Older people's independence and mental wellbeing

Consultation on draft NICE public health guideline (PHG65)

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The National Institute for Health and Care Excellence (NICE) is currently developing a public health guideline on independence and mental wellbeing (including social and emotional wellbeing) for older people, which is due to be published in November 2015. As part of this, stakeholders have been invited to comment on the provisional recommendations set out in the draft guideline (available online here). Age UK welcomes this guideline as a positive contribution to supporting older people's independence and wellbeing. We also welcome the reference to some of our services within the guideline which make a huge difference to the lives of older people.

Key points and recommendations

Age UK's detailed comments can be seen in the NICE proforma below. Key points from our response include:

- Ensuring loneliness is more explicitly referred to and making a clear distinction between loneliness and social isolation;
- Highlighting the role of psychological approaches in supporting older people's mental wellbeing;
- Recognising the role and responsibilities of health services, particularly primary care services and GPs;
- Recognising the impact of social barriers, such as stigma, on older people's ability to lead active lives.

Age UK's comments

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Section number Indicate **section number** or **'general'** if your comment relates to the whole document	**Page Number**	**Comments** Please insert each new comment in a new row.
General		Age UK welcomes this guideline as a positive contribution to supporting older people's independence and wellbeing, as well as clarifying recommendations for service commissioners and providers around what works in this area. We welcome the reference to some of our services within the guideline which make a huge difference to the lives of older people.

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Introduction		We would recommend adding loneliness to the aims stated upfront as follows: *'-Help older people maintain their mental wellbeing, including their ability to remain independent to avoid health conditions linked to loneliness, social isolation, depression […]'*. This is notably important as the guideline does not make a clear distinction between loneliness and social isolation, and even appears to be referring to both concepts interchangeably in some sections. Although these concepts are related, they have distinct causes and manifestations, and do not necessarily require the same solutions. While social isolation is an objective state in terms of the quantity of social contacts on person has, loneliness is a subjective experience. Loneliness is a negative emotion associated with a perceived gap between the quality and quantity of relationships that we have and those that we want (Age UK and Campaign to End Loneliness, 2015). It can be a temporary, recurrent, or persistent (chronic) state. It is therefore possible to be lonely but not to be socially isolated – likewise, it is possible to be socially isolated but not lonely (Age UK, Loneliness Evidence Review, 2015). However, tackling social isolation does matter as it can be a risk factor for loneliness (Victor C et al, Loneliness, social isolation and living alone in later life, 2003).

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General		Overall, the problem of loneliness and its wider impacts on older people's health and wellbeing are not emphasised enough within the guideline. Our surveys have found that over 1 million older people say they are always or often feel lonely – with around 10 per cent of those over the age of 65 experiencing chronic loneliness at any given time (TNS survey for Age UK, April 2014). Unless action is taken, the number of older people feeling lonely is likely to increase as more of us live longer. Loneliness can have negative implications for both our mental and physical health. It can be as harmful for our health as smoking 15 cigarettes a day (Holt-Lunstad J, Smith TB, Layton JB. *PLoS Med* 2010;7(7)), and more damaging than obesity (Age UK Oxfordshire, *The State We're In*, 2012). People with a high degree of loneliness are twice as likely to develop Alzheimer's disease as people with a low degree of loneliness (Wilson RS, Krueger KR, Arnold SE, Schneider JA, Kelly JF, Barnes LL, et al. *Arch Gen Psychiatry* 2007 Feb; 64(2)). Loneliness also heightens feelings of depression, anxiety, and increases vulnerability in older people (Hawkley, LC, Cacioppo, *Annals of Behavioural Medicine*, 2010, 40 (2)). As well as impacting on people's health and wellbeing, loneliness can lead to increased demand for NHS resources. Three quarters of family doctors (76 per cent) report that between one and five patients a day attend their surgery primarily because they are lonely (Campaign to End Loneliness/ComRes, November 2013). Due to the far-reaching impact of loneliness, it should be a key measure of success for this guideline that loneliness is mainstreamed within public health strategies at the local and national level as a preventable and manageable state.
General		We recommend amending the order of the recommendations so as to follow a clearer pathway, e.g.: - Fundamental principles (recommendations 1 and 6) - Identifying the level of need and reaching out to people (7,5) - Specific interventions (2,3,4) - Removing barriers/ supporting people to participate (10,11) - Raising awareness of relevant issues and activities (9,8) - Improving training (16) - Supporting community organisations (12,13) - Supporting evaluation of services (14,15)

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General	2,7,8,20	We do not support the use of the phrase 'prematurely old'. We believe that linking people's needs to relative age as a predictor of poor health carries a risk of reinforcing current stereotypes and discrimination towards older people, particularly around people's expectation of good health in later life. Entrenched stigma towards ageing has meant that older people have often faced inequalities in accessing treatment. Public and private services, including the NHS, have a long way to go in establishing age equal practices and part of this process should be to overturn deeply entrenched cultural attitudes towards the 'value' of treating and supporting older people, and assumptions around what older people can or cannot do. The reference to 'premature old' risks further entrenching these attitudes and we would therefore recommend that this phrase is removed from the guideline.
1.1	4	Principles of good practice should take account of diversity and accessibility issues in light of duties under the Equality Act 2010. We know, for example, that loneliness can be particularly acute among older lesbian and gay people, and some evidence suggests that they experience problems in accessing mainstream services (Age UK and Campaign to End Loneliness, January 2015). Efforts must therefore be made to better understand and meet the needs of BME and LGBT communities. The guideline should also reference the importance of services becoming dementia-friendly to reflect the needs of the estimated 850,000 people living with dementia in the UK, as well as the many more that experience cognitive decline. Without such an approach, many services will remain inaccessible to the people that could most benefit from them.

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1.4	6	We would like to see a greater recognition of the role of psychological approaches in supporting older people's independence and mental wellbeing, and would therefore recommend changing the line *'a programme to help people develop and maintain friendships'* to *'a programme to help people develop and maintain friendships, and support them in changing their thinking about their social connections'*. Our recent joint report with the Campaign to End Loneliness, *Promising approaches to reducing loneliness and isolation in later life,* recommended offering psychological approaches such as counselling, cognitive and behavioural therapy (CBT) and Mindfulness, in addition to other activities already highlighted within this guideline. Although these approaches have mostly been available to those with diagnosed mental health conditions, experts involved in our report believe psychological interventions show great promise in helping people to change their thinking about their social connections, thereby addressing what Masi et al have called 'maladaptive social cognition' (Masi et al, Pers Soc Psychol Rev, 2011;15(3)). Age UK Warwickshire, for example, has been offering psychological support services, which involve counselling services for people who are over 55 or their carers in their own homes as well as a 'Support, Time and Recovery' scheme for people over 55 who have a diagnosis of depression, stress or anxiety. Initial evaluation of the services provided has shown significant improvements in the wellbeing of service-users using the Warwick Edinburgh Mental Wellbeing Scale (WEMWBS), thereby highlighting the broader benefits of such approaches.
1.4	6	We suggest changing sentence from '*offer one-to-one activities'* to *'support, promote and, if there is not enough provision, commission activities'*, in line with the wording of previous recommendations, especially as such services are currently often provided by the voluntary sector (as noted in the examples provided by the guideline in the same section). For example, many local Age UKs provide befriending services, some by telephone and some where a volunteer visits the older person at their home. At the national level, Age UK also provides a telephone befriending service called 'Call in Time' (see comment below).Such vital services provide a link to the community and act as gateway to other forms of valuable support. It is therefore important to recognise the contribution of the voluntary sector in providing one-to-one services and adopt a consistent terminology, in line with previous recommendations.

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1.4	6	We would recommend amending *'brief visits providing befriending opportunities'* to *'regular, brief visits or telephone calls providing befriending opportunities (for example, Age UK's Call in Time service or local Age UK befriending services)'*. As well as home visits, the guideline should recognise the role of telephone befriending services, which are particularly important to older people living in areas where home visits may not always be possible such as remote rural areas or areas where service provision is limited. For example, Age UK's Call in Time, our a national telephone befriending service, tends to serve older people in areas where no face-to-face services are available, sometimes due to a lack of funding, or difficulties recruiting volunteers. As part of the scheme, volunteers call someone for half-an-hour a week. An independent evaluation of the project has found that self-reported wellbeing and mood as well as activity levels had improved among service users, including those that had reported being affected by chronic loneliness or depression. It is also worth noting that one of the key features of all befriending programmes is their regularity, hence the addition of 'regular' to the line mentioned above. (Age UK, Campaign to End Loneliness, *Promising approaches* […], January 2015).
1.6	8	We would suggest adding a point below the fourth line, as follows: *'- Recognising the potential referral pathways through primary care, for example GPs' social prescribing or integrated care pathways, which help older people to access non-medical services that support their independence and mental wellbeing'*. This is particularly important as GPs, for example, regularly come into contact with older people at risk of losing their independence or experiencing a decline in their mental wellbeing (see point about loneliness above). This could be through an integrated care pathway across health, social care and the voluntary sector, or through social prescribing whereby GPs refer people to non-medical services often run by the voluntary sector. In one example of social prescribing, users showed statistically significant improvements in depression; anxiety; isolation; wellbeing; perceived economic wellbeing; and physical activity after three months (Kimberlee RH, University of the West of England, 2014). Overall, and in response to question 5 specifically, we would like to see a greater recognition of the role and responsibilities of health services, particularly primary care services and GPs, in supporting older people's independence and mental wellbeing.
1.7	8	We would recommend adding '*regularly*', as follows: '*Regularly carrying out a needs assessment to'* (see line 8). It is indeed important to ensure such needs assessments are undertaken on a regular basis.

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1.8	9	In line with our previous comments regarding the important role of primary care in supporting older people's access to support, we would recommend amending the last point in the section as follows: '*Publicising the service to other agencies and organisations working with older people, for example, local older people's forums and groups or local GP practices'*
1.10	11	We would suggest adding the following line, after line 8: *'- Supporting initiatives that address social barriers to participation such as prejudice against ageing and older people (for example supporting the development of age-friendly cities, positive ageing activities as well as intergenerational projects)'*. We would indeed like to see a more explicit recognition in this section of the need to tackle both environmental and social barriers to older people's participation in society and community activities. Solutions to this not only include ensuring that older people have access to transport and technology to remain socially connected (which were both identified as 'gateway services' in our *Promising Approaches* report), but also involve creating the right environment for wellbeing interventions to work and thrive. As such, our joint report emphasised the importance of 'structural enablers' such as positive ageing (age-friendly cities/communities), neighbourhood approaches and asset-based (intergenerational) community development, which not only help to tackle stigma against ageing (an important social barrier to participation), but also enable the development of community and voluntary interventions that support older people's independence and mental wellbeing.
4	17	We welcome this public health guideline as an opportunity to shine a light on the importance of access to mental health support for older people as well as challenging the on-going perception that issues such as loneliness and depression are inevitable parts of ageing. As such, we would recommend that the 'Context' section, which has more details on current practice, sets out more clearly the current challenges that older people face when it comes to mental wellbeing: public attitudes must change in this regard, so that more people feel empowered to seek help and are treated with dignity and compassion. Older people with mental health issues are currently confronted with dual prejudice against older age and mental health. Their experience of NHS funded services is worsened by the increasing cuts to specialist old age mental health services which make access to appropriate support even more difficult. Enabling them to prevent their mental wellbeing from deteriorating and supporting access to person-centred interventions, for example through implementation of this guideline, is all the more important in this context.

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6	25	In response to the research gaps identified in the guideline, it is worth noting that Age UK's own Research Team has developed a 'Loneliness Risk Index'. This research, applying the English Longitudinal Study of Ageing (ELSA) findings to the Census (2011), gives us a deeper understanding of possible causes of loneliness – e.g. poor health, household composition, age and marital status – and therefore its types. It was conducted in partnership the Office for National Statistics (ONS), and the findings are now available on the ONS website. Thanks to this research, Age UK can now identify 'hotspots' where older people have the highest risk of being lonely, not only at local authority level but now at neighbourhood level, and we will be working with our local partners in using this index to help target our services more effectively. We also expect to publish a methodology paper for the ELSA research and also one, jointly with ONS, on the local statistics shortly. While we appreciate this evidence was not available at the time of the development of the guideline, we would like to highlight this new resource as a means to target services and interventions more effectively in the future, and as a response to some of the research gaps around loneliness.
10	29	Local Age UKs are independent charities, which form part of the Age UK network. As such, 'local Age UK branches' should be replaced with 'local Age UK partners'.