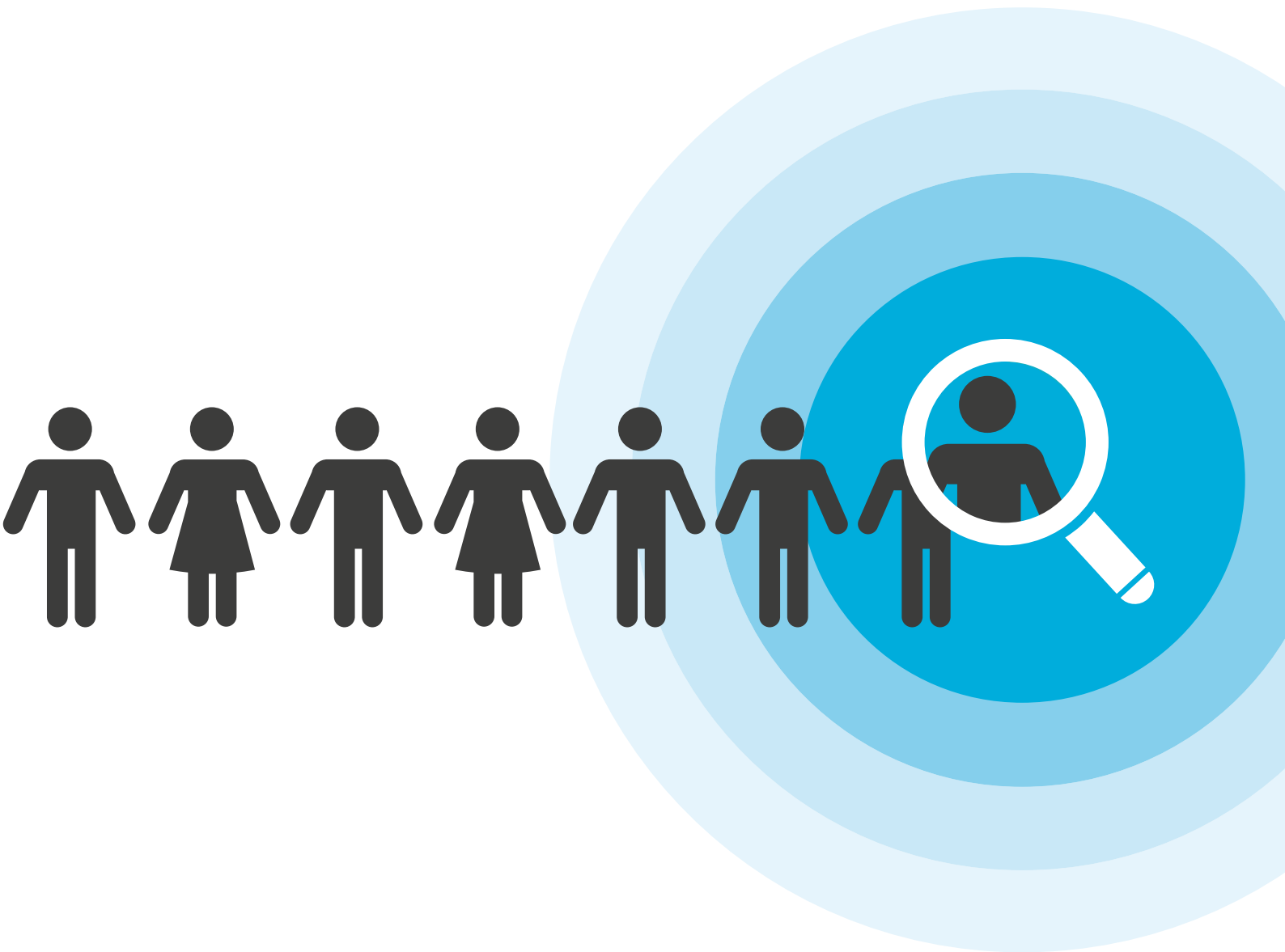# THE MISSING MILLION:
A PRACTICAL GUIDE TO IDENTIFYING AND TALKING ABOUT LONELINESS

Campaign to
End Loneliness
CONNECTIONS IN OLDER AGE

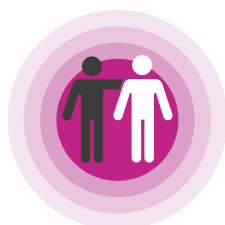# IN THIS GUIDE

INTRODUCTION

In recent years there has been a significant increase in public interest in loneliness and the issue is rapidly moving up the political agenda. Yet, in the United Kingdom, it is estimated that in excess of one million people over the age of 65 are chronically lonely.

The *Missing Million: In Search of the Loneliest in Our Communities*[1] report, published by the Campaign to End Loneliness in June 2016, provided a comprehensive overview of the existing methods being used to identify and engage with people experiencing loneliness. Drawing on this evidence, the purpose of this document is to provide practical guidance for commissioners, service providers, front line workers and volunteers; helping you to identify older people experiencing, or at risk of experiencing, loneliness and to better understand and engage with these missing million lonely older people.

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1   See http://www.campaigntoendloneliness.org/blog/the-missing-million-in-search-of-the-loneliest-in-our-communities/
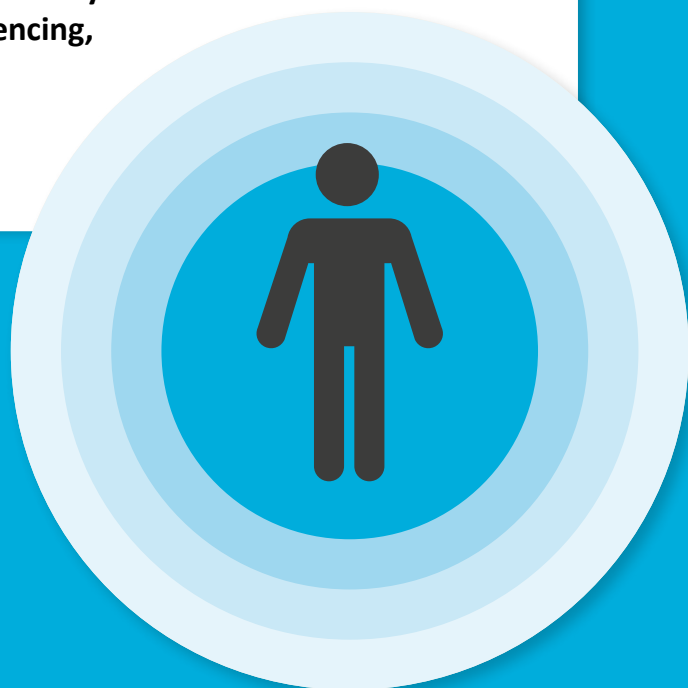
KEY TO SUCCESSFULLY IDENTIFYING LONELINESS IS:

- Using a variety of different data sources, including open data, data visualisation packages, and health informatics

- Working with local communities and tapping into existing knowledge and capacity

- Developing partnerships with a range of individuals, groups and agencies

TO BETTER UNDERSTAND AND ENGAGE WITH OLDER PEOPLE EXPERIENCING, OR AT RISK OF EXPERIENCING LONELINESS, IT IS CRUCIAL TO:

- Understand what loneliness is and why it occurs

- Facilitate a conversation about loneliness, using the skills and qualities of empathy, openness, warmth and respect, and help people to understand their own circumstances and plan their own solutions

- Provide support which is appropriate for the individual and encourage them to engage with external groups, resources and technology

HOW TO IDENTIFY LONELINESS

Before engaging with older people experiencing, or at risk of experiencing, loneliness, commissioners, service providers, front line workers and volunteers need to be able to effectively identify loneliness. The Campaign to End Loneliness' *Missing Million* report highlighted three key approaches:

1 Using a variety of different data sources, including open data, data visualisation packages, and health informatics

2 Working with local communities and tapping into existing knowledge and capacity

3 Developing partnerships with a range of individuals, groups and agencies

This section outlines some of the different data sources available and explores ways in which working with communities and in partnership with others can help you to identify loneliness.

USING DATA

Our _Missing Million_ report identified three main sources of data which can be useful in helping to identify loneliness.

1 AGE UK LONELINESS HEAT MAPS[2]

Age UK and the Office for National Statistics (ONS) have produced a series of heat maps illustrating the relative risk of loneliness across 32,844 neighbourhoods in England. These are based on data from the English Longitudinal Study of Ageing (ELSA)[3], which compiles survey data on the health, social, wellbeing and economic circumstances of the English population aged 50 years of age and above.

The loneliness heat maps are built on analysis of the following key factors associated with an increased risk of being lonely:

- self-reported health status
- activities of daily living (ADLs)

- household size
- multiple eye conditions

- housing ownership
- marital status

For example, the poorer your health, the smaller your household, having a mortgage, and being divorced or separated are all associated with an increased risk of being lonely.

These loneliness heat maps are currently being applied and tested by Age UK and local partners, as a means of identifying which localities have a higher risk of loneliness among the older population, through a series of pilot projects across the UK.

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2   See http://www.ageuk.org.uk/professional-resources-home/research/loneliness-maps/

3   See http://www.elsa-project.ac.uk/

CASE STUDY - USING THE HEAT MAP TO TARGET RESOURCES

Bromborough is an area within the Metropolitan Borough of Wirral, in Merseyside, and is situated within the geography covered by Age UK Wirral. Bromborough has pockets of very high and high risk loneliness, as shown in the Age UK loneliness heat map (below).
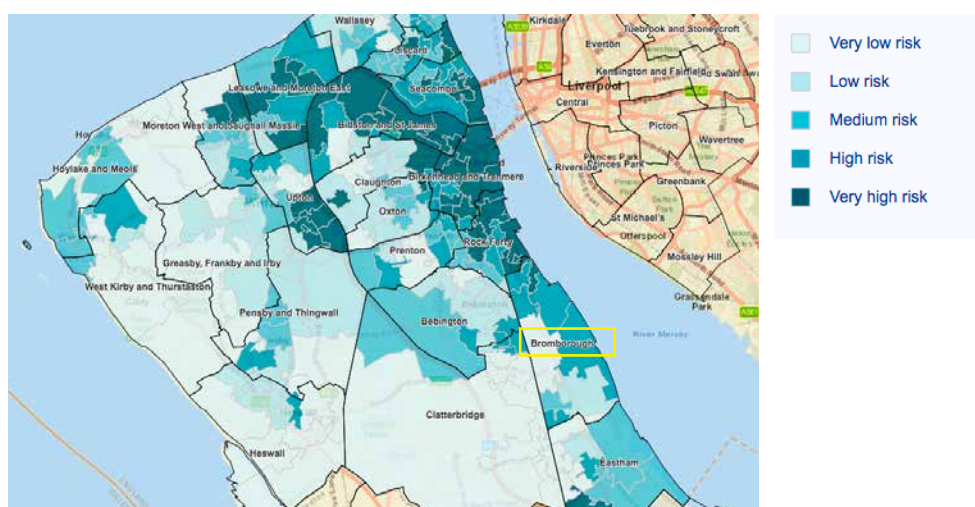
One of the services offered by Age UK Wirral is a scheme called Friends in Action, which offers friendship and companionship, and provides support with a range of everyday practical tasks. The Friends in Action team overlaid the Age UK loneliness heat map with local data on who the organisation was reaching. The comparison revealed to the team that there was a gap in provision of social activities for older people experiencing loneliness in Bromborough.

The Friends in Action team then set up a monthly coffee morning, which has around 10 to 15 older people regularly attending and older people who attend have made friends and exchanged phone numbers. This coffee morning is soon to be extended into a monthly lunch club. The identification of this gap and provision of service has provided support to help older people build their social network and in turn reduce their sense of loneliness.

A Friends in Action team member said:

> *"The loneliness heat map has been very beneficial in identifying the local hotspots and has helped identify an area where Age UK Wirral had no venues or any social hubs for clients to meet and engage with each other. Therefore this has provided a great opportunity to set up a regular meeting place venue in Bromborough every month."*

RECOMMENDATION:

▶ Review the risk of loneliness within your community using the Age UK loneliness heat maps.

▶ Overlay your service locations and the locations of individual service users onto the map, and identify whether they are located in high risk of loneliness hotspots.

▶ Consider what more could be done to increase your penetration rates into high risk areas and ways in which you can better communicate your services and ensure they are accessible to older people in hotspot locations.

2   EXETER DATA SYSTEM

The Exeter system is a database of all patients registered with an NHS GP in England and Wales, and provides accurate and up-to-date information about individuals and activities based on GP presentation data.

An advantage of this data set is the ability to identify individual households containing older people with a high risk of loneliness (although their names are not made available, meaning that a visit or some other contact with an identified household is required in order for a local service to engage with the individual person). It also means that older people who are lonely but who live in 'low risk of loneliness' areas are more likely to be identified.

In order to protect patient confidentiality, access to the data is restricted but there is a growing trend of collaboration between the NHS and the Fire and Rescue Service. In 2015, fire services carried out 670,000 home safety checks. Since April 2016, 46 fire and rescue services have begun carrying out broader 'Safe and Well' visits, to assess both fire and health risks. This means that there is huge potential to form local partnerships with fire and rescue services, making use of their access to Exeter data and also capitalising on the trusted status and operational capacity of local fire services.

CASE STUDY – NHS AND SPRINGBOARD[4]

A pioneering data sharing agreement between the NHS and Springboard (a partnership between Cheshire Fire and Rescue Service [CFRS] and Age UK Cheshire), illustrates the potential value of the data in combating loneliness.

Exeter data, supplemented with other indicators of loneliness from open data sources, allowed households to be ranked and prioritised according to certain risks. For example, older people living alone (particularly those having suffered a fall) are a higher risk group for domestic fires and this aligns to a high degree with those at risk of loneliness.

CFRS officers carry out home visits to vulnerable people and households and can then broker contact between them and a range of support services. The trusted brand and status of the fire service and of officers carrying out home visits means a high success rate in engaging vulnerable people at home and brokering contact to local agencies.

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4   See http://www.cheshirefire.gov.uk/partnerships/springboard and http://www.springboarddirect.co.uk/

RECOMMENDATION:

▶ **Engage with your local fire and rescue service and explore how you can collaborate around loneliness among older people, within a broad 'Safe and Well' agenda. Guided by Exeter data, fire and rescue service officers and volunteers can prioritise visits to particularly vulnerable households and act as a broker in making connections between a lonely older person and a local service or activity.**

3 COMMUNITY INSIGHT[5]

The Community Insight tool was developed by the Housing Associations' Charitable Trust (HACT) and provides neighbourhood maps and profiles which draw on the most recent open data sources. Specific indicators of loneliness (for example, levels of poverty, dementia, and bereavement) can be mapped against precise locations.

The Community Insight tool gives rich information about localities and can help point to determinants of loneliness in a given neighbourhood. This can help commissioners and service providers to identify potential loneliness hotspots and to target resources accordingly.

RECOMMENDATION:

▶ **Consider investing in access to the Community Insight tool. Using the mapping tool, indicator dashboard, and detailed automatically-generated profiles for each area, can help you to understand a range of indicators of loneliness within specific geographical boundaries.**

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5   See http://www.hact.org.uk/communityinsight

WORKING WITH LOCAL COMMUNITIES

Alongside data driven approaches to identifying loneliness, commissioners, service providers, front line workers and volunteers can benefit from bottom up approaches which harness the hidden wealth of communities: the informal, local intelligence, social networks, and community assets that support and are vital to achieving social outcomes.

CASE STUDY – CONNECTED COMMUNITIES[6]

Connected Communities seeks to understand neighbourhoods predominantly in terms of individual and community assets, and the formal and informal social relationships that exist. In understanding how a community functions through its social infrastructure, local networks can be 'woven' to be more inclusive and socially productive. By this we mean that new and different connections between people that better help to deliver social outcomes for people in a community, such as reduced loneliness, can be encouraged and sustained.

The Connected Communities method is based on:

1 **Partnership** – Commissioners, service providers and local residents come together to discuss their understanding of the neighbourhood and the dominant issues as they see them.

2 **Team** – A team of local residents (alongside commissioning and/or service provider staff and volunteers) are trained in the Connected Communities method.

3 **Mapping and analysis** – Neighbourhood assets, relationships and loneliness are mapped by a survey carried out by the team of trained community researchers, supported by local staff and Connected Communities researchers.

4 **Co-design interventions** – Results are relayed to the partnership group and to the local community through open, reflective workshops.

5 **Test, learn and adapt** – Interventions are implemented and evaluated against key metrics (for example, measures of loneliness).

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6   See https://www.thersa.org/discover/publications-and-articles/reports/community-capital-the-value-of-connected-communities/.

The Connected Communities approach was a partnership between the Royal Society for the Encouragement of Arts, Manufactures and Commerce (RSA), the Centre for Citizenship and Community at the University of Central Lancashire (UCLan), and the Personal Social Services Research Unit at the London School of Economics (LSE). It was tested across seven neighbourhoods in England, in a five year action research project to improve social inclusion and mental wellbeing.

RECOMMENDATION:

▶ **Methods such as Connected Communities should be used to harness local intelligence and capacity to identify older people experiencing loneliness, understand the reasons why they are lonely, and engage in supporting them to become more socially included.**

DEVELOPING PARTNERSHIPS
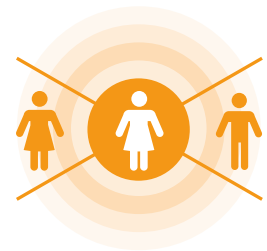
While the above methods can be used to good effect within single organisations, their value is amplified when results are shared across multiple partners. This aids common understanding and dialogue between interested parties.

Commissioners and service providers all work in partnership to varying degrees and effect, whether that is through Joint Strategic Commissioning, multi-agency partnerships such as health and wellbeing boards, or transactional arrangements between commissioners and providers. Indeed, health and wellbeing boards increasingly have an explicit focus on loneliness, particularly among older people.

All localities have, at least to some degree, a mix of public services, community and voluntary sector organisations, informal groups, and public spaces and amenities. Working with partners to create a community resource directory, which details a range of appropriate services and support for older people experiencing loneliness, can prove extremely valuable.

RECOMMENDATION:

▶ **Consider producing a community resource directory, in a range of electronic and hard copy formats and distribute widely, including to staff and volunteers who may come into contact with older people experiencing loneliness. The process of constructing the directory may in itself raise awareness of the issue of loneliness, and also help to identify new organisations and groups that come into contact with older people experiencing loneliness.**

HOW TO ENGAGE WITH LONELY OLDER PEOPLE

The *Missing Million* report concluded that to better understand and engage with older people experiencing, or at risk of experiencing, loneliness, it is crucial to:
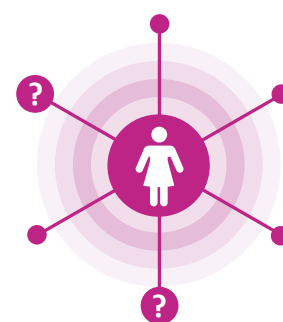
- **Understand what loneliness is** and why it occurs

- **Facilitate a conversation about loneliness,** using the skills and qualities of empathy, openness, warmth and respect, and help people to understand their own circumstances and plan their own solutions

- **Provide support** which is appropriate for the individual person and encourage them to engage with external groups, resources and technology

The following section focuses primarily on providing recommendations on how best to engage in a dialogue about loneliness and also offers some examples of effective and innovative approaches to supporting older people experiencing, or at risk of experiencing, loneliness.
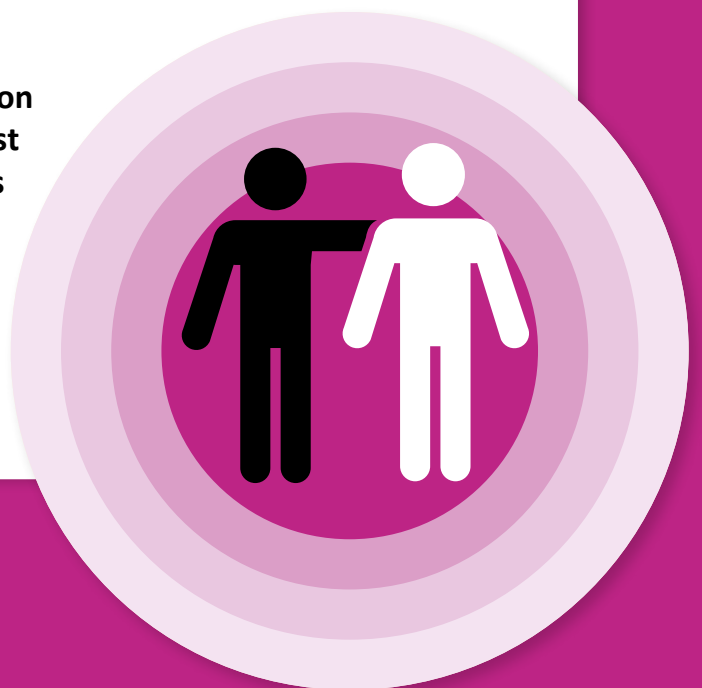
WHAT IS LONELINESS AND WHY DOES IT OCCUR?

First and foremost it is important to understand what loneliness is and why is occurs. Our *Hidden Citizens*[7] report describes loneliness as:

> *"a negative experience that involves painful feelings of not belonging and disconnectedness from others. It occurs when there is a discrepancy between the quantity and quality of social relationships that we want, and those that we have. Thus, loneliness is a subjective psychological perception."*

The Hidden Citizens research also identified a number of pathways into loneliness, which separate into internal and external factors.

Internal factors reflect the importance of understanding the person:

- Their socio-economic characteristics
- Values
- Beliefs
- Personality
- Resilience
- Self-esteem and confidence (or lack thereof)
- The way they understand and relate to themselves and others

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7   Goodman, A., Adams, A., and Swift, H.J. (2015) Hidden citizens: How can we identify the most lonely older adults? London: The Campaign to End Loneliness. Available at http://www.campaigntoendloneliness.org/hidden-citizens/

External factors reflect the importance of understanding the person in context:

- What does their social world look like to them, and how is it experienced?

- Does the person have supportive relationships with family and friends?

- Are there local formal or informal social groups to which the person belongs or could belong?

- Are there factors that prevent social connection, such as a lack of transport?

- Has the person experienced a recent significant change in their life (this might include bereavement, moving house, retiring, physical ill health, stopping driving)?

While these factors are important to understand as triggers for loneliness, it is also helpful to understand why loneliness occurs. Why do we feel loneliness at all and what is its purpose?

Professor John Cacioppo[8], a social neuroscientist, argues that loneliness evolved as an aversive biological signal aimed at promoting vigilance with regards to our wellbeing and survival. Just as hunger is an aversive biological signal telling us to nourish and protect our body, so loneliness is a signal that tells us to attend to our social connectedness. As our brains are hard-wired in such a way that make us 'social creatures', attending to loneliness is important for our long-term survival.

Feeling lonely means our biological systems are doing what they are supposed to be doing; they are telling us that there is something we need to change about our social world and the way we are interacting with it. It is normal to feel lonely but we need to listen to and act on the signal.

RECOMMENDATION:

▶ **Before you engage a lonely older person in conversation, know what loneliness is, what it means, how it is experienced, and what its purpose is.**

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8   Cacioppo, J. (2010) Connected Minds: Loneliness, Social Brains and the Need for Community. London: RSA. Available at: https://www.youtube.com/watch?v=iu6RM_Ib30A

TALKING ABOUT LONELINESS

It is important to note that there is no single best way of having a conversation about loneliness. Loneliness exists in many different contexts and those experiencing it have differing internal and external resources to call upon; while those engaging with older people experiencing loneliness have different types of knowledge, experience, capabilities and support to mobilise, institutional remits, obligations, and time. The *Missing Million* report does, however, offer some general guidance on how best to have a conversation about loneliness.

One interviewee, with long-standing expertise on social marketing and communicating with older people, drew a contrast with communicating with young people, which generally employs a higher degree of segmentation and sophistication. They described many attempts to engage older people as:

"Shockingly stereotypical: it is all caravans and cardigans."

RECOMMENDATION:

▶ **Consider whether your communication (content and visuals) and channels are appropriate to your target audience. Ensure good copywriting. Test different types of messages, visuals formats and channels with your target audience and evaluate which means of communication prove most effective. Consider whether directly approaching your target audience about loneliness is more or less effective than emphasising the benefits of engaging in a service.**

Implicit in empathic communication is the importance of paying attention to tone. The use of an infantilising voice is more often than not experienced as disrespectful and humiliating, and can bring about a self-fulfilling prophecy. Older people can come to believe that they are no longer independent, contributing members of society and assume a passive, dependent role which can reinforce a sense of loneliness.[9]

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9   Arluke, A. and Levin, J. (1984) Another stereotype: Old age as a second childhood, Aging, 346: 7-11
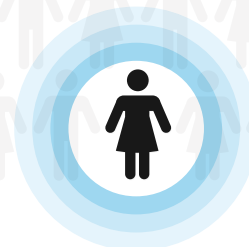
Similarly, 'over-accommodation', in which speakers adopt overly polite, simplified, slower and louder verbal communication, is often experienced as patronising and can have the effect of 'instantly ageing' older people spoken to in this way.[10]

Instead, the foundations of an effective dialogue about loneliness should be based on:

- **Empathy** – generating a deep, accurate understanding of what loneliness means to the individual and how they experience it; what is it like to inhabit their internal frame of reference and world of feelings, attitudes, experiences and behaviours?

> *"Don't make assumptions about what older people can do and want to do. Ice-skating and tenpin bowling with older people and young people have been our most popular activities. Bingo has been among the least successful – and it is effectively played in isolation. We try and remove limits and expectations about roles and interests. Older people just need the opportunity and some support and encouragement to try new things."*
> Stakeholder interview

- **Congruence** – being genuine, honest, and 'real'. In this context, it also means noticing what you are experiencing in trying to help someone and sharing this with them, if it is in their best interests to do so.

> *"You have to be honest with yourself to work here, to work genuinely with older people and like what you do. And you have to be honest with older people, don't be afraid to challenge or speak to them in the same way you would anyone else, always gently and with respect of course but be consistent."*
> Stakeholder interview

- **Unconditional positive regard** – warm, non-judgemental acceptance of the other person as whatever they are in that given moment during your helping relationship with them. Understanding that confronting painful feelings and changing their behaviour in some way can be a big step and a daunting challenge.

> *"If you're having a conversation with a lonely person, let them talk. Find out about them, be interested, just accept them for who they are. My daughter asks me why people are nice to me. I say to her it's because I'm nice to them."*
> Older People Focus Group Participant

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10 Giles, H., Fox, S. and Smith, E. (1994) Patronizing the elderly: Intergenerational evaluations, Research on Language and Social Interaction, 26(2): 129-149

RECOMMENDATION:

▶ **Base your approach to engaging in dialogue about loneliness with an older person on the following core principles:**

- **Empathy**
- **Congruence**
- **Warmth**
- **Respect**

APPLYING THE RECOMMENDATIONS

Just as there is no single best way of having a conversation about loneliness, neither should there be a "one size fits all" approach to engaging with older people who may be at risk of loneliness. Below are a range of case studies which apply some of the recommendations around identification and dialogue and put them into practice. When given, support must be appropriate for the individual person and, where possible, encourage them to engage with external groups, resources and technology.

For more detailed information on the variety of methods that exist to support older people experiencing loneliness see our publication *Promising approaches to reducing loneliness and isolation in later life* [11].

11 http://www.campaigntoendloneliness.org/wp-content/uploads/Promising-approaches-to-reducing-loneliness-and-isolation-in-later-life.pdf

CASE STUDY – SOCIAL PRESCRIBING

Social prescribing is a mechanism through which primary care services refer patients with social, emotional or practical needs to a range of local, non-clinical services, often provided by the voluntary and community sector.

One example is **Brightlife[12]**, a multi-agency partnership testing 'social pharmacies' that 'stock' access to social assets and issue 'prescriptions' to people who are referred to them by GPs or who self-refer. A wide range of social prescriptions are available, such as exercise classes and activities, or access to 'men's sheds'.

The social pharmacy is itself a commissioning hub, with local organisations applying to join a bank of potential providers and older people deciding which of those providers they would like to commission. Brightlife encourages innovation from local providers and offers support to local organisations in developing their ideas to make them as sustainable and impactful as possible.

# CASE STUDY – FACILITATING DIALOGUE

Talk for Health[13] is a social enterprise and programme that brings together a group of up to 12 people and teaches them how to understand and talk about their own experience and feelings, how to listen effectively and respond emphatically to others, and how to set up an ongoing Talk for Health group for sustainable connection and wellbeing. The programme has been evaluated and found to significantly improve wellbeing in individual, intrapersonal, and social outcome domains.

The programme is based around empathetic, respectful and congruent communication. In order to have a meaningful conversation about loneliness, all participants are encouraged and helped to 'unmask' themselves. People often compare their internal selves with others' external selves. By acknowledging loneliness and vulnerability, feelings become validated and normalised.

In some cases, people experiencing loneliness will need help in developing relationship skills. For example, an individual may be low in confidence, or egotistical, hyper-vigilant or aggressive in some way without meaning to be. The fostering of these skills in a safe group helps to build the capacity in an individual to connect with others and alleviate loneliness.

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12 See www.brightlifecheshire.org.uk

13 See http://www.talkforhealth.co.uk/programmes/
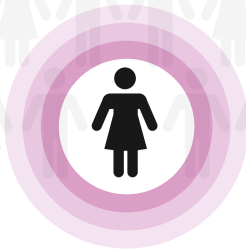
CASE STUDY – UTILISING TECHNOLOGY

Social media, smartphones and tablets, health informatics, the internet of things, and other forms of technology can all serve to increase loneliness and social disconnection for those unaccustomed to using them. However, the **Castlehaven Community Association (CCA)**[14] recognises the usefulness of technology as a means of addressing loneliness, as well as the nervousness many can feel around unfamiliar software and hardware.

In response, CCA have run 'tea and tech' sessions. Traditional means of engagement (tea and cake) are put alongside engaging technology. Older people are invited to bring in their kit and are taught to use them by young adults working in local businesses and local secondary school students.

The process of enabling older people to use technology to help alleviate their loneliness is also beneficial in creating inter-generational contact, and, in the case of secondary school students, older people have participated as research subjects for oral history coursework assignments, adding depth to contact between older and younger people as well as a sense of reciprocal expertise and usefulness.

14 See http://www.castlehaven.org.uk/

About The Campaign to End Loneliness

The Campaign to End Loneliness inspires thousands of organisations and people to do more to tackle the health threat of loneliness in older age. The Campaign to End Loneliness is a network of national, regional and local organisations and people working together through community action, good practice, research and policy to ensure that loneliness is acted upon as a public health priority at national and local levels.

About the Author of *The Missing Million*

Steve Broome is a freelance researcher, evaluator and project/service developer working across community development, mental wellbeing, social networks, substance misuse, criminal justice, and local economic development. He was previously the Director of Research at the Royal Society of Arts (RSA) for six years, and has worked as a visiting lecturer in research methods, a programme manager in community regeneration, and as an economic development consultant. Steve is the co-author of *What's Normal Anyway?*, a book exploring the lived experience of various mental health problems, and is an Associate at the Centre for Citizenship and Community at the University of Central Lancashire.
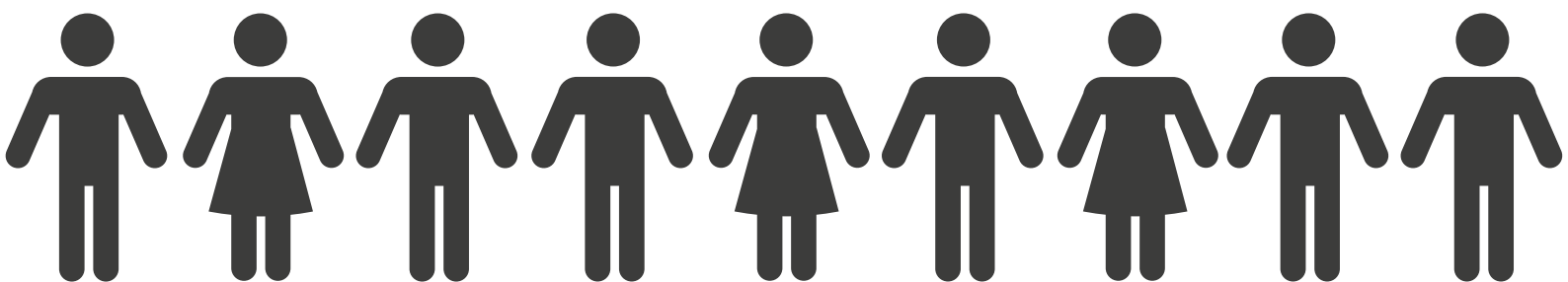
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