed the reference to dignity and respect here, emphasising that people may well try to hide their difficulties and a sensitive, patient approach would be needed.

Ensuring continuity of care and links with specialist services

'I believe in continuity of care…always have done…it gets a bit scary when you don't know who's coming in'

1.5.12 Participants welcomed the role and responsibilities of the named care co-ordinator as described in this recommendation but were concerned that it would be extremely challenging to deliver in practice. Participants found it difficult to see how the named care co-ordinator could ensure continuity of care, and felt that the lack of integration would prove a real challenge to improvements on an important issue:

'..absolutely crucial – great in theory, but pie in the sky?'

Care in care homes

1.5.13 Participants felt that this recommendation should be worded more strongly, as nutrition and hydration are so crucial to health and wellbeing. They felt the wording needs to convey a requirement to for care home staff to 'make every effort'. They also felt that this recommendation was at least as important for people living in their own homes.

1.5.15   This must not override the preference of residents.

1.5.16   Being warm enough is absolutely crucial. One participant had experienced a stay in a care home where he was so cold a friend had to bring in a heater for him.

1.5.18   This recommendation was considered very important, and particularly for those without family or friends visiting. Participants felt that the local community could potentially offer valuable support with social needs.

1.5.19   Participants expressed some concern at this recommendation, wondering what exactly 'make publicly available' means. They felt it could perhaps be a divisive action, given the different tariffs paid by self-funded and publicly-funded residents.

Preventing social isolation

General comments:

For participants in the Broadstairs group, this was the single most important area in the guideline:

> *'Loneliness is the worst disease ever'*

From their experience, all participants felt that early intervention is imperative if social isolation is to be prevented. They also expressed a strong belief in the power of peer support to reduce the sense of isolation. They felt it is important that this section acknowledges the underlying principle of people remaining in their own homes wherever possible, looking at social activities and relevant services near to where they live.

Comments on specific recommendations:

1.6.2   Participants felt that maintaining links with the community could be particularly difficult for those with complex care needs, and even more so where a wheelchair was needed for mobility. The transport barriers need to be recognised. In their experience health and social care practitioners are just too busy, with little time to help solve these issues. They also wondered how practitioners are going to identify loneliness. It can be a very delicate and private issue. It should be a specified part of the assessment process. In their experience the possibility of depression is not often considered, and is not readily diagnosed. Participants also felt that the wording should reflect that there is a difference between loneliness and isolation, and very varied personal preference.

1.6.3   Individuals need good quality information if they are to be able to make the right choice of care home, but the experience of participants suggested that there tends to

be little choice and often only one option. Experiences of care homes were not positive:

> *'It's like life has stopped'*

Extra Care housing settings were seen as a far better option than care homes, but participants commented that it is still too easy to become isolated and feel cut off from the local community.

1.6.4   Participants felt that this would be a significant change from current practice. They suggested that practitioners would need local information and a good knowledge of the individual to achieve this. They were also concerned that the impact of health conditions, costs, and support needs be fully understood. In some cases the contacts would need to come to them - getting out may be too big a challenge for some. Participants also shared experiences where the rigid timings of care services had limited the opportunities available to them to join in with activities or to get out:

> *'It just wasn't a convenient time'*

1.6.5   Participants felt these were good recommendations, but suggested that they will
1.6.6   prove very difficult to achieve given the scale of budget cuts affecting local authorities, and in turn the funding available for charities.

<u>Next steps</u>

Following the two main consultation session and analysis of the content, a first draft of this report was sent to Sutton Age UK for quality assurance purposes. Amanda McGrath (Development Director) and Silvia Schehrer (facilitator) provided comments and feedback and the report was amended accordingly.

It was then sent to NICE before the consultation period closed on 13th July 2015, to ensure the views of the participants could be considered alongside all other stakeholder responses. GC members received the report prior to their final GC meeting at the end of July and had the opportunity to share their thoughts on the content as part of that meeting. It was also used to inform the needs assessment and support plan for this guideline, and forms the basis for one of the support tools to be developed.

A copy of the report was sent to all participants.

Supporting documents

1. Information leaflet for participants

2. Report of preliminary meeting facilitated by Age UK (Sutton)

3. Consultation session outline – Sutton

4. Consultation session outline – Broadstairs

Appendix E – Consultation with older people: Final report

1. Information leaflet for participants

Introduction

Thank you for agreeing to take part in a group discussion about the draft NICE guideline *Social care of older people with complex care needs and multiple long-term conditions.*

What role does NICE have in social care?

In 2013 NICE (National Institute for Health and Care Excellence) was asked to start producing guidance and standards for social care. They work with experts, including people who use care and health services and carers, to do this. NICE guidelines give advice on the care and support that should be offered to people who use health and care services.

Why has this guideline been developed?

The number of people who have long-term conditions increases with age. It is important to prevent or delay or slow the progress of these conditions. And it is important that older people who do have long-term conditions still feel they have a good quality of life, and that they receive the care and support needed to do so. Often, people with long-term conditions find that services to support them are difficult to find and use, and don't seem to be joined up. This guideline will make recommendations to improve the experience of older people with multiple long-term conditions.

How has the guideline developed?

A group of experts, including people who use health and care services, looked at what the research evidence says and used it to produce some recommendations about what works best for older people with multiple long-term conditions. The group also heard from expert witnesses about issues where there isn't much research.

The first version of the guideline is now ready for people to read and comment on. It will then be changed, based on what people say, before the final version is published in October 2015.

What is this meeting for?

The next few weeks will be a chance for people to read and comment on the first version of the guideline. The group of experts who developed the recommendations would particularly like to hear what older people themselves think. They will then use that information to produce the final version of the guideline.

This meeting will be an opportunity to look at some of the recommendations in this guideline and think about:

- How relevant they are to you and your situation
- What difference they could make
- What might be missing

Appendix E – Consultation with older people: Final report

- How they could be improved

The recommendations to be discussed have been chosen by older people consulted at an earlier stage.

The short version of the draft guideline is provided for you to have a look through before the meeting. This contains all the recommendations. The full draft guideline can be provided for anyone who wishes to see it.

The meeting will last for 2 hours and will include a break for refreshments.

2. Report of preliminary meeting facilitated by Age UK (Sutton)

Pre-focus group (9th June 2015) looking at the draft NICE guideline on social care for older people with multiple long term conditions and complex needs

6 attendees (all over 65 years of age)

Most important areas of the guideline identified for further comment in the planned focus groups on 16th and 18th June 2015:

1. **Identifying and assessing social care needs**
2. **Care planning**
3. **Care delivery**
4. **Preventing social isolation**

Consideration of other areas of the guideline and why they were not chosen:

Training of health and social care professionals was seen as vital, but the group felt ill-informed to comment or focus on this other than to say that it is crucial and that it underpins all of the chosen recommendations above. For example, training of staff is vital for appropriate assessment of social care needs, for effective care planning and delivery, and for staff to have sufficient knowledge of available social activities in the borough to effectively signpost people and help prevent social isolation. It was felt that statutory health and social care professionals often lack sufficient training and information on what voluntary sector services can provide (such as befriending and social opportunities, for example).

It was additionally felt that newly introduced training requirements for care staff should apply to new and existing staff (rather than only to new staff) so as to embed the NICE guidance and good practice in general.

The integration of health and social care planning was also viewed as very important, but it was seen as too strategic and beyond the scope of our focus groups. One participant described integration as 'pie in the sky', another as 'wishful thinking' and everyone seemed

quite pessimistic about this guideline being able to significantly enhance true integration in planning of services, or indeed to reduce the need for lots of chasing round different services by families or older people themselves. It was felt that national structural change was required to really make this happen. Only one participant felt that health and social care could be, or indeed was already integrated, but this seemed to be more from a theoretical point of view (based on his role as a volunteer Director for local Healthwatch), rather than from personal experience of accessing services for himself or for someone else.

Whilst supporting carers was also felt to be very important, it was agreed that caring for the older person themselves was more important for discussion at the next focus groups than supporting the carers who support the older people with long term conditions and complex needs.

Comments on broad scope of guideline

There is nothing in the guideline specifically for home care providers, although there are specific recommendations for care homes. While participants were aware that the bulk of the recommendations refer to all health and social care staff (including home care providers), they felt that specific recommendations would be useful for home care providers too.

Example 1 – couple I know from church have carers who come in. The personal care is awful, the smell hits you as they open the door, they ask the carers to help with a bath, but they say no to them as they have no time, and they never have the same carers twice.
Example 2 – the carers record in the book that they have visited for an hour but they never really stay an hour

Comments on area 1 – Identifying and Assessing Social care Needs

What is missing from these recommendations?
- There is no recommendation as to how the staff that identify and assess social care needs should be trained or qualified.
- Who will be doing this assessing?
- How long should the assessment process take?

How could these recommendations be improved?
- Need more specific recommendations as to how different health and social care professionals should ensure referrals are made for specialist medical opinion (e.g. from a geriatrician or an old age psychiatrist) where needed. This recommendation is a bit vague. Not all health and social care professionals have the power to make referrals to a consultant - how should they go about ensuring this happens?
- Need to be more specific about how health and social care professionals should attend to the needs of carers (i.e. not just referring them on to a carers association and thinking that this action is complete)

Which of these recommendations are most important and might make the most difference?
- Giving sufficient information about options and costs is very important and makes a lot of difference, but there are vast amounts of information that the health or social

care professional is required to be familiar with in order to give sufficient information to the older person - how will professionals be kept informed? Where is the role of the voluntary sector in this process? How will their workers be kept informed? How will the older person given the information remember and be able to refer back to this information – what format will it be given in?

Example: The cost of a service may impact on someone's choice of service procurement, whether they are a self-funder or a funded via the local authority. E.g. a 15 min care visit may be chosen over a 45min care visit as it is cheaper.

Comments on area 2 - Care planning

What is missing from these recommendations?
- Nothing highlighted.

How could these recommendations be improved?
- The support required to try out direct payments should be specified more clearly, including any external agencies that can help with this. Substantial support should be available (not just a leaflet), as using direct payments can be a minefield.

    EXAMPLE: It is hard to ensure strength and depth in planning when using Direct Payments, and you need additional back-up. It is extremely difficult to appoint and employ a carer, and to ensure sufficient additional cover for sickness or leave, especially if you've never engaged staff before.

Which of these recommendations are most important and might make the most difference?
- Having a named care coordinator is very important but they should ideally be a stable contact (i.e. the same person as far as possible), rather than different people owing to staff turnover or change of roles. Ideally it would be the same care coordinator who reviews the care as who is involved in the initial assessment and setting up of a care package.
The inclusion of medicines management in the care plan is vital, to prevent problems arising.

    EXAMPLE: a couple with carers had tried to get their own medication ready for the day, but got muddled and the carer who came later simply finished off what the couple had started wrongly, without checking which medication actually needed to be put out at that time of day.

Comments on area 3 – Supporting Carers

What is missing from these recommendations?
- There should be a recommendation about liaising between the carer and the older person requiring care (when respite for the carer is needed), to ensure that the needs of the older person requiring care are still met when the carer goes on a carers' break

and professional care is brought in to substitute.

> **EXAMPLE: an older person may not want to go into a care home while their carer has a break, it would be better to provide good care in their own home.**

How could these recommendations be improved?
- It would be better to say "carers **should** be helped to access services such as carers' breaks" rather than "**consider** helping carers to access services such as carers' breaks", as this is too weak.
- The support required to explore direct payments should be specified more clearly, including any external agencies that can help with this. Substantial support should be available (not just a leaflet), as using direct payments can be a minefield.

Which of these recommendations are most important and might make the most difference?
- There was general feeling that the needs of the carer should be secondary to the needs of the older person requiring care, so none of these recommendations were considered more important than the others.

Comments on area 4 – Integrating health and social care planning

What is missing from these recommendations?
- Lack of transport is often a barrier to older people getting between services and centres in different places. How should this be addressed? Many services are not co-located, so how can seamless referral and transition between multidisciplinary services actually take place?

> **EXAMPLE: a person has 3 separate hospital appointments at three different sites, on different days, and has to get the bus on their own each time. When I go to the Brompton, I have to get a cab, a train and another cab – then someone has to be with me when I get home!**

- There should be more specific mention of voluntary sector services and integration between statutory and voluntary sectors.
- There should be some consideration of staffing levels and staff retention/turnover in services in order to achieve these recommendations – care coordinators often have too high a caseload to make following these recommendations effectively feasible. Local authorities are struggling to retain staff and need support, e.g. from social work assistants, to help coordinate this work. Maybe use volunteers and voluntary sector more, as they have a smaller number of clients and can offer more personal services.

How could these recommendations be improved?
- More specific guidance on who should do all the chasing between different sector services, trying to ensure that information is shared appropriately and that services are talking to each other. Currently it is the older person and/or their family who has to do the bulk of this, even though the GP and the care coordinator do some of it.

Appendix E – Consultation with older people: Final report

Which of these recommendations are most important and might make the most difference?

- There was a general feeling that while very important, these recommendations were "pie in the sky". Integration is not happening currently and these recommendations won't change that. On an individual level, it would take a PA for every older person who has complex needs and multiple long term conditions to make things happen more smoothly. On a national level, more structural change is required for true integration to occur.

  EXAMPLE: I know someone who is housebound and was in hospital after an accident. On discharge back home she has been referred to several specialists and is waiting for hydrotherapy and physiotherapy. No one is chasing up all these referrals for her. She is having to try and do this herself, but she hears nothing about progress or timescales.

Comments on area 5 – Care Delivery

What is missing from these recommendations?

- Who selects the Care Coordinator? Does the older person have a say in who becomes their Care Coordinator?
- Specific mention of promoting telecare options should be made in this section of the guideline, as telecare can be very useful for managing incontinence, as well as for maintaining independence with dignity for older people.

How could these recommendations be improved?

- The specific recommendations for care home providers should also refer to home care providers and workers - i.e. nutrition and hydration, making sure people have a range of choices of meals and snacks – this is just as important for people living at home with domiciliary care as it is for people in care homes.

  EXAMPLE: I know older people who have meals on wheels delivered but nobody checks whether they are eating them. The meals just pile up uneaten and the person gets thinner and thinner.

- People living at home should also be directed to Advocacy services where required.
- The manner in which health and social care staff offer opportunities for social interaction is important. It is hard to ensure that empathy and a pleasant manner are maintained by staff.

  EXAMPLE: I know an older person who told her care worker that she was not happy with her manner. The care worker said 'call the police then' and carried on as before. This is unacceptable.

Appendix E – Consultation with older people: Final report

Which of these recommendations are most important and might make the most difference?
- The recommendations for care home providers are very important, but are staffing levels in care homes sufficient to ensure these recommendations can actually be followed? Do staff really have enough time to attend to individual residents' nutrition and hydration? The same applies to hospital staff too.
- The recommendation about offering opportunities for social interaction and peer support is very important, but the reality is that it is often the voluntary sector that provides more opportunities for this than statutory services. Do health and social care staff know enough about what the voluntary sector offers to signpost people effectively?
- Having 24hr emergency contacts as well as contact details for the Care Coordinator is very important and useful. But this is only valuable if there is continuity as far as possible in who is the Care Coordinator. Ideally the same person would have been coordinating care right from the start of the assessment process, but this does not often happen. It is also hard for the Care Coordinator to keep offering information after initial diagnosis and assessment (as per the recommendations) if the person doing the job has changed – the new person will not know what information was offered at that start and how this was received.

Comments on area 6 - Preventing social isolation

What is missing from these recommendations?
- Identifying loneliness, social isolation and confidence should be specified as part of the initial assessment process.
- Dealing with transport barriers should be specified, as this is a frequent barrier to people accessing social activities near where they live.

How could these recommendations be improved?
- Training for health and social care practitioners in this area is important, as they may not know the full range of social activities available in someone's area - these activities are often provided by the voluntary sector, of which health and social care workers have little knowledge.
- It is important to stress the underpinning principle that people should be kept in their own homes wherever possible, looking at social activities and relevant services to prevent social isolation that are near where they live (rather than putting people in care homes, even if the home is within their local area).

Which of these recommendations are most important and might make the most difference?
- The recommendation to place people in care homes that are near their social or family connections and within their local community is very important, but often hard to fulfil in practice. Beds in appropriately located and affordable care homes are not always available and people sometimes end up being placed out of their immediate locality.
- It is very important for local authorities and voluntary sector services to collaborate on preventing social isolation for older people, but the lack of money available to local

authorities to commission charities in this area will effectively scupper this recommendation being put into practice.

Comments on area 7 - Training for health and social care practitioners

What is missing from these recommendations?

- Health and social care workers need to be trained in how and where to signpost or refer older people for extra support – e.g. specialist bereavement support from statutory or voluntary sector services, specialist dementia assessment and diagnosis etc.
- Incontinence should be added to the list of common conditions that health and social care workers should be able to recognise and support with. Perhaps also other common conditions such as diabetes, COPD, heart trouble etc.
- Perhaps training on alcohol abuse, frailty and self-neglect should also be included, as these are sadly common.

How could these recommendations be improved?

- More specific mention of training for health and social care practitioners on their manner – empathy, social skills etc. (as these can sometimes be sadly lacking).

Which of these recommendations are most important and might make the most difference?

- Training on medicines management is very important and will make a big difference, as per the earlier example copied again below. There should also be a requirement for carers to educate older people in what each medicine is for (broadly speaking) and why it is important that they take them as per instructions.

  EXAMPLE: a couple with carers had tried to get their own medication ready for the day, but got muddled and the carer who came later simply finished off what the couple had started wrongly, without checking which medication actually needed to be put out at that time of day or what it was for.

3. Consultation session outline – Sutton

16th June, 10:00am, Sutton Central Library

Facilitators: Maya Albert and Silvia Schehrer

Objectives:

1. Seek comment and feedback on the draft guideline (short) from older people

2. Gather views from older people on the four key areas chosen at pre-focus group meeting:
   - Identifying and assessing social care needs
   - Care planning
   - Care delivery
   - Preventing social isolation

3. Provide more detailed comment on the recommendations

Programme:

1. Introduction – Role of NICE and Collaborating Centre for Social Care and reason for consultation

2. Ice Breaker – to introduce participants to each other and their experience and interest in health and social care

3. Summary of key recommendations in the 4 key areas:
   - Identifying and assessing social care needs
   - Care planning
   - Care delivery
   - Preventing social isolation

4. Exploration of recommendations using the following questions in each of the four selected areas:
   - Is anything missing from the recommendations?
   - Which recommendations are most important?
   - Why?
   - What good could these recommendations do?
   - How could they be improved?

5. Identifying two key messages to feed back

6. Summary and conclusion

4. Consultation session outline – Broadstairs

18th June, 10:00am, Bradstow Court, Broadstairs

Facilitators: Hannah Murphy and Silvia Schehrer

Objectives:

1. Seek comment and feedback on the draft guideline (short) from older people

2. Gather views from older people on two key areas chosen at pre-focus group meeting:
   - Identifying and assessing social care needs
   - Preventing social isolation

3. Provide more detailed comment on the recommendations

Programme:

1. Introduction – Role of NICE and Collaborating Centre for Social Care and reason for consultation

2. Ice Breaker – to introduce participants to each other and their experience and interest in health and social care, explore their experience of living with long-term conditions

3. Summary of key recommendations in the areas of :
   - Identifying and assessing social care needs
   - Preventing social isolation

4. Exploration of recommendations using the following questions in each of the two selected areas:
   - Is anything missing from the recommendations?
   - Which recommendations are most important?
   - Why?
   - What good could these recommendations do?
   - How could they be improved?

5. Identifying two key messages to feed back

6. Summary and conclusion