

Alone in the crowd: loneliness and diversity





Contents

	Foreword	2
	Kate Jopling & Andrew Barnett	
1	Below rock bottom: Older adults and alcohol abuse	5
	Simon Antrobus	
2	Caring alone	9
	Heléna Herklots	
3	Facing the fight alone: Cancer, isolation and loneliness	13
	Ciarán Devane	
4	Going back in: Loneliness and its impact for older lesbian, gay and bisexual people	18
	James Taylor	
5	I would be less lonely alone: The loneliness paradox	22
	Ruth Sutherland	
6	Loneliness in care homes	26
	Tom Owen	
7	Race is no protection against loneliness	30
	Omar Khan	
8	The most terrible poverty: Loneliness and mental health	34
	Paul Farmer & Jenny Edwards	
9	When friends drop away: The loneliness of living with dementia	39
	Jeremy Hughes	
10	Without sight and sound: Loneliness among older deafblind people	44
	Richard Kramer	
	About the authors	48
	The Campaign to End Loneliness	51
	The Calouste Gulbenkian Foundation	52

Foreword

We have all felt lonely at some time in our lives. It can be a terrible, debilitating emotion. It can leave us feeling trapped and unable to cope. But thankfully, for most of us, it is a temporary feeling: one which we suffer after a crisis or major change in our lives but which we are able, eventually, to overcome.

Unfortunately this is not everyone's experience. Research shows us that a relatively consistent proportion of older people experience chronic loneliness. Around 10 per cent say they are often or always lonely, and this proportion has remained the same throughout the past five decades. However, as our population has aged, the number of lonely people has grown. And, with the growing body of research demonstrating the damage loneliness does to our mental and physical health, we now understand that this is an issue we cannot afford to ignore.

But who are the lonely people? While anyone can become lonely, some circumstances and some characteristics seem to leave us particularly vulnerable to loneliness. There are a number of common transitions too, like relationship breakdown, redundancy, retirement, or a decline in health, which can trigger a sudden change in circumstances and a downward spiral into loneliness.

Loneliness is a subjective experience, different from the objective constructs of social isolation or social exclusion. It is this subjectivity that explains why one person can feel deeply lonely despite being surrounded by friends and family, and another can feel perfectly content alone – experiencing the bliss of being alone that we call solitude, as compared to the agony of loneliness.

This collection of essays has been brought together to shine a light on the individuals behind the statistics, helping us to understand better who experiences loneliness, and what particular challenges they may face.

What is clear is that, while the proportion of older people experiencing loneliness may have remained constant over time, the profile of lonely individuals is likely to have shifted from one era to the next. Indeed, as our population continues to become ever more diverse, and the challenges we face as a nation change, so too will the profile of the lonely.

The Campaign to End Loneliness and the Calouste Gulbenkian Foundation are therefore delighted to publish this collection of essays, written by the leaders of organisations working with groups who are at increased risk of loneliness. The essays explore what is known about how loneliness affects some of the most vulnerable among us, and, vitally, suggest what needs to change to ensure that the loneliness of these individuals is effectively addressed.

There is a clear imperative to act on loneliness. As well as being a moral outrage, and leading to the loss of the enormous potential contribution of so many older people to their families and communities, we now know that loneliness harms health and in turn costs the public purse dear. The evidence demonstrates a clear link between loneliness and a wide range of physical and mental health issues, including depression, cognitive decline, early onset dementia and cardiovascular disease.

However, tackling this highly personal and complex problem is not easy. If interventions are going to be effective, they need to be tailored to meet the needs of individuals who experience loneliness – whatever their circumstances. And we need to reach out effectively to those who are most isolated, working from our understanding of what causes loneliness, what characteristics and which transition points can make people vulnerable to becoming lonely, and how we can mitigate these risks.

We hope that these essays will stimulate new thinking and help us all, whether we are elected representatives, officials, service providers, or simply individual members of families and communities, to consider how to ensure that our response to the highly individual experience of loneliness meets the needs of those who experience it, in all of their diversity.

Kate Jopling

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Alone in the crowd



Below rock bottom: Older adults and alcohol abuse

1

When I first met John he was full of remorse. In many ways he still is. He knows he has made serious mistakes, and most in a very short space of time. He readily accepts that those mistakes have led him to where he is now – somewhere he describes as ‘below rock bottom’.

Until three years ago, everything was going well for John. He had a good job, money in the bank, a supportive family, close friends and a wonderful partner. But when John lost his job it hit him hard and seriously hurt his pride. John would also be the first to admit that he already liked a drink, and more than just “a few at the weekend”. Like many of his counterparts, John paid little attention to things like ‘health warnings’ or ‘safe guidelines’. What he did know was that when things started to go wrong, alcohol seemed to help, and for John it provided a welcome escape from his problems.

With funds already tight, the high cost of drinking soon made his money run out – and then things began to spiral even further out of control. John was never what you would call ‘pleasant’ when drunk, his behaviour led to his friends losing patience with him and, one by one, moving on. Then, in what John calls his “most shameful moment”, he was arrested after assaulting someone in the local pub, who had seemed to make advances towards his partner, and leaving the younger man in hospital. Just when he thought his life couldn’t get any worse, his partner – unable to cope any longer with his unpredictable nature, binge drinking, bouts of street drinking, and financial chaos – finally walked out on John’s 65th birthday.

A small and barely furnished flat was all that John had left. His drinking had damaged not only his health, but the way he thought of himself and how he saw the world. Finding himself unable to leave the flat without feelings of crippling anxiety, he relied on a local taxi firm to collect alcohol from the shops, which he’d then drink at home alone. John would never have imagined ending up like this, and neither would his grown up children. Like many others, they simply couldn’t imagine any older person – not least their own father – having such a problematic relationship with alcohol.

It goes without saying that any kind of isolation is never easy. But John's circumstances were compounded by two things: the knowledge that he was responsible for his problems, and his inability to see a way to overcome his addiction and regain control of his life. *"Worst of all,"* he says, *"is the never-ending loneliness."* And he isn't the only person saying it.

Loneliness is one of a number of so-called 'vulnerability' factors that can lead older people into drinking more heavily. Loss of a loved one, infrequent visits from family members, financial worries, dwindling social networks, and even retirement, can all contribute towards feelings of loneliness and isolation. At the same time, evidence suggests that loneliness can be a barrier to overcoming a drinking problem once it has been established. Even for those able to resolve their issues with problem drinking, loneliness, loss and social isolation can lead people to start relying on alcohol again.

For older people, alcohol misuse is a growing problem. Already our services at Addaction are seeing more people aged over 60 with drinking problems, and with the number of men and women drinking more than the recommended weekly units of alcohol on the rise we expect the problem to grow further. NHS figures show that since the early nineties to 2006, around 60 per cent more men and a staggering 100 per cent more women have begun drinking at unhealthy levels. Stronger alcohol, greater availability and lower prices have all contributed to this situation. And with an expected 50 per cent more older people in the next 15 years than at the turn of the century, we simply don't know how big the problem could get.

How can we help older people like John address both their loneliness and their alcohol misuse? Before anything else, we must recognise that an older person's life is as valuable and important as any other life, and as deserving of a chance to turn around and make a fresh start. It may seem obvious to most, but as a society we are very quick to dismiss the concerns and problems faced by pensioners. Our view of alcohol is a case in point; our focus has almost always been on the younger generations. Newspapers frequently carry photos and articles about young men and woman drinking to excess, but it is far from the full picture. The good news, however, is that when Addaction and organisations like us do engage with older drinkers, they are very willing to accept our help. In fact, they can be even more receptive than young people – no mean feat when you consider that they can be part of an isolated or even 'invisible' group that rarely, if ever, comes in to contact with treatment services. That's certainly how it was with John, who was helped by Addaction's pioneering 'Over 50s' service in Glasgow. This important service operates out of an inconspicuous and inexpensive building in the city, where a dedicated team works extremely hard so that people like John are able make a better life for themselves – away from alcohol.

Over the last three years, Addaction has helped over 300 people out of this difficult and lonely situation. As an organisation we have learned a great deal from working with older drinkers about the simple and effective things we can do to help. First of all, we look at the way people are living and the professionals and agencies people are already in contact with, such as their local GP or pharmacist, care at home providers or even their landlords. For our team in Glasgow, working alongside these professionals meant they were able to arrange referrals for any older people whose drinking was becoming (or had already become) a problem.

Raising awareness of the issues faced by older drinkers and addressing stigma associated with alcohol dependency are also vital, since the strong sense of shame, embarrassment and guilt among some older drinkers can prevent early access to treatment services. Whilst this sense of shame can be partly self-imposed, it can also be a response to people's perception of the reaction they will receive. I have heard some people say, "*well what does it matter if an older person drinks themselves to death.*" This sense that an older person has become a non-person, little more than a burden and that we should "*let them drink*" only serves to further isolate and stigmatise them. This is why getting information out into the community and addressing stigma is so critical: we can reduce an ever present deterrent to people picking up the phone and asking for help.

Perhaps most importantly, in Glasgow we designed a support service aimed specifically at older people. Walking into a treatment service is a brave step and can feel incredibly intimidating at the best of times – and for older people, a mix of loneliness and pride can make this step a still more daunting challenge. John, for example, would not have dreamt of entering such a place, but was willing to accept an offer of support and help that took place in his own home, a 'safe' environment where he felt able to open up and admit to issues he felt very ashamed about. We knew that such a peripatetic 'outreach' approach was essential if the service was to succeed.

We also understood how important it was for people who felt isolated to realise they were not alone with their problems, and so we provided a carefully developed programme of peer support. Befriending and group meetings with people in very similar situations are an exemplary way of allowing people to share experiences and ways of coping. It's an approach Addaction uses across all its services – whether they're for people with drug or alcohol problems, and regardless of their age group – and it's one that has been shown to work very well indeed. The realisation that others have been through similar experience is incredibly powerful, and most importantly helps people realise that their problems are surmountable. For a service to be truly effective, the creation of these kinds of processes must be an integral part of what's on offer.

At Addaction, we use a working model known as ‘Mutual Aid Partnerships’. In these meetings, the groups use evidence-based approaches (such as Cognitive Behavioural Therapy) to help address negative behaviour while also supporting each other.

Finally, we realised that the alcohol problems we were treating in Glasgow were not the only issue in these people’s lives. Instead, they were the symptom of wider problems, often related to family, finances and, of course, loneliness. We were well aware that we also need to provide holistic support, tending to the needs of the ‘whole person’ and not merely focusing on their drinking. We achieved this by working with housing and social care agencies, other members of the family, social clubs, financial advisors and more to help deal with the root causes of people’s alcohol use. As John’s situation demonstrates, a single incident such as losing a job can send lives into freefall.

John is now on his way to getting better. There is a long way for him to go, of course, but with Addaction’s help and support he has found a way to tackle his problem. There is a long way to go for us, too. Sadly, the support we’ve provided in Glasgow has been an exception and not a rule, and current support for older people with drink problems is at best patchy, and at worst non-existent. We’re only really at the tip of the iceberg in recognising and dealing with alcohol abuse amongst older people. But as our older population grows we need to provide more ways for people to overcome feelings of loneliness and isolation without turning to alcohol, and for those who do, we must provide the support to help them out of the hole they may find themselves in.

Simon Antrobus

Chief Executive
Addaction

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"It was getting tougher and tougher. I collapsed under the strain of trying to be a carer and to carry on working and I was advised by the medical professions that I needed to have a rethink. I didn't feel isolated while I was able to go out to work and do caring. Once I tried to be a carer here full-time, I felt totally isolated because your whole network's gone. People come round for a while but not for long. So you really need to rebuild that network but you don't know where to look, because you think everyone else is coping and you think it can only be me that isn't coping."

There are 6.5 million people in the UK caring unpaid for an older or disabled family member or friend, and the numbers are increasing. The 2011 Census showed that there are nearly 1.3 million carers over the age of 65, a 35% increase since the Census in 2001, representing the fastest growing group of carers. It's important to note also that the people who make up that 6.5 million are changing all the time. Every year 2 million people become carers, and a similar number find that their caring role has come to an end. The gender balance is closer than you might suppose, as 42% of carers are men.

All of us, at some point in our lives, will either be carers, or need the help of carers. So if caring or being cared for is a near universal experience, how is it that being a carer can be so isolating and lonely? This is the experience of many carers I've spoken to in my work at Carers UK and is a theme in the body of research around caring. There have been significant improvements over the last 50 years in the recognition of carers starting with the work of the Reverend Mary Webster, who founded the carers' movement. But the fundamental challenges of being a carer haven't changed significantly. So whilst the word 'carer' is increasingly recognised today, people's experiences of being a carer are not so different from those Mary had in the 1950s and 60s.

The loneliness carers experience is caused by a range of circumstances, many of which are imposed on them. You may be so busy that you have no time or energy left to see friends and other family, or they may drift away as your life becomes so different from theirs. You may find the emotional demands of caring for a loved one and focussing on their well-being means that you neglect your own. The costs associated with caring, particularly if you have had to give up work to care,

can mean that you are struggling financially and cannot afford to do some of the social activities you did before. You can find that your relationships become increasingly transactional rather than affirming and sustaining. For many carers, the world simply shrinks. Your role can become one of providing and co-ordinating care, taking your loved one to medical appointments, going to the chemist, liaising with care workers. You can feel invisible, as you fade into the background and the needs of the person you are caring for take centre stage. It can be lonely bearing so much of the responsibility of caring for a loved one.

The Reverend Mary Webster was 31 when she gave up her work as a church minister to care for her elderly parents. It was 1954 and there was no concept of a 'carer', no recognition of the role, and no support. Mary was a single woman and as the demands of caring grew, her isolation also grew. Mary described her situation as like being under 'house arrest' – a phrase that resonates strongly today. Thinking that there might be other women in the same situation as her, caring for elderly parents and being cut off as a result, she reached out through the newspapers to tell her story and was inundated by letters from others in the same situation. Mary brought what had hitherto been a private issue, into the public domain. It is thanks to this pioneering work that the carers' movement was born and the charity that became Carers UK was established in 1965.

Each day 6,000 people become carers and the transition to caring, and particularly to full-time caring, can plunge you into isolation.

*"Nothing prepared me for the loss of identity...when I had to stop working – overnight I stopped being superwoman and became a nonentity, a scrounger living on benefits. I feel that I am invisible now – as soon as you mention that you are a carer, whether talking to a professional or a stranger at a bus stop, their eyes glaze over. Once you are a carer it is as if you cease to exist, or only live as a shadow. It is hard."*¹

"My experience came as a complete shock with a cancer diagnosis so there was no time to prepare. There was an overwhelming sense of shock and loneliness."

At the same time, when people's caring roles come to an end this can also bring feelings of loneliness.

"After my caring role ended I felt out on a limb... Even when you know it's going to happen it is a change in lifestyle and is very frightening; just as frightening as when caring begins. You feel lost and alone and have no idea what to do with your time. After caring long term carers especially should be given time to grieve and get their head back in some sort of order."

These individual experiences are reflected in the research that Carers UK has undertaken over many years. In our 2013 *State of Caring*² survey – completed by

over 3,000 carers – 92% said that their mental health has been affected by caring. Research carried out for Carers Week 2013 showed that 6 out of 10 carers had found it difficult to maintain friendships, 42% had had a breakdown in a relationship with a family member, and 71% of carers were not prepared for the change in relationship with the person they cared for.

“I had no idea...[of] the degree that [caring] would impact on my life, particularly my ability to leave the house, have a social life of my own, follow my own interests, have holidays, and be able to look after my health. In becoming a carer, I’ve lost my own identity to a great extent, strange though that might sound.”³

What can be done? We need nothing less than a societal shift in recognition and understanding of caring. Although caring is such a normal part of life, it is not seen as a shared experience. Contrast it with parenthood, where there is a societal understanding of a shared experience and an ease of talking about it with friends, at work, with family. We need to find ways to ‘normalise’ caring, so that it is acknowledged as the universal experience it is, and so that carers too are recognised, valued and supported.

As a society we need to reach out to carers so they know that they are not alone. We also need to ensure they can get both practical and emotional support. Crucially we need to do this in a way that doesn’t always rely on people identifying themselves as carers. It can take years before someone self-identifies as a carer, and this can mean essential support doesn’t reach them. But we can all play a role in tackling loneliness amongst carers. The cultural shift to break the isolation and loneliness of carers starts with small conversations:

- The GP who asks how you are, not just about the person you are caring for
- The employer who you’re able to share your circumstances with and who gives you the flexibility to manage working and caring
- The social worker who understands your situation and who helps you arrange the support that you need as a carer
- The pharmacist who sees you picking up the prescription regularly and chats to you about your own health
- The carer who recognises that you are a carer too, and understands and helps you feel less alone
- The public figure who talks about their own experiences of being a carer and acts as a catalyst for other conversations
- The friends who stay with you, and the new friends that you make

These conversations won't solve everything, and have to be accompanied by practical and financial help and support. But they really can help to break the loneliness that many carers experience. Some of these conversations happen already, but they need to happen more consistently, for example with health and care professionals who are so important to ensuring that carers get practical help and support. For this to be achieved, understanding and awareness of carers needs to be built into training, education and ongoing practice. For instance, we know that the role of the GP is crucial, which is why, funded by the Department of Health, we are working with the Royal College of GPs and Carers Trust to raise awareness and support for carers amongst GPs. The work that NHS England is carrying out under its NHS Commitment for Carers also has the potential to improve the recognition and support that carers receive from the NHS.

Alongside the cultural shift that is needed, there must also be better practical support for carers. Reliable, high quality health and social care for the person they are caring for is vital, as is the opportunity to take a break from caring. Also essential is the right financial support for carers – whether caring full-time or trying to balance caring with working. And when the caring role ends, carers need time, understanding and support to adjust to the life change, and to rebuild a life after caring.

How we care for each other is one of the biggest challenges we face as a society, and one of the most important things any of us do in our lives. We shouldn't have to do it alone.

Heléna Herklots

Chief Executive
Carers UK

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- 1 Carers Week (2013) *Prepared to Care?*
 - 2 Carers UK (2013) *State of Caring 2013*
 - 3 Carers Week (2012) *In Sickness and in Health*

Facing the fight alone: Cancer, isolation and loneliness

3

“Either too old, too young, or too far away.” This is why one 68-year-old woman living with cancer said she lacked support from her family and friends.¹ Sadly, she is far from alone in experiencing this kind of isolation. At Macmillan our research shows around one in five people over 55 with cancer will lack support at home during their treatment and recovery.²

Every year, around 150,000 people aged over 50 are diagnosed with cancer in the UK.³ In addition to the shock of having a life-threatening illness, cancer is often a hugely isolating experience socially and emotionally. Even if people do have friends and family around they can struggle to open up about the emotional and physical realities of the disease and its treatment. Their loved ones may not know what to say or how to help. Almost two in five of those aged over 55 will keep their diagnosis a secret from most of their family and friends. Cancer isolates young people too, from the children and teenagers who have to drop out of education, to young adults unable to take part in the world of work or start a family. Young or old, the social dimension of cancer is as important as the clinical.

A lack of support from family or friends is not the only reason why some people with cancer face isolation and loneliness. Standard surgery, radiotherapy and chemotherapy can leave people feeling too ill and exhausted to socialise, and more specialised treatments can pose additional challenges. Some people who have thyroid cancer will be treated with radioactive iodine, causing the body to give off radiation for a short time afterwards. Imagine not being able to hug your partner or children because you risk making them ill, at a time when you need comfort more than ever. For those needing a bone marrow transplant, like many leukaemia and lymphoma patients, a weakened immune system may mean facing several days or weeks in an isolation unit.

If, after all that, your treatment is successful, you might expect to feel euphoric. The opposite can often be true. Though cancer treatment itself may end, the physical and psychological effects can continue to be isolating. Around one in four of those with cancer will face disability or poor physical or mental health after treatment.⁴ The loss of routine and regular interaction with a healthcare team after treatment ends can feel like having a safety net taken away.

People feel isolated, lost and abandoned. Some people feel guilty, as if they ought to simply feel grateful for being alive. Many will experience long-term anxiety and depression.

The longer-term physical impact of cancer and its treatment can include bowel incontinence, which may mean someone is unable to leave the house unless they are certain of every public toilet on their route. Sexual difficulties can put a huge strain on self-confidence and on intimate relationships. Limbs swollen with lymphoedema can make people feel so self-conscious that they stop socialising with friends. The effects of radical surgery on the head or neck can mean people feel uncomfortable eating in public.

“The embarrassment was terrible. I was left so weak from treatment I had to be lifted into and out of the shower, and helped to go to the toilet. I didn’t talk to anybody. I didn’t want people coming to look at me, so I stopped all visitors.” David, 74, South Wales

People affected by the consequences of cancer and its treatment can find it very hard to talk about the issues they face and to seek help. There are often simple, effective remedies that can help, but they are not discussed enough, and many healthcare professionals aren’t made aware of the issues or don’t take them as seriously as they should.

And what of those for whom treatment doesn’t work? More than two in three of those who develop cancer will still die from the disease.⁵ Though everyone knows, on some level, that they will one day die, it’s a very different experience to be told that day is only a matter of weeks or months away. A Dignity in Dying survey has shown that people’s greatest fear about dying is dying alone,⁶ and isolation as people approach the end of their lives is a particularly complex issue. One thing we do know for certain is that too many people with cancer are denied their last wish to die at home in familiar surroundings.

Isolation among people with cancer can be a vicious circle. Poor health itself can cause isolation, but a lack of support during treatment and recovery can also have a negative impact on people’s health and wellbeing. At Macmillan, we’re concerned it may even reduce someone’s chances of surviving cancer. Not having support from family and friends at home can stop people attending GP or hospital appointments, or picking up prescriptions. Some facing isolation will skip meals or not eat properly because they feel too tired or unwell to do so. A large US study has suggested that not having the support of a loving relationship increases the risk of dying from cancer by 20%.⁷

“Living alone, I didn’t have the energy to do anything during my radiotherapy, so I just lived on ready meals. There were days when I went to bed having had nothing more than a glass of milk and a biscuit because I was too exhausted to cook.” Lis, 67, Surrey

There are currently 1.3 million people aged over 65 living with cancer. By 2040, this number is expected to grow to 4.1 million.⁸ The number of older people who live alone is also predicted to grow in coming years and there are already tens of thousands of people with cancer experiencing isolation and loneliness today. It is clear we are heading for a crisis if we don’t take action now – but societal issues such as scattered families go far beyond cancer. Where do we even start?

Some people blame our increasing obsession with the internet and technology for making us more isolated, but at Macmillan we believe technology is a tool that can ultimately help bring people together. Already the 79,000 members of our online community provide each other with advice and support on a 24/7 basis, but we are taking things further. Working with Skype, we’re developing a new service that will enable those living with cancer to talk to someone who has had a similar experience, either through video calls or online chat. And in Brighton and Hove we’re piloting an exciting scheme, ‘Team Up’, which will use an innovative new website to connect people who have a little spare time to carry out minor errands with those in need of that kind of help. Forging connections online is becoming increasingly relevant for older adults with cancer – the proportion of those aged 65 to 74 who have the internet at home has shot up from 38% in 2009 to 61% in 2012, and is set to keep rising.⁹ It is important that we harness the potential that new technology can offer.

Other crucial changes are needed. People affected by cancer should be helped to recognise that isolation can have a real impact on their health and wellbeing, and then be supported to seek help if they need it. Health and social care professionals must also recognise the impacts of isolation on health. Care teams should always ask how much support someone with cancer has at home and should make allowances for those who lack support wherever possible. This includes directing isolated patients to alternative forms of support such as the Macmillan Support Line. Ensuring this happens is both a moral duty and a medical one.

We also want NHS leaders to make sure that everyone diagnosed with cancer receives a ‘recovery package’ of care and support, to help them after treatment ends. One of the key components of this package should be a ‘holistic’ needs assessment designed to assess a cancer patient as a whole person, examining

their emotional, social and financial needs alongside their immediate medical needs. In addition, local authorities should look at how well social care is meeting the needs of those with cancer.

These steps would make a huge difference to people who lack support, but we can't expect the system to solve this problem by itself. Anyone who knows someone with cancer can help ease the burden of loneliness and isolation. Talking to someone about the condition or treatment is unlikely to increase their distress, and Macmillan offers resources to help people with cancer and their loved ones get started. For those unsure what to say, there are always practical ways to help, such as providing transport to and from hospital, or cooking someone a hot meal once a week.

Ultimately, helping address issues of loneliness among those with cancer is about having compassion for another human being. We hear a lot about a lack of compassion being behind some of the recent failures in our health and care services, but we are all capable of kindness. Realising that by 2020 almost one in two of us will get cancer during our lifetime should be another powerful personal motivation.¹¹ While there is much we can do to reduce our risk of developing cancer, as the population ages, as more of us get cancer, and more of us live longer with our cancer, we have to hope the social support we need is as good as our clinical support. No-one who gets cancer should face it alone, irrespective of who we are, where we live, or which cancer we get. Together we can ensure that no-one will.

Ciarán Devane

Chief Executive

Macmillan Cancer Support

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- 1 Macmillan Cancer Support/YouGov online survey of 1,794 people living with cancer in the UK. 437 respondents were identified as isolated (i.e. received no support from friends or family during treatment or recovery, or only received support some of the time/occasionally) and completed a follow-up interview. Fieldwork conducted 10–20 July 2012, with additional fieldwork conducted in Northern Ireland 26 November–13 December 2012. Survey results are unweighted.
 - 2 Macmillan Cancer Support. *Facing the Fight Alone*. 2013. http://www.macmillan.org.uk/Documents/AboutUs/MAC13970_Isolated_cancer_patients_media_reportFINAL.pdf
 - 3 Cancer Research UK. *Cancer incidence by age*. <http://www.cancerresearchuk.org/cancer-info/cancerstats/incidence/age/#Adults5>
 - 4 Macmillan Cancer Support. *Cured – but at what cost?* http://www.macmillan.org.uk/Documents/AboutUs/Newsroom/Consequences_of_Treatment_June2013.pdf
 - 5 Macmillan Cancer Support. June 2013 mortality trends research. http://www.macmillan.org.uk/Aboutus/News/Latest_NewsBy2020almosthalfofBritonswillgetcancerintheirlifetime%E2%80%93but38willnotdiefromthedisease.aspx
 - 6 <http://www.dignityindying.org.uk/wp-content/uploads/2013/05/Dying-Alone.pdf>
 - 7 'Marital status and survival in patients with cancer.' *Journal of Clinical Oncology*. <http://jco.ascopubs.org/content/early/2013/09/18/JCO.2013.49.6489.full.pdf+html?sid=65b850a2-3d2f-467f-8744-0bcf1021b2da>
 - 8 Macmillan Cancer Support. *Older people living with cancer*. <http://www.macmillan.org.uk/Documents/AboutUs/Research/Keystats/Olderpeoplelivingwithcancer.pdf>
 - 9 Ofcom. *Consumer Experience of 2012*, pg 45. http://stakeholders.ofcom.org.uk/binaries/research/consumer-experience/tce-12/Consumer_Experience_Research1.pdf
 - 10 National Cancer Survivorship Initiative (NCSI) *The Recovery Package*, <http://www.ncsi.org.uk/what-we-are-doing/the-recovery-package/>
 - 11 Macmillan Cancer Support. June 2013 mortality trends research. http://www.macmillan.org.uk/Aboutus/News/Latest_NewsBy2020almosthalfofBritonswillgetcancerintheirlifetime%E2%80%93but38willnotdiefromthedisease.aspx

Going back in: Loneliness and its impact for older lesbian, gay and bisexual people

4

Most of us have experienced loneliness at some point in our lives. Most of us have had periods where we've been uncomfortable with how other people might react to who we are. Most of us have been scared to be ourselves.

Lesbian, gay and bisexual teenagers know how this feels. When you're bombarded with homophobic language from the playground and the side of the football pitch, it's no surprise that growing up gay can be a lonely and isolating experience. But it's getting better. Teachers and schools are learning how to talk about being gay. They're learning how to tackle hurtful and abusive homophobic language in the classroom. On our television screens we're slowly starting to see touching and positive storylines about gay young people which focus on characters not stereotypes. We're a long way off living in a society where lesbian, gay and bisexual teenagers can grow up free from prejudice. But when viewers tune into Eastenders and see Danny Dyer playing a dad, who, on finding out his son is gay, tells him that he loves him and is proud of him, it's safe to say that we live in a country where it's that little bit easier to be young and gay than it was ten years ago.

That's why it's so important to look at what's happening for lesbian, gay and bisexual people in later life. Whilst some older people will continue to enjoy life as they age, for many, declining health and the onset of disability can mean that going out to visit people and getting ordinary household tasks done can become more difficult. In some cases this can mean becoming far more dependent on those around us, on our friends and family, or on care workers. For any older person the feeling of losing independence can be daunting and lonely. For the one million older gay people in the UK it can be the start of a journey to a place where they no longer feel comfortable being open about their sexuality.

Why does growing older affect gay people in such a disproportionate way? At least part of the answer is that they don't always have access to the same circles of support that many of us take for granted. That's something that became incredibly clear when, at Stonewall, we began researching the experiences of older lesbian, gay and bisexual people.

Between 2010 and 2011 we worked with YouGov to produce *Lesbian, gay and bisexual people in Later Life*, a piece of research that surveyed the experiences of over two thousand people over the age of 55 across England, Scotland and Wales.

We asked them about their hopes and fears for getting older, as well as a whole range of questions about their health and wellbeing.

What we found is that, compared with heterosexual people, older lesbian, gay and bisexual people are more likely to be single, more likely to live alone and less likely to see a biological family member on a regular basis. In some ways these findings are not surprising: many respondents grew up in a time when it was illegal to be gay, when teachers were forbidden to mention sexual orientation in the classroom, and when it was all too common for them to face rejection from their families just for loving who they loved. Teresa told us:

*"I would like to think that my daughter will speak to me again.
My two grandchildren (8 and 4) don't know me."*

Giles revealed that:

"I find that I sometimes view those with children a little enviously, as having a support in old age and partner-bereavement that I will not have."

Teresa and Giles are far from unusual. Less than a quarter of older gay people see a family member once a week, compared to more than half of heterosexual people. They miss out on the chance to catch up over a cup of tea, to have someone listen to their problems, and to know that someone's thinking of them throughout the week.

Time and time again the people we spoke to told us that their friends are their family. More than half of lesbians and bisexual women would turn to a friend if they were ill and needed help around the home, compared to just one in five heterosexual women. Among men, the picture looks similar, with over 40 per cent of gay and bisexual men feeling the same, compared with only 14 per cent of heterosexual men. Some might question whether these findings are significant, since everyone relies on their friends from time to time. But for people who have been rejected by their families those ties of friendship can be absolutely vital in combatting loneliness. Daniel described his friends as:

"The ones that know me better than anyone and put me first before themselves."

But many older lesbian, gay and bisexual people have to exist without those networks of support. Some, like Sandra told us:

"I didn't come out until my late 40s so didn't have a chance to build up my network of lesbian and gay friends."

Others, like Karen, worry about what will happen to their friends as they all get older:

"I have a strong number of friends around me, but as I get older they too will die and I may be left isolated."

The pain that comes with losing a friend is a horrible thing for anyone to experience, and even harder for those who don't have a supportive family to help ease the burden. Lack of personal support means that lesbian, gay and bisexual people are twice as likely as their heterosexual peers to rely on a range of external services as they get older. They have to navigate a world of GPs, carers, and housing services, while all the time fearing the ignorance and homophobia they might experience if they reveal their true sexual orientation. For many of them this means going back into the closet all over again, afraid of what might happen if they come out. James told us about his fears:

"I would, by virtue of the need to have carers in my home, be at a particularly vulnerable stage of life. The thought of being in my own home requiring help from someone who brings in with them the prejudices and judgements of the world I experience 'out there' fills me with dread."

He's not alone. Almost half of lesbian, gay and bisexual people don't feel comfortable being out to their carers, and seventy per cent feel like they could not be themselves in a care home. The expectation of discrimination by itself has a huge effect on the wellbeing of older gay people. But for too many of them experiencing prejudice is an everyday reality. Many older lesbian, gay and bisexual people feel they are invisible and are extremely fearful of how they will be treated by care staff. Those who have spent much of their lives being hounded by police and potentially medicalised simply for who they are may well feel that the rights and protections they fought hard for no longer apply.

Howard and his partner Rod have volunteered with and supported Stonewall for over ten years. In the early years of their relationship, Rod would have to pretend to be Howard's brother just so that he could sit by his bedside when he was ill. Only two years ago Howard found himself at A&E, arguing with a receptionist who insisted that he class himself as single, despite his civil partnership. He told us *"the last thing you want when you or your partner is ill, is to have a battle"*. Their experiences cast doubt over whether the people in charge of their healthcare would be able to meet older lesbian, gay and bisexual people's needs in other ways. Getting the paperwork wrong might seem like a small thing, but it points to something bigger: what if something had gone wrong? Would the staff be able to understand and respect the fact that they were civil partners? Now Howard is looking for care homes for his mother, all the time wondering what it will be like for him. He worries that none of the places he has seen would be places where he could feel comfortable and open.

Tackling loneliness for older lesbian, gay and bisexual people means creating environments for older people where everyone can feel comfortable being themselves. That's something that has to happen at every level. Carers and care homes need to be alive to the concerns of the lesbian, gay and bisexual people

who use their services. This isn't about treating people differently. It's about realising that treating people equally means understanding their specific needs. The kind of steps carers can take range from making sure that same-sex couples are allowed to hold hands and express affection just like opposite-sex couples, to remembering not to assume the sexuality of the older people they work with.

Kent County Council launched a working group of staff and service users to look more closely at the needs of lesbian, gay, and bisexual people. It developed a toolkit for adult social care staff on sexual orientation equality, and its in-house residential care homes went on to ask for further training in how to assess how gay-friendly their homes were. Staff are now encouraged to talk openly about sexual orientation, to challenge homophobic language and to display gay-affirmative imagery in windows and communal areas. The Council's training package for its homes has improved the knowledge of care staff, including supporting a number of staff to come out themselves. The training looks at the personal experiences of older gay people, the history of criminalisation and medicalisation, real life examples of older lesbian, gay, and bisexual people, and their experiences of care and tackling homophobia. The toolkit and training have influenced the way staff work with gay people and given them the confidence to ask what they think are difficult questions, but which are important to ensure a person receives individual support.

Crucially we also need to realise that there's a gap in the provision of community groups for older gay people. All too often they find themselves caught between a gay scene which focuses on younger people, and traditional community groups where they feel unwelcome and unable to be themselves. Places like Opening Doors in London are starting to change that reality. They run lunch clubs, coffee mornings, classes and support groups as well as a befriending programme which aims to reach the older gay people who can't leave their homes. By providing a safe space for older gay people to meet and spend time, they're helping them experience the kind of friendship and community feeling which every older person should be able to enjoy.

Finally we need to make older gay people visible again. Gay young people are starting to look at the world around them and see other people with whom they can identify – but we need to be able to say the same for older people. It would be wonderful to get to a point where we can see older gay characters on our screens but even something as simple as a poster in a GPs office or care home can send the message that older gay people exist, and are welcome. We need older gay people to know that it's getting better.

James Taylor

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I would be less lonely alone: The loneliness paradox

5

“He is everything. But I’m... I’m really lonely. And to be with someone, when you’re not really with him can... it’s... I think I might be less lonely alone.”

These lines from the film *Hope Springs* would certainly have struck a chord with many in the audience. Being in a poor quality relationship – characterised by high conflict, ranging from silence to violence, little positive communication and support, and lack of intimacy – is a lonely experience, and one played out in the counselling room on a daily basis. Relationships are often the subject of films and TV programmes, but what made *Hope Springs* unusual was its focus on an older couple, with adult children and grandchildren, who – when their relationship had lost many of the qualities that had made it strong – sought relationship counselling. Meaningful connections are essential to wellbeing, and lacking them will increase an individual’s propensity towards loneliness. For many, the deepest and strongest social connection is with their partner, and experiencing difficulty with this relationship can be a very isolating and lonely time in life.

The importance of relationships with partners does not diminish with age: if anything, it becomes increasingly important. But as people begin to take stock after retirement and raising a family, often spending considerable time with their partners for the first time in many years, distances between them can be exposed, impacting both the quality and stability of relationships. Getting older can also change the dynamic of other relationships, with family and with friends. Loneliness among older people has justifiably gained political and popular attention as a major social problem, described as the ‘the new poverty of the developed world’.¹ The loneliness epidemic raises questions as to the extent to which the state should intervene in tackling low quality relationships, and the scale of the problem suggests that current policy is simply not working for too many people. No one wants to be lonely in older age, but it appears that getting older and getting lonelier are increasingly entwined.

Relate’s daily experiences from the counselling room and beyond highlight the need to distinguish between social isolation and loneliness – a distinction widely recognised in academic literature, but often overlooked in policy.² Being alone may be a risk factor for loneliness, but the two are not synonymous. Meanwhile, having abundant relationships or a significant couple relationship

does not guarantee escape from loneliness. We know that marriages characterised by poor relationship quality, with increased conflict and low levels of support, lead to higher levels of loneliness.³ This risk of 'intimate loneliness' is particularly heightened at older age. Retirement is a key factor: at this time social networks change, and partners often become a more important source of support. Alongside, other friendships become more disparate and more difficult to maintain because of health, or other issues.

This problem is especially pertinent for today's baby boomers, as couples begin to spend much more time with each other after having led busy and often independent lives. As baby boomers enter older age, they are experiencing higher levels of divorce than ever.⁴ Divorce and separation are substantial risk factors for loneliness, both directly, through the loss of an intimate relationship, but also indirectly through the loss of friendship networks. Even where divorce or separation ends a bad relationship, it is likely to lead to heightened risks of loneliness unless individuals find a new partner. Relate finds that many of those who divorce or separate at a later age lack the confidence to form new relationships, and to recover from relationship breakdown. Perhaps aware of difficulties with self-confidence in finding a new partner, more baby boomers will remain in unhappy relationships. In addition, though baby boomers have been at the vanguard of many changes in family life they still, as a group, share the reluctance of older generations to access relationship support. Data suggests that just five per cent of Relate's clients accessing couple counselling are aged 60 and over, and that around 14 per cent are aged 50 and over. Despite relationships being crucial shock absorbers for dealing with transitions such as retirement, health problems and changing care needs, many baby boomers and older people may be unwilling to take action, or be unaware as to what they can do to improve these relationships.

Existing interventions rarely address forms of intimate or couple loneliness among older people, instead concentrating efforts on reducing social loneliness. A number of Relate centres offer innovative services to support relationships through the changes people experience in later life. Our work in Relate Cymru with Macmillan helps support relationships where one partner experiences changes in their health (in this case cancer). At Relate Bradford we support older people's relationships and wellbeing where one partner is a carer. Furthermore, while our services recognise the need to support older people's relationships around significant life changes, our public policy work also aims to ensure that the potential of older people's relationships to be supportive, nurturing and romantic is recognised by policy-makers and public alike. For example, recent research uncovered how only a fifth of older people were satisfied with their sex lives, but emphasised that sex remains important to older people, and that all couples should be supported in this expectation.⁵

Both central and local government must play a role in supporting the continuity and quality of relationships through all the transitions that characterise ageing. This means promoting the creation of services that help strengthen couples, families and friendships at every stage in life, including services helping people to manage conflict and to maintain and improve relationships. A more preventative and prepared approach is helpful, recognising that ageing is a gradual process, rather than an event only occurring once an individual experiences long-term health conditions or care needs. Existing relationships – including those between couples, families and other social connections – are an untapped resource, and policy and services should aim to exploit them. The strength of these relationships can determine the success of policies devised to help society adapt to an ageing population, whether in social care, housing or healthcare.

As a first step in meeting these challenges, we are advocating, with the Relationship Alliance, that Directors of Public Health should be required to measure the quality of couple, family and social relationships to inform the planning and commissioning of services, including those aimed at reducing levels of loneliness.⁶ We believe this will provide a clearer and more nuanced understanding of the overall relationship health of an area, recognising the importance and potential of intergenerational relationships in lowering levels of isolation among older people.

In the past, Richard Layard has eloquently outlined the case for placing mental health and wellbeing on a par with physical health and with economic factors. The happiness paradox he describes – in which, despite rises in incomes and living standards, levels of happiness remain unchanged – shows the risk of neglecting *“the problems that come from inside ourselves”* in forming social policy.

Similarly, I would argue that we are witnessing the ‘loneliness paradox’, in which – despite greater densities of social networks and ways of maintaining these relationships – we continue to see unacceptably high numbers of people experiencing loneliness. This paradox highlights the need for policy-makers to explicitly consider the impacts of relationships in forming their social policy. Specifically, if policy-makers were to apply a relationship test across all areas of policy – from crime to welfare – not only would we see much improved policy outcomes across these domains, but through improved relationship quality we would also likely see substantially lower levels of loneliness across all ages. For example, scrapping the free bus pass for older people is often a source of political speculation⁷ and a relationships test might consider the extent to which removing the bus pass might adversely impact upon older people’s couple, family and social relationships. The test would ideally consider the potential cost implications of weaker relationships on other areas of government spending, and consider particular social groups whose relationships might be

disproportionately impacted. Another example might involve housing policy, and the extent to which new programmes of development of older people's housing in local areas may strengthen relationships, particularly intergenerational relationships.

Getting older doesn't have to mean getting lonelier, but much of this rests on laying the foundations to good quality relationships earlier on in life. Not only should organisations seeking to reduce loneliness pay attention to the couple relationship in people's lives, but policy-makers must embrace new forms of relational policy-making if they are to reduce loneliness across the life course. This includes having effective ageing strategies that are accountable on the ministerial level, that truly encompass the density and quality of relationships, and that are based on sound locally available data on these relationships. Otherwise, generations will continue to feel, often mistakenly, that they "might be less lonely alone."

Ruth Sutherland

Chief Executive

Relate

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- 1 See Charles Handy's essay at <http://www.relate.org.uk/userfiles/documents/Publication-ageing-essays-2013.pdf>
 - 2 <http://www.relate.org.uk/userfiles/documents/Publication-ageing-essays-2013.pdf>
 - 3 de Jong Gierveld, J., van Groenou, M. B., Hoogendoorn, A. W., & Smit, J. H. (2009). 'Quality of marriages in later life and emotional and social loneliness.' *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 64(4), 497-506.
 - 4 <http://www.ons.gov.uk/ons/rel/family-demography/older-people-divorcing/2011/sty-divorce.html>
 - 5 <http://www.relate.org.uk/about-us/media-centre/press-releases/2014/2/06/sweetest-taboo-almost-half-older-people-talk-no-one-about-sex>
 - 6 <http://www.dailymail.co.uk/news/article-2261935/Loneliness-map-help-isolated-elderly-amid-concerns-effects-nations-health.html>
 - 7 <http://www.mirror.co.uk/news/uk-news/iain-duncan-smith-targets-poor-3109721>

Moving to a care home involves a huge emotional upheaval. It is perhaps the biggest transition that any of us will face in our lives. Imagine that one day you are relatively independent, getting on with your usual day-to-day activities, when suddenly you slip on the carpet at home, or stumble on a loose pavement in the street. The next thing you know you are admitted to hospital with a hip fracture only to be told that there are complications and that you have a couple of weeks to find a care home.

Suddenly everything feels like it has been taken away from you. You have lost your health, your independence, your home and your identity. All you know about care homes is what you've read in the tabloids and seen on the television. You feel like you've lost everything. You experience trauma, helplessness and a profound sense of being alone in the world.

Of course, this is only one pathway into a care home. For others, the transition to a care home is much slower. You gradually lose the ability to function in the way you used to, with *"little bits of you falling off"*. You begin to lose your sight, hearing, mobility, and perhaps your mind. This slow deterioration in physical and mental health may create a sense of disconnection between *"who you think you are as a person"* (your identity) and *"who you have become"*. You may start to withdraw and to experience loneliness, depression and significant social isolation. At the stage when domiciliary care can no longer guarantee your safety at home, you may decide to move into a care home.

Loneliness often does not begin at the point of admission to a care home; for many, it begins much earlier. In my work with My Home Life, I was privileged to spend time with the late great Margaret Simey in her final year of life. Her wisdom on what it is to be old will always stay in my heart and mind. She described to me the constant battle to retain a real sense of who she was, when *"the onward creep of decrepitude"* she experienced was taking over and taking on its own identity. She described the *"appalling sense of isolation"* that it brings and the *"crushing boredom of the life"* that she now led. Her loneliness and isolation was related more directly to the loss of her own 'sense of self' than to anything else. It is important, therefore, for all of us to recognise that the losses that we experience in older age are potential triggers for loneliness and need to be responded to as early as possible. Given these significant losses, the lack of referrals to counselling for those in later life is shocking.

Many older people will arrive in a care home at a point of crisis and trauma. This can manifest itself in a feeling of 'aloneness'. Care home staff will try their best to support people through this transition, but one has to ask whether it is fair and realistic, given the typically poor funding and lack of staffing in care homes, for them to take on a 'counselling role' in helping our oldest and frailest citizens come to terms with what has happened to them. When I worked in a care home, there was a stock phrase that was used in reporting to family or the social worker on how a new resident was getting on. We would typically describe how "*Mrs Smith has settled in nicely*" and this tended to mean that Mrs Smith was quietly and passively fitting into our routine. This message seemed to be welcomed by social workers who were keen to 'close the case'. Yet, it is clear and obvious that 'settling in well' is not a natural response for anyone who is admitted to a care home in a period of crisis. Surely, we should assume that Mrs Smith should be feeling a profound sense of despair, anger, fear, grief and shock in response to the significant losses that she had experienced, or conversely a sense of relief that finally she had escaped the horror of feeling isolated in her own home. Either way, if she is not expressing any emotional response this might suggest that, rather than settling in well, Mrs Smith is withdrawing into herself and may be unable to process what has happened to her. Care professionals may feel too busy or too stressed to engage with the real emotional impact of loss in later life that people experience.

Where care homes work well, care staff provide extraordinary support in helping new residents to have the time and space to make sense of what has happened to them. To talk about how things were at home, to cry, to be angry, to process the traumatic journey and, finally, to look forward to a new beginning in the care home, potentially a very positive one. But again, I question whether this is a realistic ask of the majority of care home staff. To provide that level of therapeutic support requires time, skill and real support. To do this, care homes should be surrounded by social workers, counsellors, volunteers and geriatricians making themselves available at this critical time to help support older people through this huge transition. Sadly the opposite is more often true: an older person's move to a care home typically results in social work cases being closed, rather than held open to start the really difficult work of helping the older person to recover. How disturbing that at our greatest time of need, we can be forgotten in care homes, the islands of the old, where staff, residents, and families have to fend for themselves, often in isolation from wider support.

As noted earlier, the sense of loneliness that manifests itself in care homes often begins when older people are still living in their own homes. I regularly hear horrifying stories of how older people with very high needs will rarely see anyone other than homecare workers who are too busy to have a conversation.

In contrast, we have heard many stories of how older people begin to thrive in care homes having previously become very withdrawn and isolated in their own homes. But often people are prevented from coming into a care home at a time of their choosing. We hear stories of older people who have agreed with their family that moving into a care home would be the best option, only to find that the local authority disagrees and cannot fund a placement. These decisions, which are ultimately about budgets, can have such a damaging impact on older people's wellbeing. The minute-by-minute support and friendship that we all crave is too often seen as low priority for budget-holders.

Of course, even without a properly planned admission to a care home, the experience can be a positive one. However, this largely depends upon the leadership of the care home manager and whether they can instil a culture of emotional connection between staff, residents and relatives where everyone feels 'seen', 'heard' and 'involved'. These relationships are not easy to foster. It requires a strong manager who provides a nurturing role in supporting staff to both reflect upon the meaning of their work and to take responsibility for the relationships they have with residents and families. This is a tough ask of managers who spend much of their time reacting to the day-to-day crises in the home, responding to external demands, and fending off the negative attitudes and behaviours of the outside world who are sometimes too quick to apportion blame. But, even where care homes are making a huge difference to the lives of older people, staff cannot be expected to fulfil every aspect of an older person's needs and aspirations. In the same way that we all typically rely on a variety of sources to support our sense of identity, purpose, and belonging, older people in care homes need to be able to connect with the wider community, to re-establish connections with the people and places that they know, and to forge new relationships with the outside world.

In Essex, the council has invested in My Home Life to help support better connections between the community and local care homes and there are signs of some very positive results. That said, it hasn't been easy to bridge the divisions between care homes and the communities in which they reside. Firstly, care homes often struggle to find time to bring in and support volunteers or community organisations. Secondly, the public are often unprepared for what they might experience when visiting a care home. We should not forget that care homes are not easy places to visit if you don't understand the nature of the work done there and the frailties of the individuals living and dying in them. All community organisations need to recognise that older people living in care homes should be a priority group for their outreach work. We should work hard to reduce the paperwork required of care home practitioners who are bringing in volunteers, schools, and colleges, or who are supporting residents to go out. We should offer better access to community transport. We should allow older

people who have made friendships in local groups and daycentres to continue to attend these places once they move to a home.

Most importantly, as a society we have to decide what we want our care homes to be like, and that means working positively with them, rather than turning our back on these places. There are already more care home ‘beds’ than hospital beds across the UK and it is likely that the number of care home places will double over the next 30 years. There are places that will touch all of our lives. With support, these are places which can offer value to us. There is potential for them to become positive places that we cherish for ourselves, for the support they offer us as we become older and frailer. We only have to look at how hospices are viewed in society to see where we are going wrong: they are valued, their role is recognised. Each hospice has over a hundred volunteers; care homes have very few, if any.

In imagining a positive future, we need to learn about what currently works well in care homes. At My Home Life we are aware that there are many care homes that are leading the field in nurturing, engaging environments which support older people to feel part of things again; in working to bridge the gap between themselves and the wider community; in advocating for the right health services for residents; and in reducing the impact of the losses that older people experience. We have the evidence that it is possible, we just need the motivation to support it to happen more often.

Tragically, despite all the public outcries over quality, our discomfort with what care homes represent to us (places where people are put to die), mean that it has become unbearable for us to “turn towards” care homes and convey value and appreciation for what they do. If care home staff do not feel valued, supported and appreciated, it is so much harder for them to provide support, value and appreciation to older people in their care. Perhaps we need to resort to shock-tactics to remind ourselves that our lives are much shorter than we dare to think and soon it will be us whose bodies and minds will deteriorate. At that moment love and attention from kind and caring staff will be our biggest priority. If we don’t care for care homes now, we cannot expect any different for ourselves in the future.

Tom Owen

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My Home Life

Race is no protection against loneliness

7

One of the most common myths surrounding the issue of loneliness is the idea that some groups – and particularly black and minority ethnic (BME) older people – enjoy greater protection against loneliness, when compared to the white British groups. At Runnymede we are aware that ethnic minority households are commonly perceived to have more ‘traditional’ family structures, with young relatives looking after, or even living with, their older relatives, and it is often assumed that this will mean they are less lonely. While there is an element of truth in this narrative, there are a number of reasons to doubt the notion that older ethnic minorities are always less vulnerable to loneliness overall.

Examining the demographic trends amongst older BME groups reveals a complex picture. Research suggests a real problem of ‘hidden loneliness’ among BME older people. For example, even when BME groups have large social networks and household sizes, they are less likely to say they take part in social activities they enjoy (44% compared to 79% in the general population).¹ In other words, having regular or frequent interactions with others doesn’t necessarily mean that people aren’t experiencing loneliness.

There is a widely-held belief that older BME people are more likely to live in multigenerational households than their white British counterparts, with children, parents and grandparents all living in the same home. This is certainly true for South Asian groups, and especially Pakistani and Bangladeshi households, among whom nearly 1 in 10 households are multi-generational, compared with only 1 in 100 among white groups. However, among black groups and Chinese people, the rate of multi-generational households is much lower (between one and two per hundred).²

It is essential to understand the detailed makeup of households and families if we are to understand the potential for loneliness. A key feature of the current UK BME population aged over 65 is that the vast majority were born overseas. People who turned 65 in 2013 were born in 1948, the year of the first major post-war migration to Britain from the Caribbean. For these older people, it is likely that the experiences of ageing – and of loneliness – will be affected by their migration history. They will not necessarily share this history with other members of their household and family, who are much more likely to have been born and raised in the UK.

Overall, black and minority ethnic groups tend to be younger than the white British population. Whereas nearly one in five white British people are over 65, less than 5% of Bangladeshi, Pakistani, mixed race, black African, black other and Arab people are. The black Caribbean population has the greatest proportion of older people, with 14% over the age of 65, followed by the Indian population at 8%. As a result, though there may be more younger people in the community to help and support older BME people, there may also be less potential for meaningful peer relationships between those who are much older.

A final relevant demographic feature is that older BME people are much more likely to live in poverty. As with ethnic minorities generally, this is explained both by their lower wages and their higher likelihood of unemployment, meaning they are less able to save for retirement. As a consequence, while less than 18% of white pensioners live in poverty, nearly half of Pakistani and Bangladeshi pensioners are poor, with around 30% of Indian, Black Caribbean and Chinese pensioners living in poverty.³ And we know that there is a high level of correlation between loneliness and poverty.

When we examine the research evidence on loneliness, the surprising truth is that some older ethnic minority groups experience much higher levels of loneliness than their white British counterparts: with 24% to 50% of those born in China, Africa, the Caribbean, Pakistan and Bangladesh reporting that they are lonely. Those born in India reported much lower rates with around 8–10% of older people feeling lonely – a similar level as for white British older people.⁴

Importantly, loneliness is not simply a question of lacking physical or day-to-day interaction with other family members. Loneliness is a subjective experience, and therefore the quality of the interactions, and their value to the individual, is also important. There are several reasons why the nature or quality of older BME people's social interactions may not always fulfil their needs.

Perhaps most obviously, the high proportion of older BME people born overseas may lead to their feeling disconnected from British-born relatives, and from the wider community, especially as they grow older. While it is important not to exaggerate cultural differences, even people who felt wholly satisfied and settled in Britain during their working lives may begin to feel differently as advancing age leads them to reflect on memories, their legacy, and even funerary arrangements. For those who have come to Britain more recently, 'growing old far from home' may lead them to feel that their children or grandchildren do not fully understand their experiences, especially as older BME people accept that they will not move back to their country of birth. However, evidence does suggest that adult children of immigrants (mainly born in the UK) aged 45-64 report much lower levels of loneliness than those aged over 65.⁵

Language issues can be particularly important here. Not only are older BME people more likely to have poor English, there is significant research showing that those experiencing dementia often lose whatever second-language ability they had. Where children and grandchildren do not speak a parent or grandparent's mother tongue, experiences of loneliness are likely to be considerably heightened. This may partly explain why 36% of respondents to a survey of ethnic minority communities in Britain said they would like more companionship or contact with other people, compared to 20% of the general population surveyed by ONS.⁶ We also know of many cases where children of migrants have some facility in their parent's language, but not enough to understand their parents as their dementia progresses. Losing the full emotional breadth of a relationship with a parent will always be hard for a child, but for those who cannot even understand their parent's basic needs this distancing can be particularly painful.

Higher rates of both poverty and disadvantage may also lead to older BME people feeling more anxious about their own prospects, and those of their children and grandchildren, who are also much less likely to inherit any wealth. We have interviewed a number of older people from ethnic minority groups whose primary aim in moving to Britain – improving the lives of their children and grandchildren, has not been realised – and this can cause further distress and loneliness, especially if they, understandably, do not want to raise these concerns with other family members.

These particular cultural issues suggest that, whilst population wide loneliness services may play some role in supporting BME older people as they age, there is likely to be a need for specific support that is more effectively tailored to the full range of the challenges they face.

If councils and central government are serious about tackling loneliness – and the poor health outcomes that often result – they must act more effectively to respond to genuine needs among older BME people. One area that needs strengthening is language service provision, including translation services and better support for ESOL programmes.⁷ Another key area is care provision, where services are not always suitably developed to meet the needs of older ethnic minorities – in terms of language needs, but also wider cultural needs and preferences. Since BME organisations may not always have the resources to develop their services in a way that local authorities or social care services expect, options such as 'brokering' or facilitating larger existing service providers in sub-contracting and supporting BME services can provide more personalised care. There is real demand for culturally competent services and services in other languages, but not adequate supply. An increased supply might well lead to less reliance on family-based care, which may not always be the cultural preference, but can ultimately help to ensure provision that is better able to meet the individual's needs.

Support for activities bringing people together, such as lunch clubs or exercise groups designed to appeal to older people is vital. Programmes tailored to people from particular ethnic backgrounds and events supporting mixed interactions are both likely to be beneficial. Services that cater for the general population also need to ensure that they are sensitive to the needs of older BME people. For example, reminiscence activities should take into account that some older BME people may have negative memories of their first years in Britain, when they may well have encountered overt racism. Those born outside the UK may have a wealth of different cultural memories to explore. With high rates of poverty among BME groups, it is also essential that services helping people connect with each other remain affordable.

In the next generation, the profile of risk factors for loneliness – such as language issues and, potentially, overseas birth – will change. However, so too will the presence of potential ‘protective’ factors, such as the prevalence of multigenerational homes and the size of ethnic minority households. Indeed, multigenerational households may largely come to an end, as those people born in the UK will have grown up familiar with the notion of a welfare state that can provide protection in older age, rather than seeing this as a purely family concern. There will, therefore, be an ongoing need to listen to BME older people, to understand the issues they are facing and to provide tailored solutions where these are required.

We must not, of course, imply that all older BME people experience loneliness. However, careful consideration of their experiences and needs will help us to better understand why loneliness cannot be accounted for simply by totting up the number of social interactions, and why it can be hard to identify – even for those who experience it.

Omar Khan

Acting Director

Runnymede

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- 1 Mental Health Foundation, *Lonely Society Report*, 2010.
 - 2 Cacioppo, J. T. and Hawkley, L. C. (August 2007) ‘Aging and Loneliness: Downhill Quickly?’ *Current Directions in Psychological Science*
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 - 6 Bowling A. 2012. conference presentation: <http://www.campaigntoendloneliness.org.uk/loneliness-conference/>
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The most terrible poverty: Loneliness and mental health

8

“The most terrible poverty is loneliness” Mother Teresa

We often hear that smoking, obesity, alcohol and lack of exercise are bad for our health. However, there is a less obvious health harming condition – loneliness. The evidence shows it can significantly reduce our chances of living to a healthy old age and that it can be very damaging to our mental health and wellbeing.

Loneliness and solitude should not be confused. Loneliness is not about being alone, but a subjective experience of feeling isolation. Some people may seek solitude but few, if any, would choose to feel lonely. Although many of us experience loneliness at one time or another, it is often overlooked or dismissed, because our social norms praise independence and self-reliance. It is hard to own up to feeling lonely and a third of us say we would not admit to this.¹ But when loneliness sets in long enough to create a persistent, self-reinforcing loop of negative thoughts and sensations, it can wear us down and become difficult to treat. People who are chronically lonely can get stuck in a loop of negative behaviour, and might push others away or seek transient contacts.

Being lonely can have serious consequences on our mental, emotional and physical health.² Our happiness is derived from our strong and loving relationships, as research from the Nobel prize-winning psychologist Professor Daniel Kahneman shows. Those of us who lack these strong relationships are more likely to have poor physical and mental health outcomes, including increased propensity to depression, sleep deprivation, problems with the cardiovascular and immune systems, early morbidity and even dementia.

The Mental Health Foundation’s report, *The Lonely Society*, raised awareness of loneliness as a causal factor in poor mental health. More people live alone nowadays with the percentage of households occupied by one person doubling between 1972 and 2008. People are living longer but many older people are doing so alone. Work pressures have also had an impact: people feel pressure to be ‘productive’ and busy, and as a consequence neglect vital relationships with friends and family despite surveys revealing that we would like to spend more time with them.

The Lonely Society reveals that 42% of people have felt depressed because they were lonely. Lonely middle-aged adults drink more alcohol, have unhealthier diets

and take less exercise than the socially contented. Lonely individuals are more prone to depression and more prone to cognitive decline and dementia. Loneliness alters our behaviour, increasing the chances of indulging in risky habits such as drug-taking, and can play a role in mental disorders such as anxiety and paranoia. It is a known factor in suicide. The Marmot Review into health inequalities found that individuals who are socially isolated are up to five times more likely to die prematurely than those with strong social ties.

Loneliness as a causal factor in mental distress is well known to doctors, with its potential to increase stress levels, anxiety and depression. However it is also an effect of mental distress. We know that the stigma associated with mental health problems can increase social isolation, which in turn will have an exacerbating impact on the individual's condition. You may feel awkward in company, worrying that others will judge you for your mental health problem, and so you withdraw to avoid this. Social withdrawal can be emotionally very costly, as the individual pulls away from society and society pulls away from them; even family members may start to avoid them, resulting in a profound impact on their sense of belonging and well being.

It is unsurprising, therefore, that some surveys report that two-thirds of people affected by a mental health problem feel lonely often or all of the time. People with severe mental health problems are amongst the most isolated social group of all. They are often judged for their condition and fear rejection from others. Often people will choose just to avoid any contact, or they may make a great effort to conceal their condition from others, which results in additional stress from worrying about being found out. In particular, deliberate isolation is a classic sign of bullying, leaving someone to feel lonely and cut off even in the bustle of the workplace. This is an area where employers need to train managers to recognise and to have the skills to intervene, or they will find sickness absences increasing.

So loneliness is both a cause and an effect of mental distress. When the person isolates more, they face more mental distress. With more mental distress, they choose to isolate themselves. This vicious cycle relegates many people with severe mental illness to a life of social segregation and loneliness.

“Once I was told people don’t want to be around me as I depress them, so I became somewhat of a recluse.” Comment from Mind’s booklet about *How to cope with loneliness*³

National surveys of mental ill health in British adults show that levels of social participation are the most significant difference between people with good or poor mental health. The former Minister of State for Care Services, Paul Burstow, described loneliness as *“the great unspoken public health issue.”*

For older people, loneliness and isolation are significant risk factors for poor mental health. Newspaper headlines proclaimed *“loneliness twice as unhealthy as obesity for older people”*. The University of Chicago’s study of 2,000 people over the age of 50, led by John Cacioppo, found those who reported being lonely were 14% more likely to have an early death. Perhaps it is not surprising that, post retirement, people can be lonely and risk mental health problems. After all they have lost the company and status that comes through work; their children may have moved far away; their income and ability to travel or socialise may be reduced; and they may have lost some of the people they have loved and felt closest to. However, we would not argue that loneliness should be seen as a mental health issue, or medicalised into a mental illness. In fact, we’d argue the opposite. Tackling the crisis of loneliness starts with individuals, in communities and in wider society.

In communities, the role of civil society comes into its own in helping to reduce isolation. Faith communities look out for, and reach out, to people who are isolated. Countless voluntary organisations from Age UK to Mind offer approaches that reduce social isolation – these may take the form of walking groups, gardening groups, art groups and so on, but they all fulfil the basic need to spend quality time with our fellow humans. And in wider society, there are factors that can reduce isolation and increase contact. Local government approaches to planning can help focus on designing housing and communities which enhance social interactions and community wellbeing. Effective GP practices take steps to link their patients to voluntary organisations to engage, involve and support them.

There is a growing recognition that individually we can and should look after our emotional and mental health just as we look after our physical health. Techniques such as Mindfulness are gathering significant interest and the evaluations of their impact are encouraging. The Mental Health Foundation is involved in research programmes to provide more evidence and has established an online course bemindfulonline.com. Even the simple act of having a conversation can make a big difference. People often contact the Mind Infoline and talk about how difficult it can be to initiate conversations when they are feeling very anxious or isolated. Encouragement to start small and simple can make a huge difference.

“The way I deal with loneliness is to go out and spend time outside, maybe have a small conversation with a cashier when I pay for things.”

Comment from Mind’s booklet about *How to cope with loneliness*³

The digital revolution seems to be increasing isolation, as people walk along deep in phone conversations, or reading their screens in the middle of social outings. In contrast, Mind’s Elefriends online peer support community – www.elefriends.org.uk – is a simple idea of a safe space where people can find peer support for

their mental health. With virtually no promotion, it already has 10,000 members, with an average of 15,000 very honest and open posts a month.

“To me, Elefriends means that I am not alone. It is instant access to help and advice from people who have been there and understand what you are saying. It is a safe place to say all the bad or stupid stuff that you can’t say to anyone else and know that no one will judge you. It is a lifeline.”

“It’s nice to feel I’m not alone; often I feel quite alienated because no one I know really suffers from a mental health problem, but when I come on here it reminds me I’m not a freak or weird, I just have an illness. It’s easy to forget when you’re trying to live our daily lives” Quotes from Elefriends’ members

The ability to physically see friends and family via Skype and Facetime can also make a difference in keeping us feeling connected to those we care about, particularly those who are physically isolated. There are also new communities of interest that can link people through a common interest or reconnect them to old friends.

Some people may find that they are unable to get the social contact that they need, or that they experience feelings of constant loneliness that they can’t resolve by themselves. In these cases, a talking treatment, such as counselling or psychotherapy, can help. Talking to a counsellor or therapist allows people to explore and understand feelings of loneliness and can help develop positive ways of dealing with them.

“After living a life full of loneliness, I thought nothing could change. But after I started therapy I realised things can actually get better.”
Comment from Mind’s booklet about *How to cope with loneliness*³

If anxiety about social situations has made people isolated, cognitive behaviour therapy (CBT) may help. CBT focuses on how you think about the things going on in your life – your thoughts, images, beliefs and attitudes – and how this impacts on the way you behave and deal with emotional problems. It then looks at how you can change any negative patterns of thinking or behaviour that may be causing you difficulties. It has been found to be particularly effective for anxiety-based conditions, including agoraphobia and social phobia. The Improving Access to Talking Therapies programme or IAPT, has helped to make some of these treatments more easily available, but there is still a long way to go.

So what needs to change? We urgently need to raise awareness and have a public debate that tackles attitudes that can create the stigma of loneliness and the stigma of mental health. Too many people simply don’t understand the challenges. Some don’t want to try. We need to build a stronger understanding of the impact of loneliness on mental and physical health amongst the medical and social

service professions, so that their assessments take loneliness into account and direct people to the appropriate local services and opportunities. At present, for example, NICE pathway guidance for primary care to strengthen the mental well-being of older people focuses on exercise and physical activity, missing the importance of social connections.

We need much greater access to counselling and talking therapies that help lonely people overcome the negative thinking that leads them to become increasingly sensitive to, and on the lookout for, rejection and hostility. We also need to see a greater emphasis on commissioning local and neighbourhood schemes that engage proactively with people at risk of isolation. With increased funding, this is a role the voluntary sector would be ideally placed to deliver.

The good news is that it is in our hands to do something about this. Our core strong relationships support us, encourage us and give meaning to our lives. Our broader social relationships help us feel connected, at home in our communities and networks, and give us a sense of social worth. We need both. If we lose touch through moving home, changing job, separation, illness, or bereavement, we need to invest time in reaching out and building new relationships. Giving ourselves time to keep our close social relationships thriving and fulfilling is not just one of the key ways to look after ourselves, it is one of life's greatest pleasures.

Paul Farmer
Chief Executive
Mind

Jenny Edwards
Chief Executive
Mental Health Foundation

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- 1 Mental Health Foundation, *The Lonely Society* Report, 2010.
 - 2 Cacioppo, J. T. and Hawkley, L. C. (August 2007) 'Aging and Loneliness: Downhill Quickly?' *Current Directions in Psychological Science*
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When friends drop away: The loneliness of living with dementia

9

“Before my husband, Andrew, developed dementia we used to refer to our home as ‘the railway station’ because there were always people popping in and out. When Andrew’s dementia progressed and his behaviour became increasingly unpredictable, friends and neighbours stopped coming around because they felt uncomfortable. People would look at me with pity. I was left alone grieving for the husband I’d lost while he still shared the same house as me. Grief like that isn’t socially sanctioned. Sometimes I felt so alone I’d just walk in to another room and scream because I couldn’t stand it anymore.” Ann cares for her husband Andrew who has vascular dementia

800,000 people in the UK are currently living their lives facing a condition that slowly robs them of their ability to remember, speak and connect with their loved ones. By its very nature, dementia can compound feelings of social isolation and loneliness, as the world becomes increasingly fractured, and memories of recent social contact are quickly lost. For people like Ann, caring for a person with dementia can result in a different kind of loneliness as the dynamics of a family fundamentally shift and relationships change. It is an all too familiar story that people with dementia and their carers feel isolated and cut off from their local community. But with an ageing population, where one in three people over the age of 65 will develop dementia in their lifetime, it will take a whole society response to eradicate the spectre of loneliness before it becomes endemic.

Last year, we, at the Alzheimer’s Society, published a report *Dementia 2013: The hidden voice of loneliness* which found that people with dementia are more at risk of loneliness than the general population. Unsurprisingly, this risk increases if the person with dementia lives alone. As many as two-thirds of people with dementia live in the community, with a significant and increasing number of them living on their own. The report laid bare a systemic problem, with 62 per cent of those living alone with dementia saying they felt lonely and a third of all respondents (35 per cent) reporting to have lost friends after receiving a diagnosis. We found a variety of factors contributing to loneliness, including a reluctance to leave the house due to the fear of getting lost or confused in public, loss of confidence, and the stigma surrounding the condition which can leave people feeling they have been ‘written off’ by society.

For Viv and her husband Bill, close friends became former friends as Bill's behaviour began to change as a consequence of Alzheimer's disease, leaving them feeling incredibly isolated:

"It first started when my family and I noticed that Bill wasn't always making sense in conversations. He would say odd or inappropriate things. Friends started to drop away then. He was diagnosed with Alzheimer's a year later at the age of 68. Our best friends – people we had known for 25 years and had been on holiday with – haven't been to our house since. They don't even pick up the phone. It's been heart-breaking for the both of us. Thank goodness we have family that live nearby – but it's hard, you can't always talk to your children in the same way you would a friend."

Viv's story is sadly indicative of the all too common public response to this illness, where stigma robs individuals of the everyday social interaction many of us take for granted. A YouGov poll commissioned by Alzheimer's Society found that a large proportion of the general public are not sure that they could have a conversation with a person with dementia. Nearly a fifth of respondents (19 per cent) said they do not know if they would feel comfortable talking to a person with dementia, while a further 16 per cent said they would not feel comfortable. It can be extremely frightening for a person with dementia to find their mental abilities begin to decline. To have friends pull away around this time is an additional loss that no one should have to bear. Our services and support groups help put people with dementia and their carers in touch with others in a similar situation, and we hear many stories about the lasting friendships that are formed. However, it shouldn't be the case that having dementia restricts your friendship base to only those who have the condition or have a close experience of it.

Something that really struck me about *Dementia 2013: The hidden voice of loneliness* was that it was based upon a survey of people with dementia and their carers who use Alzheimer's Society services – so those who tend to have fairly frequent face-to-face contact with dementia advisors and support groups. The stark reality is that these are likely to be a better supported and informed group, rather than a truly representative sample. In the shadows are those whose stories would probably reveal an even bleaker picture of loneliness and social isolation. It is also important to recognise that people with dementia who live in residential homes are also vulnerable to becoming isolated – and eighty per cent of people living in care homes have either dementia or severe memory problems.

What can be done to improve the lives of people living with dementia who feel lonely and are socially isolated? Sadly, the truth at the moment is that our social care system is inadequate and doesn't counter loneliness. This was brought in to sharp focus in October 2013 when a report by the charity Leonard Cheshire found that two-thirds of local councils commission 15 minute visits for people who require

care at home. If this is one of the only forms of face-to-face interaction a person has to look forward to, it is wholly insufficient. Coming in to someone's home and helping them to wash and dress is a personal service and should be accompanied by conversation – otherwise it renders the person receiving home care feeling like a tiresome product on a conveyer belt. There is no doubt that for care workers such an inflexible schedule is also distressing as, forced to rush, they only have time to exchange the odd pleasantry with a person desperately craving human interaction.

Even if we had adequately resourced social care, people affected by dementia still need to see a change in society as a whole. This change comes in the form of Dementia Friendly Communities – cities, towns, villages or streets that do as much as possible to support people with dementia, reduce stigma and tackle isolation. Developed by Alzheimer's Society, the rationale for this idea comes from the voices and experiences of people living with and affected by the condition. If people with dementia felt welcomed and empowered to get involved with activities and continue to participate in daily life instead of languishing at home, the difference to them would be extraordinarily positive.

Becoming a dementia-friendly community doesn't always mean a big investment. It can start with a network or action group of interested parties that are personally committed to making a difference for people affected by dementia. The next step is to encourage a broader awareness of dementia in the local area from key local businesses, services and ordinary people. One way is through a Dementia Friends awareness initiative. This involves changing attitudes and behaviour towards a condition that is frightening and difficult to comprehend. It encourages tolerance and thoughtfulness as Dementia Friends try to see the world through someone else's eyes. By addressing the basis of stigma, we hope that education and information can become more effective in targeting the causes of negative reactions to dementia and people with dementia. Dementia Friends is this country's biggest ever project to change the way people think about dementia. We aim to have a million people with a changed attitude and an improved understanding of what it feels like to live with the condition, so that we can begin to breakdown the stigma of the dementia which so often leads to exclusion and loneliness. This can be a vital first step in helping prevent friends from pulling away from someone experiencing dementia.

As we have previously heard, carers can often also suffer feelings of loneliness and isolation which can lead to despair. For Ann, building a Dementia Friendly Community was a salvation from the loneliness she felt as a carer:

“When I finally mustered up the courage to speak out and talk openly about Andrew's dementia things got so much better. We've formed a dementia friendly community which is all about social inclusion. People no longer see dementia before they see the person living with it.

“It’s given Andrew a renewed sense of purpose as he volunteers at the local school and takes part in regular activities including singing and indoor bowls. Communities have become the families of old – I’m surrounded by a group of people I can reach out to and no longer settle for a life that is just about bearable.”

A Dementia Friendly Community can also make a profound difference to those like Philip who are living alone with dementia

“Since my diagnosis of Alzheimer’s, I don’t like going out on my own often. An incident with a rude bus driver left me shaken, confused and upset. He threatened me and drove off without letting me get off the bus. It’s set me back and I have been worried about going out ever since.

“Although I have great support from my partner and carer who visits me each week and calls me every night, I don’t have many others to talk to. Without Mary, and the Alzheimer’s Society’s support group, I don’t know what I would do. My life would be over.”

Ensuring that a community has accessible, safe and reliable forms of transport is critical to building community participation and ensuring that people aren’t left isolated. Often it is just about communities assessing the way they deliver services and changing the way they respond. For example, in Salford the taxi firm Mainline Sevens has trained their 500 drivers to spot the signs of dementia and how to help. They have also set up accounts for regular customers with the condition so they don’t have to worry about having the right money on them for their fare.

Last year the Prime Minister challenged Alzheimer’s Society to have twenty communities becoming dementia friendly by 2015, and we have already surpassed that target. From Debenham in Suffolk, where the community has established a confidential telephone support line for carers finding it hard to cope, to a pie shop in Yorkshire with a designated sales space for people with dementia, there are some wonderful examples of Dementia Friendly Communities in action. The Alzheimer’s Society offers support and guidance on how to become officially recognised as Dementia Friendly with a variety of practical ideas and inspiring stories of communities that have already started to transform themselves.

Alongside towns and cities, businesses are also keen to engage. Following the G8 summit on dementia research in December 2013, leaders from the High Street including Marks & Spencer, Argos, and Lloyds Bank have pledged their commitment to becoming dementia friendly. It is extremely encouraging to see major employers working to make a difference for people with dementia. Given that 670,000 people in the UK are carers for someone with dementia and need to juggle their working responsibilities with caring for a loved one at home,

businesses must continue to recognise how dementia affects their workforce. Also for those with early onset dementia who may still be working, being able to speak out about their dementia without fear of discrimination from managers or colleagues is vital. Maintaining a routine by going to work for as long as they feel able is an important way for people with dementia to contribute to society and have regular opportunities for social interaction.

Everyone needs human contact for comfort and security, and to feel involved and active in everyday life. For people with dementia, having a helping hand can be all they need to catch a bus they've felt too scared to use on their own, or to enable them to leave the house to go to the shop. Together, Dementia Friendly Communities and the Dementia Friends initiative strive to ensure that people with dementia and their carers are offered the support to live a fulfilling life, rather than merely existing. With cases of dementia in Western Europe set to double by 2050, bringing about change in the lives of people with the condition is not something we can just leave to governments. All of us have a part to play. Each of us can become a Dementia Friend and help make our communities more dementia friendly. We can, and must, work to alleviate the burden of loneliness among people with dementia.

Jeremy Hughes

Chief Executive

Alzheimer's Society

Without sight and sound: Loneliness among older deafblind people

10

Loneliness can affect those who develop hearing and vision problems as they age, but it can also affect those who are already deafblind, as they are often marginalised from the wider disabled community and society. Research we commissioned at Sense from The Centre for Disability Research found that approximately 250,000 deafblind people are aged over 70. Many have significant combined visual impairment and hearing loss, and by 2030 this number is expected to increase to 418,000. The potential for deafblind people to be isolated and lonely is likely to increase as they get older, and this is a concern not just for these individuals, but also their families and wider society.

Failure to address the issue of loneliness for deafblind people now will only exacerbate the problem, leaving many more people with dual sensory loss feeling isolated and alone. Dual sensory loss can be frustrating, and many people can become depressed, angry or withdrawn. Our research has shown that, at some point in their lives, every deafblind person will become socially and emotionally isolated, and this isolation almost inevitably leads to feelings of loneliness. People may be left with no means to communicate their feelings and anxieties, an isolating situation which has to be addressed.

The case of George, who has dual sensory loss, illustrates clearly the importance of deafblind people getting appropriate support to manage loneliness and isolation:

George, 77, is visually impaired with little useful central vision. He is also severely deaf, relying on two hearing aids to amplify speech and other environmental sounds. Even with hearing aids and in quiet environments, he struggles to follow speech. George and his wife had a supportive relationship and managed life well without support, but following his wife's death George became depressed. His GP requested an assessment because she was concerned about his ability to cope on his own, understanding that if George became isolated his depression would be hard to treat. A specialist assessment was arranged, which identified key areas of provision for George that have enabled him to build his confidence in going out alone in the local area, attending a group where his communication needs were catered for.

In the case of George, early intervention by an experienced and empathetic professional was crucial to having his needs met. He has been able to get help to communicate with others and to be active in his local area, helping prevent increasing feelings of isolation and loneliness. But there are many who are not fortunate enough to receive such help, due to the failure of professionals to identify deafblindness at an early stage, or to act on the issue effectively.

Our research has found that 19% of deafblind people received no social care at all, and that 75% of deafblind people who had received no social care reported problems in their lives, including difficulties with mental health and communication. One person we surveyed commented:

“When I got no social care, my mental health got bad, I was very stressed and suffering from depression. I came very close to losing my job on more than one occasion. I got very close to suicide on more than one occasion. I have gone without prescriptions on a fairly regular basis. I have had to cancel hospital appointments because I couldn’t get there. My relationship with my family has always been difficult but it’s worse now because I can’t go to see them much and when I do see them we can’t communicate – but they don’t understand and think it’s my attitude problem!”

Lack of support can have a very damaging impact on people, meaning they are unable to access the kind of services which helped George, and are at risk of becoming lonely and isolated even from their own families and friends.

There are a number of initiatives designed to alleviate loneliness, but many – such as The Silver Line phone help service – are simply unable to address the specific needs of deafblind people. Those with little or no hearing are unable to communicate by phone unless they are equipped with special technology; alternative approaches are needed. At Sense our specialism means we are uniquely placed to deliver a befriending scheme that responds to the complex needs of deafblind people, and we are currently piloting a bespoke befriending service. Our carefully recruited volunteers have received a minimum of eight hours preparation and twelve hours supervised practice. They are all trained in communication, mobility, and deafblind awareness, but also on broader health and practical issues so they can ensure that the deafblind person they will work with is referred on to any extra support they need.

Not only does befriending help reduce loneliness, it provides a deafblind person with increased independence, and respite for carers, by helping people engage in leisure and social activities on a regular basis. Befriending is also a reciprocal enterprise: befriending volunteers gain new experiences and transferable skills, in addition to developing a close friendship with a deafblind person. Building these relationships allows people to benefit from direct involvement in activities and,

indirectly, through the lasting impact of those activities and the connection they have made. For example, deafblind people can peer-mentor others in the use of deafblind manuals, sharing their experiences of accessing services. This can break down barriers and help equip members of the community with the necessary skills to communicate with deafblind people.

Through our forums deafblind people and their families can meet and share their experiences. These forums provide a place to foster friendships, and can make a very positive contribution to people's lives. We should not assume that because a person is older, or is deafblind, that they have to give up activities they once enjoyed. People who use our forums have told us:

"It was a little bit lonely until the group started meeting."

"The most useful thing I find at the forum is companionship."

"I enjoy being able to come here. Sense helped pay for someone to bring me, a person to help me whereas if I'm on my own stuck indoors, I'd go nowhere."

Sense is also piloting a social prescribing service in two areas of Yorkshire which links to a regular social group we offer for deafblind people with activities that focus on improving wellbeing through arts, sports or culture. This type of service offers people with a dual sensory impairment an opportunity to be part of a group of like-minded people with similar needs and aspirations, and to connect with various functions of their local community. Most importantly, it is an alternative health promotion service, and can form part of an individual's ongoing health and social care plan in coordination with their GP.

In our pilot programme of social prescribing services, we were able to reach over 40 socially isolated older people with sensory impairments in one community. The programme has been highly successful in combatting social isolation and loneliness for all involved. Participants have been supported to better understand their sensory impairments and the ways in which they can access different services. Signposting to other services is incredibly valuable for deafblind people when faced with new challenges in the social care sector, such as acquired sensory loss. This is particularly important where channels of communication are restricted by sensory loss, and where older people are less likely to recognise how their impairment can isolate them from others and from support services. Social prescription can help fill the social, educational, emotional, health and wellbeing gaps that may exist in current statutory provision. If a social prescription service targets older people with sensory impairments, the social engagement opportunities that the service provides can lead to better community cohesion – and better understanding of older deafblind people's needs.

Alongside developing new services, we need to maintain the existing support that is so vital to deafblind people. With tightening resources in the public sector, local authorities especially are cutting back the support they can provide to older people. This is especially of concern to older deafblind people who require specialist services (such as a communicator guide and rehabilitation services) which empower them to live independent lives. Rehabilitation if delivered appropriately can help people to be more mobile, provide support for aids and adaptations and ensure people are knowledgeable about using them. Limited or no access to these essential services can lead to deafblind people finding it harder to adjust to hearing and sight loss in older age – and this in turn can limit their ability to lead independent lives, venture out as they once did, maintain friendships and build new ones.

Cuts to essential support for older people experiencing dual sensory loss will inevitably lead to increased loneliness, and could be storing up huge costs to the NHS in treating resulting health conditions, particular those resulting from high blood pressure. Those who are deafblind are more at risk of ill health due to the isolation which can be brought on by their dual sensory impairment. The cost of treating these additional conditions for deafblind older people is estimated to be £365 million per year. This figure will increase as the number of deafblind older people increases in line with an ageing population, and their health and well-being deteriorates due to loneliness and isolation. If professionals and practitioners identify deafblind people sooner, ensuring they are provided with the help and support they need, then already over-burdened local and national health budgets can be relieved. Sense has access to a large pool of trained volunteers with experience of supporting deafblind people, and a national infrastructure to support community activities. The benefits of working with networks such as these to deliver services like befriending programmes far outweighs the costs. Indeed, the real costs occur from not taking the right preventative action.

We must maintain the essential support that deafblind people receive through the social care system both at a national and local level. Alongside this, charities and organisations supporting people with sensory and dual sensory loss in the public and private sector should work together to reduce the impact of isolation and loneliness deafblind people will face as they get older. With the right support, deafblind people can live active and socially engaged as full, connected members of their communities. Together we can make the lives of deafblind people less isolated and more enjoyable.

Richard Kramer

Deputy Chief Executive

Sense

About the authors



Simon Antrobus has been Chief Executive of Addaction, an organisation which works at the heart of local

communities supporting adults, families & young people to beat addiction. Simon has worked in the voluntary and community sector for over 20 years and has held senior positions in a number of national voluntary organisations. Prior to joining Addaction Simon was Chief Executive of Clubs for Young People – now Ambition.



Jenny Edwards CBE has been the Chief Executive of the Mental Health Foundation since October 2013.

Her career has expanded over a number of sectors and she is very passionate about social justice. Previously she was Chief Executive of Homeless Link and has also worked in arts organisations. She was awarded a CBE for services to disadvantaged people in 2011.



Ciarán Devane joined Macmillan Cancer Support as Chief Executive in May 2007. Ciarán co-chairs the

National Cancer Survivorship Initiative and is a trustee of the National Council for Voluntary Organisations and the Makaton Charity. In January 2012, Ciarán was appointed as a Non Executive Director of NHS England. He holds a Masters Degree in International Policy from the George Washington University and prior to joining the charity sector worked for Gemini Consulting and ICI.



Paul Farmer has been Chief Executive of Mind, the leading mental health charity working in England and Wales, since May

2006. Amongst other things Paul is Chair of the Disability Charities Consortium, Chair of the NHS England Mental Health Patient Safety Board, and an elected member of the ACEVO board. In 2013 Paul was selected as most admired charity chief executive by Third Sector.



Heléna Herklots joined Carers UK as Chief Executive in February 2012. Prior to this Heléna was Services Director at

Age UK with responsibility for the organisation's charitable services for people in later life, and for supporting local Age UKs. Heléna has 25 years experience in a range of service development and provision, policy and strategy roles. Heléna is co-chair of the Department of Health Care and Support Transformation Group, and serves on a number of other national advisory groups.



Omar Khan is Runnymede's Acting Director. Prior to this he was Runnymede's Head of Policy and led the financial

inclusion programme. Omar sits on the Department for Work and Pensions' Ethnic Minority Advisory Group. He is also a 2012 Clore Social Leadership Fellow and holds a variety of advisory roles including chairing the social enterprise Olmec as the UK representative on the European Commission's Socio-economic network of experts.



Jeremy Hughes joined Alzheimer's Society in November 2010. Jeremy co-chairs the

Dementia Friendly Communities Champions Group with Angela Rippon, as part of the Prime Minister's Challenge on Dementia. He was previously Chief Executive of Breakthrough Breast Cancer where his leadership galvanized the charity's research platform and authority on campaigning and policy.



Richard Kramer joined Sense in 2013 as deputy CEO and is also responsible for the Policy and Communications

Directorate. Prior to joining Sense, Richard worked for over ten years at the social enterprise Turning Point in a number of Director posts and was instrumental in leading the delivery and strategic direction of the charity's Connected Care service. Richard has a wealth of experience in policy, service development, and driving growth in charities.



Tom Owen is the Co-Founder and the Co-Director of My Home Life, a UK programme (and social movement)

promoting quality of life for those living, dying, visiting, and working in care homes. Tom has been working with older people for 25 years as a campaigner, researcher and practitioner. He began his career working in care homes and as a community worker before taking up research roles at Oxford University, and with Help the Aged (now Age UK).



James Taylor is Head of Policy at Stonewall, leading the lesbian, gay and bisexual equality charity's work on

health, care, sport, immigration, asylum and parliamentary engagement. James has been at Stonewall for four years. Previously he was a civil servant at the Department of Health working in the Policy and Strategy Unit.



Ruth Sutherland, CEO of Relate, has worked extensively in social justice, health and wellbeing arenas.

The value and significance of healthy relationships have been a consistent theme across Ruth's career; she has a deep personal and professional commitment to helping create a healthier and happier society. Prior to joining Relate, Ruth held Executive Director positions at national charities including Scope, Rethink, and Alzheimer's Society.

The Campaign to End Loneliness

is a network of local, regional and national organisations and individuals working together through community action, good practice, policy and research to combat loneliness and isolation in the United Kingdom.

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The Calouste Gulbenkian Foundation

is an international charitable foundation with cultural, educational, social and scientific interests. Based in Lisbon with branches in London and Paris, the purpose of the UK Branch in London is to bring about long-term improvements in well-being, particularly for the most vulnerable, by creating connections across boundaries (national borders, communities, disciplines and sectors) which deliver social, cultural and environmental value.

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