**Understanding barriers to connection for people experiencing loneliness at key life transitions**

# A report for the British Red Cross and Co-op partnership

Prepared by: Andrea Wigfield; Royce Turner; Dave Clayton

Centre for Loneliness Studies

University of Sheffield

**Contents**

|  |  |
| --- | --- |
| Acknowledgements | 3 |
| 1. Introduction | 4 |
| 2. Methods | 6 |
| 3. Background and insight into existing literature | 9 |
| 4. Experiences of connections at two key transitions - bereavement and health | 11 |
| 5.Barriers to connections at two key transitions - bereavement and health | 27 |
| 6. Gaps in existing services for bereavement and health conditions among BAME communities | 36 |
| 7. Intersection of the experiences and barriers of connection relating to bereavement, health conditions, and ethnicity | 40 |
| 8. Conclusions and policy and practice implications | 44 |
|  |  |

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# 1. Introduction

There are few studies that explore loneliness among ethnic minorities in the UK. Indeed, despite the fact that much research has been carried on loneliness among older people, there has been little research on loneliness among older people from BAME communities (Victor *et al.* 2012). Existing research into loneliness has been said to be ‘colour blind’, despite ethnicity being a recognised risk factor for loneliness and social isolation (Victor *et al.* 2012: 8). The research that does unpick this issue suggests that the frequency that ethnic minority groups report feeling lonely often or always is greater than for White British people. For example, 24 per cent to 50 per cent of Chinese, African, African Caribbean, Pakistani and Bangladeshi immigrants over the age of 65 reported feeling lonely often or always in a large-scale comparative study (Victor *et al.* 2012). This compares with eight to ten per cent of White British people, and this statistic is reflected across Europe for older people living in their country of origin (Victor *et al.* 2012). Research indicates certain trigger points across the life-course that can heighten feelings of loneliness, including bereavement (Fried *et al.* 2015; Wenger 1996) and health conditions (ONS 2018). An ONS report in 2018 suggests that people in poor health or who have conditions they describe as “limiting” are at particular risk of feeling lonely more often. However, there is little in-depth qualitative research into people’s experiences of loneliness at these trigger points, and virtually none around BAME communities and their experiences of loneliness following bereavement and/or having a health condition.

This report presents findings of a research project undertaken by the Centre for Loneliness Studies, University of Sheffield, which was commissioned by the British Red Cross and Co-op partnership seeking to tackle loneliness. The study aimed to explore, qualitatively, the experiences of people who are lonely going through two key life transitions: health and bereavement. Individuals from BAME (Black Asian and Minority Ethnic), as well as White British, communities were studied to assess the interplay of triggers of loneliness with the aim of unpicking specific barriers to connection in various localities in the UK. It is hoped that by unravelling barriers to connection in this way we will gain a greater understanding of the kinds of interventions that could be developed to better respond to need and develop a deeper understanding of what policy and practice needs to change to facilitate a less lonely and more connected society.

The research reported on in this paper builds on the findings from *Trapped in a Bubble,* research commissioned by the British Red Cross and Co-op Partnershipwhich focussed on the triggers of loneliness amongst individuals (Kantar Public 2016). Whilst there is current knowledge about many of the risk factors which can lead to loneliness, such as ethnicity and income, there is little insight as to how and why these occur. Having a deeper insight into some of these factors and a greater understanding of how they intersect with other key risk factors and life transitions will enable us to start to develop meaningful policy and practice solutions to overcome them.

Two additional connected pieces of research were commissioned by the British Red Cross and Co-op partnership at the same time: a qualitative study of the barriers to accessing loneliness services faced by people from BAME communities, which was undertaken by the same research team at the University of Sheffield (Wigfield 2019); and a quantitative study designed to explore more about the nature and experience of loneliness among black and ethnic minority communities carried out by Runnymede (Haque *et al.* 2019).

## Lines of enquiry and research questions

The study focussed on exploring three main research questions and these form key sections in this report:

1. What are the experiences and barriers to connections among people going through two key transitions - bereavement and health?
2. What is the impact of ethnicity?
3. How do these various factors intersect?

### 2. Research Methods

A four stage, qualitative study was undertaken, with fieldwork being carried out between September 2018 and February 2019. The research study draws on: interviews with 16 stakeholders representing service providers aiming to tackle social isolation and/or loneliness and/or support BAME communities; and interviews with 42 people from the White British and BAME communities experiencing varying degrees of social isolation and/or loneliness, who had either a long-term health condition and/or had experienced bereavement. 15 of the interviewees self-identified as being from BAME communities, and were from various ethnic backgrounds including African, Pakistani, African-Caribbean, and Indian. The interviewees ranged in age from 34 to 82, and the majority (29/42) were women. Most of those interviewed were living independently in the community. The four stages of the study are as follows:

***Stage 1: Rapid Literature Review*:** a small rapid literature review was carried out and included academic and grey literature to identify the main gaps in the research literature and inform development of the research instruments.

***Stage 2: Identification of three study sites:*** in discussion with the British Red Cross and Co-op partnership we identified three sites in which to carry out the research study: Butetown in Cardiff: Chapeltown in Leeds; and Burngreave in Sheffield. These localities were selected as they have a diverse ethnic population.

*Sheffield*is a large, ethnically diverse city in South Yorkshire, with a population of 575,400. Burngreave is an inner-city ward in Sheffield with an ethnically diverse community. It has a population of around 30,000, of which the majority (64%) are from BAME communities, with Pakistani Asians forming the largest group. Burngreave is the second most deprived ward in Sheffield (out of 28).

*Leeds* is a large city in West Yorkshire, England, it has a diverse population, across 33 wards. The city lies within the United Kingdom's fourth-most populous urban area, with a population of 2.6 million. Chapeltown, is an inner suburb of north-east Leeds, where the majority are from BAME communities, (Black Caribbean people forming the largest group).

*Cardiff* has an ethnically diverse population due to its past trading connections, post-war immigration and the large numbers of overseas students who attend university in the city. According to the 2011 Census, almost 350,000 people live in Cardiff of whom 15 per cent are from an ethnic minority background (around 50,000 people). Many of the non-white British population live in Butetown in the south of the city, which has a population of around 10,000 and where ethnic minority residents make up around a third of the total population.

Due to some challenges in recruiting interviewees, particularly those who had experienced bereavement, some interviews took place outside these localities (see below for a further discussion).

### Stage 3: Telephone interviews with key stakeholders: a total of 16 face to face and telephone interviews were carried out with stakeholders in each of the three localities (six in Cardiff, five in Leeds, five in Sheffield). Stakeholders selected for interview represented organisations which are involved in providing support/services/interventions to lonely people, those who are bereaved, have long term health conditions, and to members of BAME communities. A summary of the kinds of services represented by the stakeholders interviewed is provided in appendix 1). These interviews were designed to help us gain a greater insight into the services, activities, opportunities and barriers to make social connections for people with long term health conditions and for those who have experienced bereavement. The research team also used the contacts made through the stakeholder interviews as an opportunity to identify the best ways to engage with a cross-section of residents from the BAME and White British communities in each of the three areas.

## Stage 4: Interviews with individuals who are lonely going through two key life transitions: health and bereavement: In total 42 in-depth interviews were carried out with both BAME and White British individuals who were identified as potentially being lonely and had either a long-term health condition and/or had experienced bereavement. 33 of these interviews were carried out in the three localities (15 in Cardiff, eight in Leeds, ten in Sheffield). However, due to challenges in identifying and recruiting appropriate individuals to be interviewed in each of the three localities, towards the end of the fieldwork phase we opened up the research to other localities and interviewed an additional nine people from various localities including Cambridgeshire, London, York, Swansea. We initially aimed to interview 60 individuals (approximately half to be members of BAME communities). Most of the interviews were carried out face-to-face but, in some cases, (particularly for the later interviews outside the three localities) interviews were carried out by telephone or in one case Skype. There were no obvious differences in the type or quality of data generated from the two different types of interviews. The interviews aimed to assess participants’ experience of social connections, the role that this has in their experiences of loneliness, the barriers and enablers to social connections, and the kinds of measures that can be put in place in their communities to facilitate connections and reduce loneliness. Each interview lasted on average 30 minutes, with many up to one hour and some for even longer. All interviewees were provided with a £10 gift token to support them to participate in the interview. A summary of the key characteristics of the individuals who participated in the interviews is provided in appendix 1.

### Recording and analysing data

Where possible, and with the permission of the participants, all interviews were audio-recorded and extensive written notes taken. All data were anonymised and analysed. As the data gathered were qualitative, a thematic technique was designed to capture a range of issues and any similarities/differences across respondents.

***Challenges of studying loneliness among BAME communities***

A number of challenges were encountered by the research team when attempting to undertake the fieldwork, many of which have been documented in the report exploring barriers to loneliness services experienced by people from BAME communities (Wigfield 2019), and so will not repeated in detail here but they relate to: difficulties identifying if individuals are lonely prior to interview; difficulties using the UCLA scale to measure loneliness for these individuals and for screening purposes; as well as the vulnerability and challenging circumstances within which many of the individuals are living their everyday lives. These challenges were particularly severe for people who had recently been bereaved and for those experiencing mental ill-health and many, even if identified, were reluctant to be interviewed and share their experiences. Moreover, frequently individuals would agree to be interviewed and then later change their minds, either not turning up for the interview or cancelling in advance without reason or explanation. Some, especially those who had experienced bereavement, said that sometimes they felt like talking but on other occasions they *‘couldn’t face it’*.

### Structure of the report

The remainder of the report is divided into five sections each of which addresses a separate research question or theme: Section 3 provides some background information and provides a brief insight into existing literature; Section 4 explores experiences of connections at the two key transitions - bereavement and health; Section 5 examines the barriers to connection at the same two key life transition points; Section 6 takes a more detailed look at gaps in existing services specifically for individuals from BAME communities experiencing bereavement and health conditions; Section 7 explores how these various factors intersect; and finally Section 8 provides some conclusions and identifies some possible policy responses.

**3. Background and insight into existing literature**

The research team carried out a summary rapid review of relevant literature which has explored loneliness among BAME communities, particularly focusing on the two trigger points of bereavement and health. The review certainly does not represent a comprehensive analysis of literature in this field, nor was it meant to. Furthermore, as previously stated, there is a dearth of academic research into loneliness among people from BAME communities and even less focussing specifically on their experience of loneliness at particular ‘trigger’ or ‘life transition’ points. Some of the limited existing literature is outlined in this section.

***Loneliness among BAME communities***

Khan (2014) discusses the ‘myth’ of ethnic minorities having better levels of social connection and the issue of ‘hidden loneliness’ among older people in BAME communities. They can feel lonely within large families due to a lower chance of sharing migration history with family members, and less chance of engaging in enjoyable activities (Bolton 2012). People from BAME communities are generally younger than the White British population with one in five British people over 65 but less than five per cent of Bangladeshi, Pakistani, mixed race, Black African, Black other and Arab people being over 65 (Khan 2014). This means there may be less chance for peer connection outside of the family among older BAME people.

Visser and Fakiri (2016) found that people from BAME communities in the Netherlands experience higher levels of social and emotional loneliness than Dutch people, and this can be ascribed to ethnic differences. Morrocan, Turkish, and Surinamese people reported feeling less healthy, more discriminated against, and lonelier than the Dutch group in the study. Perceptions of financial difficulty and the neighbourhood not getting along contributed to anxiety, depression, and higher loneliness levels among the minority groups. Feeling less healthy (mentally and physically), alongside ethnic differences, produces higher levels of loneliness, according to this study. Similarly, Bécares *et al.* (2009) explores the link between ethnicity and health in the UK. They discuss the health inequalities that exist between people from BAME and White British communities that are promoted by fear of societal racial harassment experienced by some people from BAME communities. This fear of racial harassment can result in social isolation and loneliness among some BAME communities. Miyawaki (2015) studied black, Hispanic and white groups in the United States and found that social isolation experienced by minorities led to negative health outcomes. Miyawaki attributes this to a lack of access to resources such as transport, because of distinct socio-economic disadvantages. Miyawaki (2015) concludes that If a person is in unfamiliar surroundings for a long time, they are more at risk of losing their autonomy related to culture, food, and language of their country of origin, which can lead to increased feelings of loneliness.

***Health conditions and loneliness***

The links between poor health and loneliness are well established. Lonely people have higher rates of depression, dementia, dysfunctional sleep, cardiovascular disease and cancer (Yang 2018; Hawkley and Cacioppo 2003; Cacioppo *et al.* 2002). Social support is linked to better immune function and health (Cohen *et al*. 1997). Holt-Lunstad and Smith (2012) discuss the benefits of social relationships on both physical and mental health. They compare poor social relationships as equivalent to smoking 15 cigarettes per day, or as having double the risk of premature death compared to obesity. Arguing along the same lines, Cantarero-Prieto *et al.* (2018) found that people who participate in social activities have a lower probability of suffering from chronic disease, showing social isolation as a key health risk factor.

While loneliness can cause the health problems discussed above, some sources found that having health conditions can also cause loneliness. In a very large-scale survey of the UK, the Office for National Statistics (ONS 2018) show that those at risk of loneliness include people with life limiting health conditions. The ONS resource shows that people who report their general health as bad or very bad are significantly more likely to be report being always or often lonely. Yang (2018) similarly analysed data to find out about causal conditions for loneliness. The results showed that if someone is living alone, not engaging socially and has existing health problems these factors interplay to cause loneliness. Victor *et al*. (2005) found a strong relationship between loneliness and socio-demographic factors, health, social resource limitations and access to material resources. This may relate to problems with physical mobility and inability to engage with others in public. Victor *et al.* (2005) conclude that ill-health is not an independent cause of loneliness, but that it interacts with other factors such as gender and household status to produce a higher likelihood of loneliness.

***Bereavement and loneliness***

People going through a bereavement are highly likely to experience loneliness (Wenger 1996). Fried *et al.* (2015) found in their study of bereaved older people that loneliness is a key symptom which activates other conditions such as depression. Loneliness is often reported as the hardest part of loss (Fried *et al.* 2015). Fried *et al.* (2015) describe bereaved older people as difficult to help due to their complex needs and depressive symptoms, but other authors have found social support is highly beneficial after loss of a loved one. Utz *et al.* (2014) discuss how social support eventually decreases after bereavement whilst loneliness still prevails. However, if social support is continued it can have positive effects on the bereaved. This social support is most effective if the bereaved person can express themselves freely and the support is readily available. Lund *et al.* (2010) also discuss the importance of friendship networks after a bereavement. If a person does not have a good friendship network, they are more likely to suffer from loneliness after a loss. Utz *et al.* (2002) describe the importance of social support during the grieving process after losing a spouse but they highlight that not everyone has access to this kind of support.

During the difficult transition to becoming a widow or widower it is likely, especially among men, that there will be a decline in health of the survivor (Williams 2004). This is due, in part, to the lack of health reminders that used to be given by a spouse or partner. In this vein, widowhood undermines health, particularly when health risk behaviours increase as a reaction to grief (such as alcohol abuse) (Williams 2004). Loneliness is common among the widowed, therefore alongside the health implications discussed above there is a twofold health risk to them, showing a need for support services targeted at people going through bereavement.

The remainder of this report aims to provide a greater insight into people’s experiences of loneliness at the two transition points of bereavement and having a health condition and where possible draw out any issues which are particularly significant for BAME communities.

# Experiences of connections among people going through two key transitions – bereavement and health

## This section explores the experiences of the interviewees in relation to their feelings of loneliness and covers the following issues: assessing and measuring loneliness; understanding experiences of loneliness resulting from bereavement and ill-heath; and the role of place and sense of belonging in experiences of loneliness.

## Assessing and measuring loneliness

Many of the 42 interviewees had been identified by local service providers in Cardiff, Leeds and Sheffield as being lonely and experiencing bereavement and/or a long-term health condition. In the case of those nine participants who were interviewed in other localities towards the end of the fieldwork phase (see Section 2 for an explanation) all had self-identified as being lonely due to bereavement by responding to posters and social media requests. Experiences of loneliness among the interviewees were assessed through the interviewees in a number of different ways: through the UCLA three item Loneliness Scale, through a single direct question *‘how often do you feel lonely’* and through a series of more indirect questions and prompts which were returned to throughout each of the interviews. When taking all three approaches into account the majority of the interviewees can be classified as being lonely. Many indicated that they were not satisfied with the existing social connections that they had, as an older, white British, woman in Cardiff explained: ‘*Not really, only family I am in contact with is my brother and sister-in-law who live in America and the other family members have died.’* Another woman, of Arabic heritage and living in Cardiff, talked about constantly ‘*crying and isolating herself from others’*. She talked about how, after, visiting the women’s centre where she had some social contact, she was left to return back to her *‘painful isolation’*.

The UCLA scale scores ranged from three (not lonely) to nine (lonely). Just over a quarter of the interviewees (12/42) scored between three and five on the UCLA loneliness scale and were therefore assessed as not lonely, while the majority (30/42) scored between six and nine on the scale and were therefore assessed as lonely. However, some of the interviewees (particularly, but not exclusively, those from BAME communities) had some difficulties understanding and responding to the UCLA questions. These issues were also identified in the accompanying study of barriers to loneliness services experienced by members of BAME communities (Wigfield 2019).

Issues identified with the UCLA scale among some of the White British interviewees, particularly those experiencing mental ill-health, often related to understanding the term ‘companionship’ and what this meant. Some of the White British interviewees actually commented on the questions being difficult to understand and answer; some worried that there was a right and wrong way to respond (despite assurances to the contrary by the researcher); and others worried that they had given contradictory responses to the series of three UCLA questions, with one appearing to note that a contradiction in her answer might mean she had given a *‘wrong’* answer. Interviewees from BAME communities appeared to struggle with the UCLA scale questions even more. Many people, even those with a good level of English, needed translation of the scales, not necessarily just the words but the *meaning* of the words. This was especially evident in relation to the term ‘*lack of companionship’*, but also in relation to *‘feeling left out’*. An Arabic woman said in response to the UCLA scale that ‘feeling left out’ would be translated as *‘being forgotten about’*.

When asked the specific direct question about how often the interviewees felt lonely, the vast majority of the 42 interviewees said they were lonely, with around half of these saying they were lonely either always or often, and half saying they were lonely occasionally or some of the time. There did not appear to be a difference in responses to this direct single question by the loneliness trigger (i.e. bereavement or health condition), or by ethnicity, gender or age. A very small number of participants (two) said they were *never* lonely, and one said they were *hardly ever* lonely.

The findings of the interviews query to some extent the usefulness and validity of the UCLA scale when used alone. Similar issues were raised in the Identifying barriers to BAME access to loneliness services report (Wigfield et al, 2019). Some individuals who were classed as lonely on the UCLA scale said they were not lonely and vice versa. One example of this relates to a Black African woman in Leeds in her late 40s, with sight impairment, who was assessed on the UCLA score as lonely (with a score of seven) but then when asked how often she was lonely her response was ‘never’, she followed this up by pointing out *‘Never have the time to be lonely. On Mondays and Tuesdays, I feel good, I’m not lonely. A meal, exercise, magazines. I don’t have time to be lonely. There are social activities and events’.* Further probing through the interview with this person then revealed that she does not have regular contact with people, apart from her family on occasions and a group to support people with vision impairment (which operates on Mondays and Tuesdays), and that this is primarily due to an inability to travel due to her vision loss. Her feelings of loneliness, consequently, vary throughout the week, and this is a factor that the UCLA scale alone does not appear to pick up. This particular example highlights the need to explore in a more qualitative way people’s experiences of loneliness *alongside* the use of the UCLA scale in future research studies.

Despite many of the interviewees feeling lonely at the current time, the majority said that they had experienced a time when they were really connected to others. These connections were sometimes with other *people* for example when they were in touch with old school friends, or a had a relationship with a particular person to whom they felt close, but they were also sometimes linked to connection to a *place* such as a café, football or rugby stadium or place of worship such as church or mosque that felt welcoming. As a White British Man, aged 47, with mental health issues living in Cardiff, said: *‘Stonehenge, football stadiums, rugby stadiums. I used to really buzz when I went to those places. I stopped raving 10 years ago, but I still go regularly to football matches and rugby matches’*. He went on to explain that these places enabled him to connect with others who were like minded (this theme is returned to in Section 5. Three of the interviewees, all of whom had mental health issues, had never really felt socially connected throughout their lives. As one of these, a person who had had a difficult relationship with his parents, stated:

*‘I grew up in total isolation. I was with people, but totally isolated. It was like being in a crowd but an alien. So, socialising for me was quite difficult. In my twenties, I was scared of people, I was terrified of people coming near me, touching me. I had to learn that not everyone was going to attack me, not everyone was bad. I had to learn to be with people at a level actually at which you could relax a bit. I had a breakdown, and I couldn’t be with people. I still find it hard’*.

This link between mental ill-health and difficulties forming social connections has been found in other research, although evidence of the direction of the causal relationship is not conclusive (See for example Findlay 2003, Graenade and Balby 2008).

## Understanding experiences of loneliness resulting from bereavement and ill-health

The findings of the interviews across the localities, different ethnic groups, different ages and for both men and women highlight that bereavement and/or long-term health conditions present a unique set of challenges for each individual. As can be seen in appendix 1, the 42 participants interviewed were experiencing a wide range of long-term health-conditions (both physical and mental) and/or had been bereaved (for some the loss was very recent in the last few months, for others it was many years ago). These unique set of issues include: persistency of experiences of loneliness; multiple triggers; breakdown of family and friends; meaningful relationships; and reliance on support service for social contact. Each of these issues are now explored in turn.

***Persistency of experiences of loneliness***

For some of those with a long-term health condition, the impact of this on their ability to make connections with people, and consequently their experiences of loneliness, was an on-going challenge, often because they were physically or psychologically unable to leave the house, or to engage in activities which enabled them to make social connections, or because they faced challenges sustaining social connections. These issues are picked up in more detail in the section 5. However, for some interviewees with health conditions in Sheffield, Leeds, and Cardiff, social connections and experiences of loneliness increased and decreased over time as their condition improved or got worse and this could fluctuate over the course of a day, a week, a month, a year. This was the case for those experiencing mental ill-health but also for some with physical health conditions such as arthritis. As a 63-year-old White Irish man in Leeds highlighted this:

*‘my arthritis and gout mean that you sometimes can’t put your shoe on, so you can’t go out. And the arthritis is so painful I can’t go out…When I get an attack, I’d prefer to be on my own...a lot of the times then that you don’t feel like talking…you just want to lie down on the bed’.*

For those who had been bereaved their ability to connect with others and feelings of loneliness were often likely to reduce in intensity over time, as they adjusted to life without the person who had recently died. However, this was not the case for everyone. In Cardiff, for example, two interviewees from BAME communities stated that they lost a family member, and were still being impacted by the experience, in terms of loneliness, even though it happened a relatively long time ago; nine and 18 years ago respectively. The former was a woman from Iraq, where and many of her family members still live. She says her continuous experiences of loneliness are linked to the multiple challenges she had been facing since her sister died nine years ago which include both physical and mental ill-health. She explained that her current physical and mental health issues meant that she *‘couldn’t support connections with others’.* She went on to explain:

*‘I have depression and take antidepressants. When I don’t take them, I get overwhelmed by my thoughts. Sometimes when I’m not feeling well, I go outside and sit on my own****…*** *My relationships have changed even more after the death of my sister… the troubles my family is facing and the war in my country.’*

For this interviewee, then, multiple health conditions, bereavement, and experience of displacement and fleeing conflict, combined to mean that loneliness had become a constant and on-going presence in her life.

For the latter woman, a Nigerian, a similar pattern prevailed. She too had multiple challenges. She had experienced two bereavements, her husband and daughter, and had mental health issues which together contributed to her ongoing experiences of loneliness:

*‘Sometimes I ask myself why I stay home. Whenever I stay home, the evil thoughts fill my head. Sometimes I look for my husband and daughter, I expect them to come and get me. Whenever I am alone I have the feeling that they are coming to me’.*

A 39-year-old White British woman living in Cardiff had also experience two bereavements, similarly both her daughter and husband. She had not been lonely for as long as the two women previously mentioned but said that her loneliness was ongoing:*‘Every day, sometimes. I miss male company, talking. Friday and Saturday night in particular; everything that I enjoyed with my husband is different now.’*

Some of those who had experienced bereavement explained that the loneliness persisted long after the death of their loved one but support from services, friends and family often ceased shortly after the bereavement had taken place. For example, a woman living in Leeds who had experienced bereavement said that although she felt more lonely immediately after her husband had died at least then acquaintances and family were around to see if she was coping, but after a while people forgot and assumed she was fine: *‘When you lost somebody people might come and check if you’re alright, but after few months that stops. I don’t see much of people now’.* This demonstrates the need to ensure that bereavement services are provided initially to help people have meaningful lives whilst living with their loss, and that they need to be available for people on a longer-term basis, and the example is directly linked to research by Utz *et al.* (2014) mentioned previously.

These experiences show that people’s experiences of loneliness can increase and decrease in intensity over time or can persist longer than expected, and therefore services need to be flexible to adapt to and accommodate both changing patterns of loneliness and persistency of experiences. At certain times people may be in greater need of support than at others and just because an individual’s need for support has fallen one week or because the trigger point was some time ago does not mean it will not increase again or continue to persist in the future.

***Multiple triggers exacerbate feelings of loneliness***

As alluded to in the previous section when discussing the persistency of loneliness among some people, the findings of the interviews show that some individuals experience multiple triggers such as both physical and mental ill-health, multiple bereavements, or ill-health and bereavement, and these can exacerbate experiences of loneliness. For some interviewees, for example, experiences of loneliness were exacerbated by multiple bereavements. The 39-year-old White British woman living in Cardiff mentioned in the previous section, for instance, explained that her daughter had died six years earlier and after that she became lonely, but the loneliness was compounded by her husband dying very recently.

Some of the interviewees had experienced both bereavement and had a long-term health condition and this often meant their experiences of loneliness were much worse. In Cardiff, for example, one participant explained that he was lonely, and although his bereavement had played a role this in his feelings of loneliness, his mental health condition was a continuous cause for his lack of social connections and overshadowed the bereavement in terms of its impact on his loneliness.

Others explained that additional factors beyond health conditions and/or bereavement compounded their loneliness, including financial problems and language. The factors came together to make it difficult for people to go out of the home, engage in social activities, and/or interact with others (see Section 5 for more detailed discussion of these barriers). The way in which these multiple triggers can combine to exacerbate experiences of loneliness is exemplified in the following case study example:

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| **Case study example: multiple triggers exacerbate loneliness**  A 57-year-old White British man living in Cardiff has mental and physical health problems and has a series of addictions (gambling, alcohol) which had led to him being chronically lonely.  *‘I’ve had anxiety since my twenties, had a breakdown at university. Been diagnosed with PTSD last year. Physically, I’ve got arthritis of the spine, pernicious anaemia, and type 1 diabetes came about 10 years ago. They [the illnesses] stop me going on, I’ve been in bed the last two days with pain in my spine, and all the flashbacks going on in my mind. It’s a full-time job just coping with what’s going on in my head, then I’ve got to inject myself with insulin eight times a day, I’ve got to check my blood five times a day. I won’t go to a pub because I can’t relax because I’ve got to keep testing my blood. It also makes me self-conscious. I’ve just injected just before I saw you. Now, I do it in front of people but in the past, I’d do it in the toilet or have to hide away. But I’ve thought ‘I can’t let that stop me socialising’. I had a breakdown in my twenties, saw a psychologist, and then I hid myself away, started drinking to cope with it, drinking every night, getting ill but not seeing the GP because I couldn’t go out, and then this Type 1 diabetes came along. I thought it was a mental thing, and I was almost dying before I got to the GP. No friends, no family, no work affected how I could get to any service. My only socialising was going down the pub, and that’s not good that’s just drinking. I didn’t talk to anybody because I was an outsider, I didn’t have any work, didn’t have much money. The only place I used to fit in was at the casino, and it was open late at night, but I used to lose my money, I’d have no money for the week. There was no help. You do it because you’re desperate. It was a horrendous existence. I lost everything I had 25 years ago, I’m still struggling here. I’ve had counselling and help to deal with it. I was a massive addict. You’ll do anything to escape how you feel. I lost an inheritance, my benefits, a car, my piano, I had thousands of pounds of debt. I lived 20 years scraping from week to week.’* |

The woman from a BAME community, living in Cardiff, who was mentioned previously and had experienced bereavement 18 years ago, also mentioned financial issues as compounding her loneliness: ‘*I always feel lonely, all days. One of the triggers is being jobless… I don’t feel like a complete person.’*

Two people from BAME communities living in Leeds similarly mentioned the additional financial issues they faced as contributing factors to loneliness. One, an African-Caribbean woman in her late 40s, said, for example: *‘transport, mobility, finance. I can’t drive, I don’t know the streets well, a taxi is the last thing I can afford.’* The other, a 78-year-old African-Caribbean man, said: *‘I have the pension. I have to be very careful with that. We go on seaside trips, bowling* [with the support group he accesses]*’*.

Some other interviewees from BAME communities mentioned additional issues related to language. One, a woman living in Cardiff, for example, said that she has a language problem as she was not confident speaking English; before going to the [support] centre she did not talk to many people. She said that people were her friends but without talking to them. All is could say is ‘*hi, hello,* *goodbye’.* This example perhaps emphasises the important role that deeper *meaningful* conversations and relationships play in experiences of loneliness, an issue explored in more detail shortly. A further discussion of language and transport barriers is provided in Section 5.

## Breakdown of family and friendship networks feature highly and influence experiences of loneliness

For those who had been bereaved the loss of a loved one or close companion in itself led to loneliness. As a bereaved 74-year-old White British man who was living in York explained: ‘*We [his wife and him] started off life together in the north east, we moved together to York, built a life there, had kids there, but now she’s gone and I’m lonely’*. He explained that he used to have work, and he played golf with friends, but apart from that his life revolved around him being with his wife. Now, he is desperately lonely.

For some of the interviewees a loss of family and/or friends was not just a result of their death but due to a breakdown of family and/or friendship networks and this had heightened feelings of isolation and loneliness. Indeed 17 of the 42 interviewees mentioned that they had experienced a breakdown in family or friendship networks and that this had left them lonely. When the interviewers probed for further information the interviewees were often not able to explain why the breakdown had occurred. A White British 47-year-old man living in Cardiff, for example, said how he had ‘*just drifted apart from family and friends’*. It was not always clear from the interviews, despite probing, whether the breakdown of the relationships had preceded the health conditions, bereavements and experiences of loneliness or had followed them. In other words, the direction of the causality was not always obvious.

Some bereaved individuals did say that they had much less contact with family following their loss. For example, a bereaved man said that immediately following the death of his wife his family (who were mostly her blood relatives) had kept in touch, but as time had moved on they no longer do and he has become much more isolated and lonely. In this example his wife previously planned all the couple’s social engagements and after she died he was not able to maintain the social network. Another man explained that his network of friends were mainly his wife’s friends and that after her death he has no contact with them.

Some interviewees said that following a life changing issue such as bereavement or diagnosis of a health condition, tension often arose among families. A Bangladeshi woman, aged 34, living in London explained how her family had experienced such tensions following a recent bereavement in the family:

*‘when you experience bereavement, people grieve in different ways within the family, although I’m very close to my father and brother but not so much with my sisters. When you grieve sometimes it can cause a divide in your family or people grieve at different paces*. *I have a big family. They are all very different, and people grieve differently, some get angry some don’t want to communicate with family because it’s too painful, some don’t. With my sisters it’s complicated, sometimes they argue who did so much or did so little, who wasn’t there when the person was dying, who didn’t give enough support, the stress level is very high. So I now have a very poor relationship with my sisters. Still I accept the fact that they grieve differently than I do and that’s why it takes time’.*

For some interviewees, family and friendship networks had broken down because family or friends did not understand and empathise with the individuals’ experiences of either bereavement or a health condition. A White British woman living in Somerset, whose husband had recently died, explained that although friends stuck by her when her husband died, her family did not. She did not know why and said that she could not forgive them for it: ‘*negative impact with my family not close at all, the fact that they had little to do anything after bereavement and all drifted further apart. Friends amazing, family useless to the point where I don’t think I can forgive them* [family] *for it’.*

Some of the interviewees in Cardiff were experiencing mental ill-health and explained how family members and friends did not understand their condition and had stopped arranging to meet or visit them because of this inability to understand. One example is provided by a man who was experiencing depression and anxiety and so had to keep cancelling meetings with friends at the last minute; he said that his friends eventually stopped contacting him and he did not feel he could contact them as if he arranged to meet them he could not be sure that he would be well enough to turn up for the meeting. A woman in Sheffield with a heart condition and anxiety, for example, mentioned that her family did not understand the seriousness of her health condition and therefore she kept face-to-face contact to a minimum:

*’I tend to see my family irregularly now because I get judged, because I have an invisible disability. I’m being pre-judged because people don’t think there might be something wrong with me and assume that I should be doing more things and should be more active’.*

This lack of understanding of existing friends and/or family during times of ill-health led to distress among some interviewees and led them to re-evaluate the benefit of their social networks, as the following short case study shows:

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| **Friends and family are not always supportive in times of ill-health**  One woman who had cared for her husband who had dementia, talked about how the experience of bereavement made her evaluate her friendships. Losing her husband affected her greatly. She still remembered the day he died and talked of difficulties of caring for him in the past 10 years. When her husband was still alive, one of her friends wanted to go away with her but when she refused her friend told her ‘*I don’t think he is as sick as you’re trying to make it’*. The woman found this deeply upsetting. She also has found little support from her friends when she was a carer: ‘*When he [husband] died they sent me 150 cards, but I needed them when he was sick. I needed people to ring me or visit me for two minutes and nothing of this sort happened’*. |

Some of those experiencing mental ill-health also mentioned the stigma associated with it and this meant they were reluctant to mention or explain their condition to friends and family (stigma is picked up again in more detail in the following section on barriers to connections) and that this often had an impact on their social connections.

Interviewees sometimes mentioned that they had better relationships with support workers whom they had contact with through local support services, than they did with their own family. In Leeds for example, a woman who was interviewed mentioned that she had a good relationship with her support worker but a fractious relationship with her daughters as they did not get on with each other because of a past incident. She felt stuck in the middle and uncomfortable. This raises interesting questions about the ability of paid support staff to provide meaningful relationships and interaction with lonely individuals, but it also raises issues about sustainability of these relationships when the paid workers change jobs or the service ceases. Another man in Leeds, from a white ‘other’ background (i.e. white other than white British), who had a son and daughter, highlighted how he did not see either but did have contact with support workers through local services he accessed: *’I used to attempt to see my daughter. Every time I’d phone up, she’d say ‘oh, we’re going to a wedding’. How many weddings can you go to? Every week? I don’t know my son’s address’.*

***Meaningful relationships are a potential significant factor in experiences of loneliness***

Some of the interviewees alluded to the importance of having relationships with people that are meaningful, implying that the loss of these types of relationships was a key perhaps to their experiences of loneliness. For some, these meaningful relationships centred around a small number of people or maybe just one person, a supportive confidant, who was often a spouse. Such a supportive confident could potentially act as a protective factor to loneliness in times of ill-health and bereavement. Indeed, evidence about the significance of the presence of a ‘confidant’ in relation to the likelihood of loneliness was found by Grenade and Balby (2008).

For the interviewees in this study who had experienced bereavement, this loss of a supportive confident clearly exacerbated the impact of loneliness. Some of the interviewees said that after the death of the supportive spouse they felt more of a sense of loss, and lonelier, than they would have if they had not had that supportive companion in the first place. For example, as one woman who was a carer for her bereaved husband highlighted: *‘We all want someone to lean on. Just think with all the grief and the problem in my family. That made me more lonely’.* A White British 74-year-old man living in Swansea whose wife had recently passed away said: *‘I feel lonely because I lack the companionship of [his wife], not others. We never had close relationships with people living locally’.*

When exploring further what a meaningful relationship consisted of, a 39-year-old White British woman living in Cardiff who had recently been widowed and whose daughter had died too, said: *‘I am friendly with a lot of people, I can make conversation with just about anybody, but I wouldn’t call them friends. I don’t find it hard to talk to people, but sometimes you don’t click with people.’*

Another White British woman also living in Cardiff, but older at the age of 60 and experiencing mental ill-health, intimated that meaningful relationships were intrinsically linked to physical contact: *‘People listening to me. Hugs. I don’t often have the opportunity to have this type of relationship with other people, but at the last friends and neighbours’ group we did have a hug.’*

A man interviewed in Cardiff, when talking about his level of satisfaction with existing social contacts, pointed out that relationships that are meaningful cannot easily be developed:

*‘you can’t just manufacture the family, the right people; they’re either there or they’re not. The rest of it is just coming here* [a local support group], *or just socialising, it’s not real. You can spend some time with some people, but then you’ve got to go back on your own. It’s not real.’*

The role of meaningful relationships and the way in which it links to feelings of loneliness is explored a little further in Section 6 and has been identified in other research, specifically in relation to older people (Wigfield forthcoming 2019) and is something which needs to be explored further.

## Reliance on support services for social contact

There was some evidence from the interviews with people who were lonely due to either bereavement and/or a health condition that, where they had accessed support services, they were making social connections through support workers or volunteers. Many of them spoke positively about these relationships, pointing out that they would be even more lonely and isolated without them. A White British 56-year-old woman living in Leeds who was experiencing mental health issues, said, for example, ‘*I’ve got a good relationship here* [support centre]. S*he* [support worker] *knows when there’s something wrong. I use this place…because I feel safe, I can open up*.’ Another 77-year-old Arabic woman living in Cardiff said similarly: *‘I’m not happy with the amount of relationships I have with people, but I am happy with the time I spend in the* [support] *centre*.’ She went on to say that this was *‘better than hours of loneliness’*. A White British man, aged 57, living in Cardiff, shared similar feelings: *‘I lived in a bedsit on my own for years. I come here now four times a week [*to mental health support group]. *I have come from nothing to this. This is my main source of contact; without this I’d be isolated again.’*

Some of those who were accessing support services explained that the support staff were understanding regardless of their mental health issues, physical health condition, or the way they felt following bereavement as sometimes families and friends are not, and many of them therefore placed a high value on these relationships. This is exemplified in the following case study:

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| **Case example 1: Valuing relationships with support workers**  A man with severe mental health problems had been on medication for 24 years. He felt he could not relate to other people in day to day life and didn’t know why. He had few friends and other people also found it hard to relate to him. This made him feel lonely and frustrated. All his friendships and social activities were through his care and support provider. He was more comfortable being around people who understood and related to his experiences of mental ill health. |

However, there also seemed to be a perception amongst many of the interviewees that these kinds of relationships with support service staff were very much ‘second best’. A White British man, living in Cardiff and with mental health issues, said that he was ‘*happy with the amount of time but not the quality of the time spent with them’*. He explained that he would prefer it if he could get to know other people more easily and better during the time he spends with them rather than relying on staff to talk to him.

It was recognised that support staff are being paid to provide social connections, and that these relationships can disappear when a member of staff moves on, or when a service is cut. Or indeed the financial model that they are operating to can mean that the social contact may not be enough, as a 69-year-old African Caribbean woman living in Sheffield explained. She said that she relies on company from her husband’s carers who visit a few times a week but the amount of time for social interaction is not sufficient: ‘*I* w*ould like carers to rush less and to talk more. Their visits are too short, and I would like them to have a time to talk to me.*’ Or in the case of a bereaved woman living in Somerset, the companionship provided by the support worker may cease even though the individual continues to desire it:

‘*When I lost my husband, people that I thought I know to say hello to, they were fantastic they came around they helped me they looked after me so well, they turned out to be the most amazing people in the world one of the worst thing all those services that had contact with doctors, district nurses are all busy, they all fall away, nobody comes back to check up on you, I could understand why some people get so incredibly lonely, nobody checked us or comes back just pick up a phone and asks if you are all right’*

She went on to say:

*‘I lost trust and faith in organizations, completely useless [naming a cancer charity] from start to finish and I did actually ask them for help and they didn’t do anything, nothing from them at all, when somebody dies everybody just falls away because there is no structure there for the people that are left behind all care all of sudden you are every alone, very very difficult time you lost somebody important and there is nobody around you, you are all alone*.’

Moreover, many of the interviewees said that they were sometimes becoming reliant on these relationships with support service staff as their only source of social contact. An African Caribbean woman living in Leeds, *said: ‘You rely on them, they are everything. Companionship, everything. They are very important. I referred myself* [to services]. *I’m very accepting of what comes along* (in terms of services)’.

This reliance on the support provided as a source of social contact is demonstrated in the following short case study.

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| **Case example: Support workers as the main source of social contact**  A woman talked about her history of abuse and mental health problems. She reported feeling lonely often. One of her daughters had died and there was conflict with her other daughters. Although she had some support from her family, she had developed an over reliance for support from a paid carer as that person was her main source of social contact. Her mental health issues made it difficult for strangers to enter the house and often prevented her leaving the house as she felt safer at home. The relationship she had developed with her paid carer, therefore, became her main source of friendship. |

Evidence of this on support workers being the main source of social contact was also found when exploring the role of the British Red Cross Community Connectors programme (Haywood *et al.* 2019).

For some other interviewees support services that they accessed had enabled them to gain a wider range of social contacts in the form of other members of the group but some said that they had sometimes become over reliant on those attending the group as a means of social contact and had not been able to establish relationships either with those attending beyond the group activities, or with others who did not attend the group. In Cardiff, most of those interviewed, regardless of ethnicity, age, gender or life transition point (bereavement or health condition) mentioned that they had some contact with people at the support groups they attended, but few had friends outside of this. Two of the interviewees in Cardiff, for example, said that the regular contact that they have is confined to people they meet at a support group or in the supported housing that they live in. This is not for any extraneous reason, such as being supported to get there. The indications were, rather, that interviewees found the drop-in support group venues to be supportive environments in which they could meet their peers.

Evidence from the evaluation of Time to Shine, a programme designed to reduce social isolation and loneliness among older people in Leeds, has highlighted the value of support staff and volunteers in the provision of initial friendship support and companionship but has also highlighted the importance of service users being able to establish their own relationships beyond programme interventions or services. This is particularly important for opportunities for sustained social relationships given the short-term funding nature of many loneliness services (Wigfield 2019).

**The role of place and sense of belonging in experiences of loneliness**

The role of place and sense of belonging in people’s experiences of loneliness were explored in the interviews. We found that a sense of belonging to the area within which people live was generally seen as positive and could possibly be a protective factor against loneliness. Indeed, for some of the interviewees, despite being lonely and not having as much social contact as they might have had in the past, or would ideally like now, a sense of belonging to a particular place was identified as one way in which they might be better able to deal with their loneliness following bereavement and/or when experiencing a long-term health condition. Across the different localities, interviewees, regardless of ethnicity, gender, or age mentioned various ‘places’ which were significant for them and provoked a sense of belonging, often the interviewees said they felt ‘comfortable’ and ‘at home’ in these places meaning that although they were often *alone* in those places they did not feel *lonely*. These places included places of worship, Mosques and Churches, sporting stadia and venues, parks and other small open spaces, particular cafes or shops, and/or their home.

However, for some who had experienced bereavement, sense of belonging possibly made them feel *lonelier*, as it was tied up with memories of their loved ones who had passed away. We now explore the factors which interviewees felt created a sense of belonging and then look at the dual edge sword that sense of belonging can have for those experiencing bereavement.

***Understanding the factors which contribute to a sense of belonging***

When people were asked in detail about their s sense of belonging to place, we found that interviewees spoke about a number of factors which could determine whether or not they felt a sense of belonging to the place where they live: the length of time they had lived in the area; feeling accepted; their ability to seek and obtain help; feeling they can interact with others and make social connections; feeling safe and secure; the presence of a diverse community.

*Length of time people had lived in an area*

Some interviewees, from both White British and BAME communities, and in all three localities, Cardiff, Leeds, and Sheffield, spoke about the length of time that they had lived in the locality as being a significant factor in promoting a sense of belonging to the area. The longer people had lived in an area, the more likely they were overall to say they had a sense of belonging to it and to point to this as an explanation of their sense of belonging. A White British man from Cardiff, originally from the south of England, said, for example: *‘well, I’ve been here since 1985, quite a long time, so yes I feel a sense of belonging’*. Another White British man from Cardiff, said: *‘Yes, I’ve always lived here, I feel like Cardiff is my home’*;and a White Britishwoman from the same locality said: ‘*Yes, I’ve lived here all my life and it’s all I know’*. The same sentiment was true for two older women in Leeds. Both had experienced bereavement. One was from a BAME community, and the other was White British, and both said they felt a sense of belonging to the area because they had lived there a long time. Many of the interviewees in Burngreave in Sheffield also said that because they had lived in the same place for a long time, they had a sense of belonging to the place they live in. It is not, of course, axiomatic that the longer one has lived in a place, the more one feels a sense of belonging to it, as some of the instances recounted below attest to.

*Feeling accepted*

The extent to which people felt accepted also had an impact on their sense of belonging to place, and interestingly this was mentioned by both White British and BAME community members. A 64-year-old Arabic woman living in Cardiff, for example, said *‘I feel accepted and loved in the place’*, when asked if she felt a sense of belonging to the local area. However, many of those who mentioned feelings of acceptance did so in a negative way, suggesting that they did not feel accepted and this meant they did not therefore feel a sense of belonging to the area within which they lived. These individuals often mentioned that they felt like they did not ‘fit’ in. Some said this was because they were migrants and had a different religion and so they felt they were different and did not fit. When asked if he had a sense of belonging to the area in which she lived, a 55-year-old Arab African woman living in Cardiff for example said: *‘Not really, dad was from Sierra Leone, my mother is Irish Catholic…some people in local area look down on me because I’m not from same religion…not everyone, but some people in the local area’*. This issue of not feeling accepted was also mentioned in relation to class, with a white woman aged 60 living in Cardiff saying that she does not have a sense of belonging to the area: *‘I feel judged because I live in a council flat and I’m not working and live in a mainly white middle class area of Cardiff’*.

Other interviewees mentioned that being accepted in rural areas was even more difficult than in urban localities, as two White British women who had experienced bereavement, both of whom lived in different rural settings discussed, attested to. One said: ‘*I’m not sure if you are ever a local in these villages, getting to know people you don’t know, it has been eighteen years’* [since she moved to the area]. The other made a similar comment:

*‘I do feel a sense of belonging now, but it took a long time. It is village; unless you are born there they never think you are one of them. I do now feel accepted, makes me feel good people have gone out their way to be nice. It makes me feel that I don’t want to leave the area now’.*

One interviewee, a 46-year-old White British woman currently living in Durham, said that she had never felt a sense of belonging to the area because she was not from the area but had moved there 15 years ago to be with her husband. She went on to explain that:

*‘…it was fine when my husband was there, it was the two of us but now he’s gone I don’t feel a sense of belongingness. I’m not from the area originally and I want to go back to where I lived before. I don’t see anyone to be or feel accepted because I’m not from the area’*.

*Ability to ask for/get help*

For other interviewees a sense of belonging is connected to the extent to which they get help or feel able to ask for help from others in their community. A White British woman who was lonely following the death of her parents said, for example:

*‘We are really fortunate I know there are people that I can call if I need help or anything some good friends, yes I feel accepted, I choose whom to share with my pain, like death of my parents, I talk to friends about loss because they experienced that before. My husband doesn’t understand he still has his parents, I tell him to have conversations with them because one day you will not be able to’.*

Similarly, a 77-year-old Arabic woman living in Cardiff, said ‘…*my neighbours are British, they are nice people and if they saw me fall, they would come to my rescue, but I do not make any sound when I fall. I can’t see the point of doing that* [drawing attention to her need for help]’. For both these women, being able to ask for help, even if they did not want to, but also for people to be understanding, was key to them feeling a sense of belonging to the area. Another ethnic minority woman, also living in Cardiff, made the same point though she felt that she could not seek help, and so felt less of a sense of belonging:

*‘I like the area where I live but I’m not able to enjoy it because everything is a struggle, when I fall, I don’t shout ... When I want to bathe, I have a bathtub and I must hold onto the water heater to get out of the bathtub. I broke it and did not tell anybody it was me.’*

*Feeling they can interact and make social connections with others*

Other interviewees said that their sense of belonging to the area was determined by the extent to which they could interact and make social connections with others, with people who are ‘like minded’, or with whom they had things in common. For example, two of the interviewees in Leeds were living in housing association flats in a small, fairly tightly knit, community and, as a result, felt they had plenty of people living close by with whom they could interact.

For some interviewees, it was especially important to have family in the area as that prompted a sense of belonging: *‘I’ve got family in the area, this is where all my cousins are and my uncles. Yes, in a way that gives me a sense of belonging’*, said a White British man interviewed in Cardiff.

Others found specific venues in their locality where they could interact. One man, White British and aged 47, from Cardiff, said: *‘I don’t talk to people in local area, so I don’t have a sense of belonging there, but I do have a sense of belonging to the pub’.* He went on to explain that he can go alone and feel comfortable, and also chat to people with a similar outlook on life*.*

Two men interviewed in Leeds, one Irish and one White British, said they felt a sense of belonging because they had social connections with others in the area. This could be as simple as someone saying hello. One said: *‘Yes, because people say hello and recognise me from different groups’.* The other said:

*‘Yes, because I talk to the people and I’m a member of the Labour Party, and I go to all the meetings. My local councillor comes and picks me up and drops me back as well. I joined for political reasons, but yes it has got me meeting people.’*

Meanwhile, some others who did not feel such as sense of belonging sometimes put this down to their lack of interaction with others*: ‘Probably not a sense of belonging because I have no interaction, it doesn’t have the home community feeling*. *I would like to live in smaller street where you can have relationship with neighbours, where children can play outside’*. This interviewee alluded to the fact that she did not feel entirely safe for herself or her children, and this adversely affected her sense of belonging. She went onto say: ‘*where I live now, children can’t go to shops, the street is busy, so the children can’t play in the street’*. This issue of security is discussed further below.

*Feeling safe and secure*

Feelings of personal safety and security emerged in some of the interviews in relation to a sense of belonging, with interviewees ether saying they felt safe and so had a sense of belonging or the opposite that they do not feel safe and so do not have a sense of belonging. A black African 64-year-old living in Cardiff said that a sense of belonging meant that she felt safe: *‘nobody harms me, and I don’t harm anyone as well’.*

A White British woman living in Leeds who was experiencing mental ill-health said: *‘I feel accepted in the house, because I won’t go out. So, I stay in, it’s my security.* AnotherWhite British woman experiencing mental health challenges, aged 45, said that she was being victimised and so did not feel a sense of belonging:

‘*No definitely not. I am currently being bullied and victimised by neighbours, feels like neighbours are really terrorising me. I have quite a good relationship with a new neighbour who is also quite creative. I feel like I need to move away from the area as soon as possible’. I am like Nelly Furtado* *“I’m like a bird, I don’t know where my home is …home is where those fuckers ain’t* [referring to those bullying and harassing her].’

Another White British woman, 60 years old, also said that she did not feel a sense of belonging as she was having difficulty with a noisy neighbour who was keeping her awake at night. She said this stopped her from living her life as she wanted to live it. She pointed out that other people she was friendly with had also moved out because of this noisy neighbour, so that had had a further negative impact on her local social networks.

*Diversity can create a sense of belonging*

There is some evidence from the interviews that diverse communities may have the potential to create a greater sense of belonging, at least for those who would not fit in a more homogenous community. Indeed, many of those who were interviewed in both Butetown in Cardiff, and Burngreave in Sheffield, (both localities with diverse populations), said they felt a sense of belonging to their immediate locality and that this was positive in terms of their experiences of loneliness. In Sheffield, a variety of the factors, many of which have been mentioned above, were put forward as to why they had a sense of belonging, as the following case example shows:

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| **Burngreave: a place where people can feel a sense of belonging**  Burngreave in Sheffield is home to a diverse community, and past research in Burngreave has highlighted that it is a community where people feel that they can be themselves and feel accepted for who they are (Wigfield and Turner 2010). Residents interviewed in Burngreave mentioned community events, such as street parties and pantomimes, saying that these both brought the community together, enabling people who are lonely to meet and interact with others. They also created a sense of community spirit, and sense of belonging, which could act as a buffer when residents were feeling particularly lonely. Those interviewed said that this made them feel ‘*happy and secure’* and gave them a *‘sense of belonging’*. People said that they felt that they could be themselves. |

*A sense of belonging as a dual edge sword*

The findings of the interviews show that although a sense of belonging can potentially be a protective factor against loneliness, it can also be a dual edge sword facilitating loneliness for some. For some of those who had experienced bereavement, a sense of belong to a particular place could have the reverse affect and make them feel *lonelier*, especially when the place that they had a sense of belonging to was one which they frequented with, or which reminded them of, a loved one who had passed away. Place of residence, for example, appeared to represent a particularly strong emotional characteristic which could have both a negative and positive effect on experiences of loneliness. For some of those whose spouse had recently died, their home had suddenly felt a very empty and lonely place to be, with constant reminders of their loved ones. To try and overcome their feelings of loneliness two interviewees mentioned that they had moved to different accommodation with one stating *‘I needed to move out because I was feeling isolated and lonely’*. Another interviewee described how challenging living on his own is for him following the recent loss of his wife and that despite regular visits from his sons and grandsons and having other social contacts he feels *‘lonely all the time’* in his own home*.* However, another interviewee, a 64-year-old Arabic woman, said that the sense of belonging and memories of her time with her late husband in the flat they shared together helped her enormously, and that if she was asked to move out she would pay extra to be able to stay. The following short case study of a man in Leeds provides another example of this.

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| **Sense of belonging to place and bereavement**  A man living in Leeds was forced to move home after his wife died because of the cost. He had found the move very isolating because he had lived in the flat with his wife since 2003. He described how, as a couple, they did not mix with many people, and so when his wife died *‘part of me went with her’*. His new accommodation did not suit him as most of the people living around him were ‘elderly’, and he said that although he knew some of them, *‘most of them stay indoors and don’t come out, so I don’t know their names’*. He said, *‘where I am now is very isolating, all I can see is trees, trees, trees’*. He said he mostly stayed ‘*indoors’* and did not socialise, and he wanted to be around more people. |

# 5. Barriers to connections among people going through two key transitions – bereavement and health

When examining the findings from both the interviews with stakeholders, and interviews with members of both the White British and BAME communities who are lonely due to a health condition and/or bereavement, we can identify a number of key barriers to connections which include both physical and psychological barriers, and quite often a combination of the two.

A number of stakeholders and interviewees highlighted that poor health often leads to physical and mental impairments which in turn means that individuals have difficulty accessing their local community and/or participating in social activities. Physical barriers were mentioned by some of the interviewees with a health condition in Leeds and Sheffield, and all the interviewees in Cardiff who had a health condition, which included long-term conditions such as diabetes, arthritis, cancer, depression and anxiety. Many of those experiencing mental ill-health mentioned that psychological barriers impacted on their ability to make social connections, as did those experiencing loneliness due to bereavement.

Many of the interviewees with a health condition said that they would like to spend more time with other people such as family or friends, or would like to engage in social activities, and many mentioned barriers preventing them doing so. This was the case for those with both physical mobility issues as well as mental-ill health. Some of the interviewees mentioned that these barriers were not necessarily experienced all of the time. This demonstrated that individuals with health conditions can move in and out of experiences of social isolation and loneliness over the course of a day, a week, a month, depending on how their condition is affecting them at that time, a theme mentioned earlier in the report in Section 4. One interviewee in Leeds, for example, had arthritis and mentioned that he is unable to leave the house to connect with others but that this only affects him when he has a ‘flare up’ of his condition.

These physical and psychological barriers to social connections that were mentioned by the interviewees linked to a variety of challenges which are now explored in detail: leaving the home; accessing transport; engaging in physical activities; sustaining social connections; completing everyday activities in the home; psychological issues; stigma; language; racism; accessing existing loneliness services specifically for bereavement and health conditions, each of these themes are explored further below.

***Difficulties leaving the home***

Difficulties leaving the home were mentioned by a number of the interviewees who had health conditions, regardless of ethnicity, gender or whether they were experiencing a physical or mental health condition.

Some of the interviewees mentioned that they were in severe pain and so frequently could not leave their home. A 50-year-old woman from an ethnic minority background living in Sheffield said, for example*: ‘my condition limits what I can and can’t do. I love walking but cannot participate because of the pain caused by my arthritis. I am constantly in pain’.* A 69-year-old African Caribbean woman, also experiencing arthritis, said they could not walk far because of the illness.Other health conditions which affected their ability to leave the house were also mentioned by interviewees, including by a White British woman living in Cardiff who had COPD, a 55-year-old African woman who had sight difficulties which meant she could not go out alone, and an African Caribbean woman in her 40s living in Leeds with serious mobility issues who said: ‘ *it makes it difficult for me to get about to see people’*. A 64-year-old Arabic woman living in Cardiff said that she is not able to walk a lot, and when she sits a lot she needs five to ten minutes to move: ‘*when I want to wake up when it is dawn to pray, I feel as if I’m 70. I can’t walk out a lot as before’.*

Interviewees experiencing mental ill-health made similar comments about having difficulties leaving their home. For example, a White British 49-year-old man living in Sheffield, said that he suffered from anxiety, panic attacks, and depression. It has a great impact on him, and when he is having a panic attack he has to stay at home. For some interviewees, being housebound is a regular feature, for others such as a 63-year-old Pakistani woman living in Cardiff, being housebound could last for a few days at a time: *‘Sometimes I can’t leave the house for two to three days, so I lay in bed unable to move a lot’.*

Some interviewee with multiple health conditions explained how *‘it’s a real struggle to get out’,* as a 62-year-old Black African woman, living in Cardiff with multiple illnesses including bladder stones, arthritis, short memory loss, backache, and mental health issues, said. She went onto say: ‘*I can barely walk, and I have to take different buses to get to services’.*

Sometimes this inability to leave the home can be exacerbated by the locality within which people live. A 77 year old Arab woman living in Cardiff with many physical and mental illness, including depression, explained that she lived in a hilly area which makes leaving the house even more difficult for her: ‘*I’m not happy with it* [the house and the area] *because it is in a hilly area and I keep falling down as I walk’*. *I cannot walk anymore’.* She explained how not being able to walk prevented her from going to places and that this this prevented her from leaving home and therefore she has become isolated.

One interviewee, a 55-year-old African Arab woman with sight difficulties, said that her sight problems mean that she cannot leave the house, even to get to health appointments: ‘*I’ve missed many appointments because there is nobody to help me walk to the doctor’.*

Some of interviewees were not necessarily housebound by their own heath condition but by that of the person they care for. These carers cannot always leave the person they care for unattended and/or feel guilty in doing so. A 69-year-old African Caribbean woman, for example, stated that she is too busy taking care of her husband to be able to get out and meet people.

***Transport***

Transport featured quite prominently in discussions about the barriers to connections. The interviewees reported that public transport was not always accessible for people with physical health conditions or for some with mental ill health conditions such as anxiety and depression. Options such as owning a car or using taxis were often precluded due to the financial expense and indeed many of the service providers who were interviewed reported an unwillingness and/or inability by many service users to pay for transport to attend support. The cost of a taxi was a major barrier for many. One interviewee, for example, said that she cannot use public transport because of her anxiety but cannot afford to use a taxi and so this means she is prevented from spending time with family and friends. A 63-year-old Pakistani woman living in Cardiff explained that: *‘Money is sometimes a problem, if the wedding or the gathering is far I can’t get there, I can’t afford the taxi fares, if it is a bus reach I have a free bus pass, if it is not I’m stuck at home’.* An African Caribbean woman in her 40s, with sight difficulties, living in Leeds similarly said; ‘*I can’t get out to meet people because of transport, mobility, finance. I can’t drive, I don’t know the streets well, a taxi is the last thing I can afford’*. And an Arabic woman living in Cardiff, aged 77, said: ‘*the distance is far, to go to the centre [of town] I have to take two buses. I cannot afford a taxi, its 20 pounds every day. My health condition does not help.’* Reporting of these transport difficulties was replicated by interviewees from both the BAME and White British communities. Indeed, a White British woman in her 40s, who had recently had a heart attack and experienced mental health issues, and was having difficulty getting out, said that she could not use public transport because of her feelings of anxiety: *‘depends on my anxiety on the day. If I have to travel any distance, to the GP I get taxi. I feel tired and fatigued very easily’.* When asked if she was able to use public transport at all*, she relied: ‘No it makes me too anxious****.*** *I can’t to pay for taxis but I’m not comfortable with the public transport.’*

There were no overwhelming differences in the way in which members of the BAME and White British communities with health conditions reported these transport difficulties, but a small number of people from BAME communities additionally mentioned poor public transport provision and language barriers preventing them from traveling on public transport (language is picked up again later in this section). Other research (Lucas 2004; Wigfield and Alden 2017; Wigfield 2019) indicates that accessing public transport can be a challenge for some people from BAME communities due to a variety of issues such as lack of availability, poverty, issues of personal safety, and language barriers. So, for some people from BAME communities with health conditions, these transportation barriers may be more intense.

***Difficulties engaging in physical activities***

For many interviewees their heath condition, the associated difficulties leaving the house, and challenges using appropriate transport meant that they were unable to engage in physical activities, which they felt were an opportunity for them to sustain or make new social connections. Examples were provided by men and women interviewees from both White British and BAME communities. A woman from a BAME community in Cardiff explained how she is overweight and so was signposted to yoga by a charity, but she said that she cannot do it: *‘people wanted me to sign that I wanted to do it [yoga], but I cannot get out of the house to get to the yoga’*. Similarly, a 64-year-old Arabic woman living in Cardiff said that there are services like gyms, but she cannot join them because she has ‘*no health to run’*. She does not want people to feel sorry for her, so she would rather stay home. A White British woman, also living in Cardiff, explained how her health condition would come and go and, although this meant that she could sometimes engage in physical activities, she found it difficult to start again once she had stopped: *‘My rheumatism means I can’t get out when its wet, then I lose contact with the groups I’m part of and then it more difficult to get back into the groups when the weather is better.*’ A White British man, also living in Cardiff, said that he used to play football for the YMCA homeless team and this had connected him to other people. But he said of his current situation: *‘I have the skill not the energy. I have had to stop because of seizures. I’d like to do again it when my health improves’.*

***Challenges sustaining social connections***

Many of the interviewees said that they faced particular challenges resulting from their health condition which meant that, even when they were able to leave the house, they were unable to sustain social connections. Some who had experienced bereavement made similar points. A White British man living in Cardiff who experienced Epilepsy explained that he had recently had an aneurysm, which had had a significant impact on his memory and his sensory awareness. As a result, he said he could not easily sustain social connections, can forget where he is, and can forget where he is going or who he is meeting.

A Nigerian woman living in Sheffield, who has arthritis, said that she can sometimes feel okay and other times feel not so good. This means she does not want to arrange to meet people because she *‘doesn’t want to let anybody down by having to re-arrange things the last minute’*. A 35-year-old White British man with mental health issues who was living in Sheffield made a similar point: *‘I suffer from anxiety and sometimes need to cancel the last minute…Arranging things doesn’t work so you end up not bothering’.* Another similar example was provided *by a*n Indian woman in her mid-70s living in Leeds:

*‘Most mornings, I feel headache or dizzy. I take paracetamol and go to sleep for an hour or two’.* *‘I get sleepy, and headaches stops me. I have to have paracetamol and then sleep. I have to sleep for one and a half hours.’*

She went on to explain that these periods of time when she felt unwell and sleepy meant it was difficult arranging to meet people or to go to places.

Another interviewee, a 55-year-old woman living in Cardiff of Arab-African heritage, with sight difficulties, said that cooking used to connect her to others. She used to cook biscuits and cookies and share them with other people. However, she said: *‘I burned the cookies and the kitchen because of my foggy eyesight. I couldn’t control the hob. I used to share my cooking...now that’s gone’*. She went on to say how her poor vision had adversely affected her willingness and ability to participate in activities with, and that this was exacerbated by the stigma associated with being unable to see, which meant that others did not always know she had sight problems and assumed that her lack of recognition of them was because she was being anti-social (stigma is returned to later). A White British woman, living in Sheffield, reported how she used to be socially active, but now, because of her anxiety and fatigue, she finds it difficult to carry out basic daily activities like shopping which was one of the main ways in which she had connected with others.

This inability to make or sustain social connections due to health conditions was sometimes even more challenging for those with multiple health conditions, including both physical and mental ill-health. For example, a White British woman in her 40s said:

*‘it affects me massively, because I’m less physically able to do, to maintain daily living. Mentally it immobilises me because of the fear and anxiety, I have panic attacks. I am tied, fatigue…it doesn’t allow me to do much, to meet people…to participate’*.

***Difficulties completing everyday activities in the home***

A small number of the interviewees mentioned that it was not just their inability to leave the home which prevented them from making and sustaining social connections but the fact that they lacked the ability and/or confidence to complete the activities of daily living to be able to offer hospitality to others who come into their own homes. For these interviewees this meant that they were both unwilling and felt unable to socialise, even in their own home. Two examples of this are provided in the following case study examples:

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| **Case study examples: inability to undertake daily living tasks means socialising at home is a challenge**  A 62-year-old Black African woman living in Cardiff has multiple illnesses and is also widowed. She cannot get out of the house easily but also finds it difficult to invite people into her home for social interaction: ‘*it affects my day-to-day life. I can’t get up from bed without becoming breathless and needing the pump... It takes me from 7 to 10 minutes of struggle to finally get up… My house smells bad and my bed is messy because I cannot do it myself… When I meet people, they are talking about me, and instead of helping me they just look at me and feel sorry. I don’t ask for help and try to do it myself.’*  A 64-year-old Arabic woman, also living in Cardiff, said: ‘*When I was healthy, I would have many people over in the house. I was always sending out invitations, even when someone comes for a short period, I make sure to fill the table with food. Now I cannot**even hold**the knife properly, I’ve lost those connections, I cannot host people and take care of them as I used to’.* |

## Psychological barriers

Some of the interviewees who had either a physical and/or mental health condition explained that these did not just create physical barriers to them engaging in their local community and making connections, but also created psychological barriers. A small number of those who had been bereaved also mentioned psychological barriers, which are explored further below.

One interviewee explained how her health condition meant she felt less confident, and was therefore anxious about accessing services which enabled her to connect with others. She said that, due to her diabetes she had had to stop attending a service due the food being served there, *‘mostly coffee and sweet biscuits’,* which she was not able to consume and, as a result of lack of food, had experienced episodes of fainting. The physical ill health had therefore obviously exacted a toll on her confidence levels. She described the impact that diabetes is having on her life, stating:

*‘I used to do a coffee morning in the local church but gave up because I fainted a couple of times. As it was unexpected and came without warning, I am now afraid to leave the house in case if it happens again.’*

Another person, an Indian woman in her mid-70s living in Leeds, stated: *‘If I feel dizzy, I go to bed and sleep, because I don’t want to speak to people…. I can’t face it.’*

Many of the interviewees in Cardiff with a health condition were experiencing mental ill-health, with some of them also having conditions which affected their physical health. They all discussed the ways in which these health conditions had adversely affected their ability to participate in social life. Their lives had often been completely disrupted by a deterioration of their health issues, meaning that they felt psychologically unable to interact socially. Mental illness had created social anxiety, the Cardiff interviewees often reported, fear of how they might be received by others, or fear of attack. These psychological issues obviously have a direct impact on a person’s confidence, with resultant consequences for their ability to interact socially. No one mentioned any other underlying reasons for this such as losing a sense of identity or sense of purpose. The following case study examples provide some insight into these psychological barriers:

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| **Case study examples: psychological barriers to social connections resulting from mental ill-health**  A White British man living in Cardiff, who experiences mental ill-health, when discussing the factors which affect his ability to interact socially, said: *‘Own inhibitions, no other factors, but don’t feel brave enough to get involved. I have mental health paranoia, I think that no-one likes me, I over think things and get paranoid…. I assume people aren’t going to like me before I meet them. I’m wary of other people’.* He said this makes it difficult for him to connect with people: *‘I’m exhausted in work, the job is hard enough as it is, but this makes it even harder. I still have some mental health symptoms, if he hears people laughing I thinks it’s about me, if I see people talking and I can’t hear them, I thinks it’s about me’.*  A White British woman, aged 40, who recently had a heart attack and experiences mental health issues, talking about relationships with Friends, stated: “*I’d like to spend more time with them but suffering with mental health issues, I don’t always feel like it. I get socially anxious; that make contacts difficult. But having a dog means that I get out more often and make contacts more often than what I did prior having a dog.’* |

For some of the interviewees who had been bereaved, the death of their loved one had triggered similar kinds of psychological barriers, with some referring to the anxiety that they experienced having to *‘get used to living on their own’,* or *‘getting out there on their own’*. A 34-year-old Bangladeshi woman, for example, who was living in London and had experienced bereavement, said:

*‘I am processing my grief maybe I am not 100 per cent utilising my energy and resources all the way I should be that is the current circumstance… I think right now I’m not ready to do too much; I just need to the do the things that can only do the things that help me now.’*

A White British woman, who had experienced bereavement and was living in Somerset, mentioned how she did not feel like interacting and so had ended up ‘*isolating herself’*. She said:

‘*factors that do stop me… the fact that I do write so I isolate myself sometimes don’t feel like it, can’t use my writing as an excuse when I should go out and do something… I use writing as an excuse to stay in, when you find yourself on your own, if you are part of couple, you don’t wanna get involved with other couples.’*

Sometimes these psychological issues affected family and friends of the interviewees, who became worried and anxious about the interviewee going out and interacting with others. A participant in Cardiff, for example, explained how he had an epileptic seizure during a walk in the park with his eight-year old daughter. The episode was upsetting for both of them, to the extent that his daughter is now worried about him going out and is checking that he has taken his medication before they leave the house. He explained how there was nothing physically stopping him leaving the house, but fear of having another epileptic seizure meant that psychologically both he and his daughter were reluctant to go out.

## Stigma

Poor health was often perceived by some of the stakeholders, and by a small number of the individuals who experienced it, as creating a stigma. Some interviewees said that they sometimes hid poor health to hide the level of dependency on others that they now experienced, and to avoid the stigma relating to it. The implication was that by hiding the health condition, and the associated stigma of dependency, they were better able to maintain their social standing within the community and their sense of personal identity. This, in turn, has the potential for individuals to become more withdrawn as their health condition worsens and/or it becomes more difficult to hide. For stakeholders aiming to support those experiencing mental ill-health, stigma and the resulting hiding of the illness was a key challenge as it created difficulties encouraging people to get involved in their service provision.

There were a small number of examples cited by the interviewees of particular ethnic cultures attaching a stigma to health conditions and the resulting implications for family life and the traditional stereotypical gender roles. A South Asian woman in Leeds fom the Sikh community, for example, had a particularly traumatic experience, leading to intense loneliness when her husband removed her from their flat following her stroke due to the stigma associated with having a wife who could not support him. She stated:

*‘then I had a stroke in 1996, ten years after getting married. I couldn’t cook, I was no use to him anymore. He had used me for ten years, but I was no use anymore. He put me in a wheelchair and put me out in the street. I called 999 and the police took me to the housing department. I got a council house.’*

Within some communities, issues such as disability, poor health and bereavement can carry a culturally-determined symbolism and may be effectively be taboo. One stakeholder, for example, of a sight loss charity supporting the South Asian community, explained what is sometimes the impact of a person’s vision loss on their social connectedness. Some members of the community might hide their disability, because of the perceived or actual stigma that they believe is associated with it.

As she noted with respect to the South Asian community:

*‘there is a lady losing her sight. She doesn't tell anybody. People pass her by, but she doesn't say hello because she can't see them. They think she's so rude, but she is not telling them, she is just making excuses like ‘I didn't see you’. She hasn't got the courage to say, “I'm losing my sight” ...this is causing more social isolation and loneliness’*.

The stakeholder explained that this individual did not mention that she had a sight problem because it was taboo among the South Asian population.

Other stakeholders had highlighted how they had struggled to get individuals from different communities to attend support as they did not want to be seen as asking for help or in need of support. Stakeholders providing bereavement support for the local Irish community and more generalised support to South Asian communities in Leeds, being notable examples. Nevertheless, it should be noted that these cultural issues did not manifest themselves widely among the individual interviewees with similar concerns being raised by members of the White British population too.

Many of the interviewees who had experienced bereavement appeared to follow similar experiences and barriers to connection linked to stigma, as those with health conditions. As with poor health, bereavement was taboo, and some suggestions were made about people sometimes walking on the other side of the road to avoid speaking to a person they know who has been recently bereaved. Attitudes towards bereavement may vary between communities and cultures, although this did not emerge from the interviewee findings. However, what did emerge is that some people see seeking support as a sign of weakness and people are often *‘too proud’* to seek support. This is particularly the case for some of the men who were interviewed, and some from BAME communities where it is expected that the extended family should provide all the support required (see Wigfield 2019 for further discussion of this issue).

***Language***

As discussed in the accompanying report *‘Barriers experienced by BAME individuals in accessing loneliness service*s’ (Wigfield 2019), language and, in particular the inability to speak and understand English, can be a barrier to some people from BAME communities making social connections and forming relationships with others. This issue was also mentioned by some interviewees in this study, and although language difficulties do not emerge directly as a result of bereavement or a health condition, they do mean that the impact of bereavement or a health condition can sometimes be exacerbated. A 63-year-old Pakistani woman living in Cardiff, for example, said that because of her health sometimes her main source of social contact was with health professionals, but she could not engage with them: *‘I have a language problem. My level has improved, and I can talk bit more. In the hospital they speak so fast and I cannot understand so they bring an interpreter.’*

Of particular importance for people from BAME communities with health conditions is that being unable to speak and understand spoken English can mean that some are reluctant to accept support for a health condition as they are wary of taking medicines when they do not understand what these medicines are. A 77-year-old Arabic woman, living in Cardiff, for example, said thatshe had a person who used to go to her house to check her medicines, but that person did not understand her; they could not communicate together. She then refused to allow the person to come to her house anymore, because she was afraid of what the person was saying and what she might say to others: ‘*if you do not know the language here, they break you, play you like a ball.’* This interviewee said that there was no-one she talked to daily. She would not see anybody for weeks, and she spoke to people a few times only each month/year. She had her neighbours, but the conversation did not exceed ‘*hello, and how are you’*. The language barrier contributed to the conversation being short.

***Racism***

A couple of the interviewees mentioned racism being a barrier to them connecting to others and again, although this did not emerge because of their health condition or because of bereavement, it meant that their ability to interact with others was exacerbated. One interviewee, a 62-year-old Black African woman living in Cardiff, said that some people will not listen to her, they will just look at her. She did not want to mention the names of the places where this occurred, but she said that she experienced this in charitable services: *‘When they look at my colour, they treat me differently’, s*he said, *‘if the people are Arab and have lighter skin, others are not as concerned as much as they are with her having a dark skin’.*

A 34-year-old Bangladeshi living in London who had recently been bereaved talking about racism said:

*‘For me because my parents migrated to England in the 50s, when I was growing up the area 98 per cent were white English, and we struggled with a lot of racism. Even though I was born in England and I have a very English accent, despite that I faced lot of racism growing up. I had major issues growing up with violent behaviour going on in the area with ethnic minorities. The only issues I have experienced with other ethnicities is probably just with white British people.’*

She implied that this affected her ability to form social relationships with White British people however she said that things have now changed and that now this racism is *‘a little bit more institutionalised and a little bit more subconscious*’. She gave an example: *‘a bit of inequality when you go to school opportunities at work, when you try to network sometimes as a minority you will experience some inequality and I have throughout my life but not so much now’*.

Clearly, people’s sense of whether they are welcome in the community, no matter what their ethnicity, has a direct bearing on their sense of belonging to an area, and a concomitant impact on their potential for experiencing loneliness.

## Gaps in existing services for bereavement and health conditions among BAME communities

The stakeholders and individual interviewees were asked about any loneliness support services currently available for those who had been bereaved or who were experiencing specific health conditions and very few knew of, or reported, any. More general loneliness services were mentioned by some of the stakeholders such as the Ageing Better programme in Sheffield (Age Better Sheffield) and Leeds (Time to Shine), but there appeared to be a lack of knowledge of any specific loneliness support services for people at these two life transition points. When more general services for those who had experienced bereavement or had a health condition were explored, two key issues emerged: a particular lack of services for people who have been bereaved; and a lack of culturally sensitive support for members of BAME communities. Each of these issues are now explored in turn.

***Services for people who have been bereaved are particularly lacking***

More generalised support services for people with health conditions, which were primarily of a medical nature, were identified by stakeholders and individuals. Those with a whole spectrum of health conditions appeared relatively positive about the general support they had received from their GPs, hospitals, and healthcare professionals. In Cardiff, for example, some participants reported getting support with their health issues from private coaching/mentoring, medical authorities, support groups, and well-being courses.

However, when reviewing the services available for bereavement, both the stakeholders and individuals felt that the experiences of those who had been bereaved were particularly under-supported by existing services. Some key aspects were highlighted by many of the stakeholders. Firstly, it was pointed out that there are simply not enough services that support people with bereavement. This became evident in the research for this study as it was difficult to identify support services for people who are bereaved and therefore recruit those who had experienced bereavement for the research. The lack of bereavement services means that there are often long waits to get any support. Secondly, GPs were reported to often prescribe more traditional ‘one to one’ counselling support they knew about and lacked the time to investigate other options. Furthermore, GPs were reported to lack the time to ‘follow up’ referrals to assess if the support was taken up and had made a difference for the bereaved person. This links to a point made in the other piece of research commissioned by the British Red Cross and Co-op partnership (Wigfield 2019) where the importance of tracking referrals through both social prescribing and other mechanisms was identified. The stakeholders pointed out that where services to support bereavement were not used or did not exist, there was a potential risk of those who had been bereaved developing mental ill-health, promoting a negative downward spiral effect on opportunities for social interaction, resulting ultimately in loneliness.

This lack of appropriate support for bereavement was mirrored largely by the interviews with individuals who had experienced bereavement. A bereaved interviewee in Leeds, for example, was positive about the way in which members of her family had supported her but much less so by the formal support service that she had tried to engage with: ‘*I’ve had a little [support] from a lady {bereavement service], but she’s not been consistent; but my sister’s always been brilliant*.’ Some mentioned professional support through organisations such as Cruse but explained that there are very few options available and those which do exist have waiting lists in operation as one woman in Leeds explained: ‘*I’ve been to doctors, they said to go to Cruse but they said there’s a waiting list and I haven’t heard further from them. Just my family.’*

Similarly, a White British man who had experienced bereavement and was living in Cardiff, said that he had been waiting for one-to-one counselling for three years, but has not had any, and said that he is now not going to be able to get grievance counselling. A 34-year-old Bangladeshi woman, who had recently experienced bereavement, said that she would love to hold a death café or a bereavement brunch in the area because nothing like that existed in the locality.

Interestingly, none of the bereaved interviewees from BAME communities reported getting any informal support following bereavement, save for one saying that friends called on the phone, and another saying that her children did the cooking. A couple of interviewees from BAME communities indicated that they would not have known where to go to get such support.

Some of the interviewees who had been bereaved said that they had tried to get formal support but had been unsuccessful due to its limited availability and had often been forced to rely on their family and/or friends. For example, one White British woman participant in Cardiff, said: *‘when things like that happen [bereavement], you realise who the people are who care for you; also realising that some of the family can be quite selfish.*’ Without a supportive family and/or friendship network, people often reported that they had to rely on self-support: ‘*I didn’t get any support…but I got myself into work, and I got myself off the tablets* [anti-depressants]’.

This interviewee mentioned the importance of people who ‘care’, and this may be one of the key ingredients to having meaningful relationships which then may provide a buffer to experiences of loneliness at times of bereavement. A definition of meaningful relationships is provided by Wigfield *et al*. (forthcoming 2019), and it is a factor that needs exploring in further research.

***A lack of culturally appropriate support for members of BAME communities who have been bereaved and/or who have a health condition***

The interviews with service providers seemed to indicate that there is sometimes limited support to meet and understand cultural need. Support services may be limited in respect of being able to meet specific cultural or community needs. Barriers of language were highlighted by stakeholders as one aspect. Staff able to communicate in the first language of the bereaved, for example, is essential for any therapeutic relationships and often bereavement support services are quite generic for the population at large regardless of ethnicity. One stakeholder highlighted that a service aimed at the Somali community based on a formal appointments system failed to recognise an informal culture of ‘dropping in’ and finding support. Some stakeholders talked about ‘long-term’ bereavement issues; people that continued to experience intense feelings of grief long after a person had died. The immediacy of support when somebody first dies may be provided by community networks. One stakeholder, for example, highlighted that within the Yemeni Muslim community in Sheffield, there was an acknowledgement within the community to support bereaved people, but in actual practice this happened usually only on a short-term basis, and yet it is obvious from this and other research that longer-term support may be needed.

Dealing with sensitive issues of bereavement and health requires creating a safe and sensitive environment for individuals who use services and require support. Stakeholders felt this could be a problem for people from BAME communities. On one hand, for some stakeholders, it was important that support could be provided by staff who understood the community and were part of the community. In this respect, the bereaved or ill individual will have access to someone who understands their culture and beliefs, and so will be able to support them appropriately. On the other hand, the sensitive nature of an issue may mean that an individual is uncomfortable disclosing these to another member of their own community for fear of being judged or, it affecting their standing in the community. One stakeholder argued that it is important not to assume that individuals from BAME communities will always want to discuss sensitive issues with people who have a connection to their own culture, and this means ensuring that all staff have appropriate training, regardless of their ethnicity, so that they can understand the needs of different communities for whom they offer a service. Several stakeholders mentioned that one of the barriers for people from BAME communities with health and bereavement issues may be that GPs, health, and community workers may not have the cultural understanding to deal with people from different communities. It is important, therefore, for support services to understand the different cultural aspects of how diverse individuals may cope with health and bereavement issues. It should be noted, however, that these issues were *not* identified by most of the people from BAME communities interviewed for this work.

The traditional notion of the ‘family’ remains central among many BAME communities. In some cases, as seen earlier in this report, particular health conditions may see a family breakdown and even disconnection from the family depending on the nature of the illness and impact on the family. A number of stakeholders, for example, highlighted that dementia may not be understood within some ethnic communities and culturally appropriate information and advice is not provided for the family or communities to make sense of the condition. The need for culturally appropriate information was one of the issues emerging out of an evaluation of a large central government investment in training for carers (Caring with Confidence) (Yeandle and Wigfield 2011). Caring responsibilities may also be shaped by what is seen as the role of the family versus the state, and experiences of individuals who need care and support can differ in this respect. One stakeholder highlighted that it may be difficult for some BAME communities to consider state support such as residential care while for others, this is acceptable. At a fundamental level, this may make it difficult for someone to access hospitals and health services and/or request support with their health and care needs from those providing services. Stakeholders felt that more personalised support focused on getting to the root of what would work for the person as an individual would help. For example, services where people can be seen in their own homes where it is difficult for the person to leave their home due to physical and mental health issues.

The interviews with the stakeholders also identified that some services for BAME communities may be provided and funded based on racialised rather than ethnic categories, which has the effect of homogenising particular groups. For example, one stakeholder talked about their service for the ‘South Asian’ community but recognised the service was shaped largely by Muslim and Sikh voices rather than the Hindu community. Accordingly, even with services aimed at BAME communities, it was important to recognise diversity and the different cultural aspects of communities whether of religion, family structure, migration histories or previous life experiences within those communities. As mentioned earlier and elsewhere, (Wigfield 2019) lack of funding may impact on such services. There may be assumptions that ‘specific’, BAME services can universally meet ‘cultural needs’, and are culturally competent but this may not always be possible. Smaller BAME communities in a locality may not be as well served as larger BAME communities within this context. Larger communities may find information in their own languages and have specifically targeted services to support them, but smaller minority cultures may not; they may also have support organisations and the resources to allow them to engage in lobbying and tendering for programmes to support their community. In this respect, newly arriving people, without recourse to an established community and so potential support, could be particularly disadvantaged and struggle to access support in terms of health and bereavement. This may be particularly difficult for people from BAME communities with multiple issues. Migrants understanding the systems when arriving in the country, their lack of language skills and lack of social capital to be able to access support were highlighted by stakeholders as problematic when working with these minority communities. As one stakeholder argued, services need to cater for diversity and that:

*‘it is very important to design and deliver the service around the lifestyle of people who are going to use the service. How are the people – what is their lifestyle like? What are their attitudes towards services? How do they move around their community? What are they used to? What are they not used to? We have to adapt to them.'*

## Some of the service providers pointed out that it is therefore important that services are co-produced by people from BAME communities. Stakeholders felt that where residents, and members of BAME communities, are involved in running support services and organisations, it ensured that their voices are listened to and heard in relation to developing services. It also ensured connections were made across and between organisations, and with community leaders. As such, stakeholders provided examples of where services were empowering people to have some control; and said that this was creating positive outcomes. For example, Asian women coming together to learn English and support each other to learn, make friends, and develop together; or spaces where people come together to chat and share drink and food. These spaces provided a conducive environment within which peer support is available for individuals from similar backgrounds, harnessing cultural aspects for their well-being. Or, another example is initiatives which see different communities working together, such as a Community Allotment Project, which was mentioned, where individuals from different communities work together to grow food and garden. These kinds of projects focus on the assets of all individuals and groups, and not just the deficits in relation to their health condition(s) or in relation to their bereavement, and so were important in this respect. A participant from a BAME community stated, for example: ‘I’d like to be more involved in meetings, decision-making meetings, for senior workers or informal meetings...but they refer you to services, but I’m not allowed to make decisions about things.’

# Intersection of the experiences and barriers of connection relating to bereavement, health conditions, and ethnicity

# There are a number of different ways in which the experiences and barriers to connection experienced by people from the BAME and the White British communities at the two specific life transition points, bereavement and experiencing a long-term health condition, intersect. These relate to: multiple factors compound experiences of loneliness; amplification of confidence issues; and the requirement of longer-term strategies with the requisite depth of support. Each of these points are now discussed in turn.

## Multiple factors compound experiences of loneliness

Combinations of physical and mental ill-health, physical ill-health and bereavement, mental ill-health and bereavement, or all three conditions were sometimes experienced simultaneously by the interviewees, and this presented additional difficulties in terms of their ability to have, and desire for, social connections. Stakeholders, in fact, highlighted an association between these various factors, which had a detrimental effect on each other, and mentioned that this together provided additional barriers to social connection and interaction for an individual. These multiple factors can create increased despair, and a higher risk of poor outcomes such as loneliness and low well-being. Furthermore, stakeholders argued that issues of health and bereavement intersected with other aspects of disadvantage like poverty, poor infrastructure, poor local services, and limited transport, and some examples of these issues were provided in Section 5 by the individuals experiencing these. In the following short case study, for instance, the impact of both physical and mental illness can be seen to have had an important effect on loneliness and social isolation for one woman from Sheffield. This, in turn, had an adverse impact on her health.

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| **The two-way relationship between ill-health and loneliness**  After experiencing a heart attack and being in rehab, a woman living in Sheffield began to suffer from depression and chronic fatigue syndrome. She said: *‘Prior to the heart attack. I was more outgoing and confident. I was more familiar with the neighbours.’* As a result of her illness she lost her job. As she felt less able to maintain her previous level of daily living, she felt unable to both physically and mentally participate in social life. In turn, she saw her family less and felt she was being judged by others for not being more active: *‘I tend to see my family irregularly now because I get judged, because I have an invisible disability. I’m being pre-judged because people don’t think there might be something wrong with me and**assume that I should be doing more things and should be more active.’* She became increasingly anxious, which made contact with other people difficult for her, and she became increasing marginalised from those around her and from her local community. When asked if she had sought any support to establish social contact with others, she said: *‘I have in some areas tried to find out people who are going through similar events, e.g. after heart attack. I’ve been on Facebook group, but it is difficult as it is for yourself and you don’t always want to read about other people. It makes you more anxious and depressed and you don’t really want to make yourself more miserable’.* |

Another short case study of a single Arab woman living in Cardiff who was very socially isolated demonstrates these compounding multiple factors further.

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| **Multiple risk factors can heighten feelings of loneliness**  The combination of physical and mental illness and loss of her sister had seen her sink into loneliness. She described herself as always being lonely. She had very little support and lived alone. She was unhappy in the area in which she lived and described how carers did not understand her needs. She had subsequently refused support. Although attending hospital several times, she did not feel her health needs were being addressed. There was no-one she talked to daily, and this turned into weeks without speaking to anyone. Conversations with her neighbours did not exceed ‘hello’ and ‘how are you?’ *‘There are no people I talk to daily. I will not see anybody for weeks and I only talk to people few times each month/year. I have my neighbours, but the conversation does not exceed hello and how are you.’*  This language barrier contributed to conversation being short; she stressed that she wanted deeper relationships with people, where she could have conversations like she used to have with her friends. She was stressed about her financial situation and paying rent and her bills. Although she attended a support centre, for her, these relationship with others were somehow superficial, she did not see them as relationships: ‘*Currently I have no relationship with others. I used to have friends, but now I’ve left everything and everyone because my health cannot support it anymore. I sometimes call my family in Iraq’.* The distance travelling to the centre also involved her taking two buses; she could not afford a taxi. |

Accordingly, where poor health, bereavement and loneliness co-existed, finding a simple solution to loneliness was difficult for these individuals. The circumstances of those with intersecting conditions were complex, and the combination of different factors made tackling loneliness extremely difficult.

## The intersection of factors amplifies low confidence

The intersection of health and bereavement factors having a negative impact on individuals’ ability and desire to maintain and improve social connections tended to amplify the lack of confidence that many have when either attempting to engage in everyday life activities outside of their home, or when attempting to engage with support services. Some of the stakeholders recognised this amplified lack of confidence as a significant barrier for individuals with various health issues. Despite what may be in their best interests, it was increasingly difficult for those affected to engage in support as a result. This intersection of factors meant that some interviewees, particularly those with mental health issues or illness, had very low self-esteem, and stakeholders explained how these individuals when presented to them often needed intensive support, or what they referred to as ‘handholding’, in order to make the initial steps to access activities and/or services. This point was also found in the report on barriers to members of BAME communities engaging with loneliness services (Wigfield 2019). In this respect, stakeholders felt that individuals who experienced poor health and bereavement may miss out on support and can become lonely and isolated if not reached effectively. In turn, this was sometimes reported as likely to lead to further experiences of poor health for individuals, as a stakeholder put it, *‘becoming stuck in their grief’*.

An older, woman, interviewee who had a health condition and had recently experienced bereavement, explained that her lack of confidence in going out and meeting people had got worse following the death of her husband. She said that she was not now confident going out alone, as she used to go out with her

husband. She went on to explain that she would like to be involved more in activities, but that she is now more apprehensive about going to places where she does not know anyone and is also deterred by a lack of suitable groups for people over 50 years old. Another interviewee experiencing a long-term health condition and bereavement mentioned that *‘having the courage to go somewhere’* had suddenly become even more prominent in his life. Another woman interviewee, who had a health condition and had experienced bereavement, mentioned that a friend had recently let her down and, whereas before this would not necessarily have affected her so much, at this time when she felt particularly vulnerable and ‘alone’ the experience had been damaging on her confidence in making other friendships.

For many of those interviewed, this amplified lack of confidence was difficult to explain or find a reason for but some alluded to the cause as being a loss of ability and skills in aspects of their life that they had previous had, for example the loss of ability to walk, or cook, or engage in physical activities. A 62-year-old Black African woman, for example, living in Cardiff with multiple illnesses, physical and mental, said:

*‘I always feel inferior. I feel like I’m the worst person in the world. Even though others tell me to think of myself as the best. I look at myself and think I’m not worthy because of my health condition because I can’t get out and about’*

This theme of amplified lack of confidence was also highlighted in the interviews with the majority of the Cardiff participants and, in particular, some of the interviewees from BAME communities, who explained that they were not happy with amount of time they spend with other people and that this often related to confidence and self-esteem issues. One interviewee who was happy with the *amount* of time he spent with other people but not the *quality* of her relationships explained that this was a result of a lack of confidence and self-esteem since her husband had died, which had led to an inability to get to know people well. Some interviewees in Cardiff explained this amplified lack of confidence further, saying they were often fearful of joining conversations or of attending meetings with people they do not know, and the prospect of having to do so in order to reduce feelings of loneliness (as a longer-term outcome) was daunting. These views were particularly mentioned by those who were experiencing more than one life transition. For some interviewees this amplified lack of confidence, together with physical barriers faced such as a lack of transportation due to mobility issues, meant that the despite a desire to make social connections it was all *‘just too much’*. An interviewee in Cardiff, for example stated that all his energy was directed at day-to-day survival and the effort to overcome these and his lack of confidence made meeting new people virtually impossible.

This links to research by Cacioppo who suggests that people are less likely to engage in ‘safe behaviours’ if isolated and lonely and that the longer they are isolated the more difficult it is to make social connections. Hawkley and Cacioppo (2010) in fact show that those who are lonely tend to focus more closely on more negative social information, they expect social interactions to be more negative and can derive less reward from positive social interactions. Similarly, Cacioppo *et al.* (2011) showed that individuals who felt socially isolated tended to regard pleasant interpersonal interactions as less pleasant than individuals who feel socially connected. Hawkley *et al.* (2003) found that greater experiences of loneliness are also associated with more negative perceptions of social interactions in general. Thus negative attitudes can lead to loneliness and loneliness itself can reinforce negative perceptions and experiences. Thus, as Hawkley and Cacioppo (2010), Cacioppo *et al.* (2011) and Jakobson and Hallberg (2005) point out, social disconnection itself leads to a downward spiral effect, a cycle of negative thoughts, which is difficult to break out of.

## Intersecting factors require a longer view and more depth

The intersection of these various factors which act as barriers to people making social connections also creates challenges for individuals in accessing existing services. There was a sense from the stakeholders that the increased ‘pace of life’ and limited time and resources allowed to support individuals, made it more difficult to support people at these two life transition points. The transactional nature of services, particularly found with statutory services (often associated with austerity), was seen by stakeholders as difficult for individuals who were experiencing multiple challenges to navigate. Furthermore, it was pointed out that it is difficult for many service providers to have the time to get to know and understand individuals’ lives and what might support them and to provide the depth of support required. A longer view, it was argued, by many of the stakeholders who were interviewed, is needed which moves beyond the transactional, to provide more depth of support to individuals with these intersecting issues. One stakeholder argued in respect of their own support: *‘I think that one of the good things in the long view that we take. Some sort of idea that need take longer rather than a short-term approach to things’.* Others mentioned the need for one to one ‘handholding’ services to help those most vulnerable and socially isolated.

A recently bereaved participant explained this further, stating:

*‘If I hadn’t had anybody, grief issues would build into more generic issues, depression issues, easily snowballing to become something much more longer term…even with all of that and having the best people around me you can feel immensely lonely and grief is so different, it’s not like you are having an activity that you can conclude. It is just extreme emotion. You have people around you who communicate based on your emotion and their emotions and then you are going through extreme emotions. You are bound to have communication breakdown, you are bound to have periods where to avoid conflict issues you isolate yourself, your way of coping with grief isolates you even if you have people you can’t talk to and will feel better when you talk to; you can’t because you are grieving and that isolates you’.*

Some stakeholders saw this as an issue which relates to funding of services. Funding for the short term can make it difficult for individuals with complex intersecting problems like health and bereavement to connect to the same service and have continuity. This may be particularly important for individuals with both health conditions and experiencing bereavement, as helping them develop new relationships is often an important aspect of helping people cope with these issues, but this can take time. Services providers, however, mentioned that they are increasingly funded to reach specific outcomes making it difficult to consider these intersecting problems and thus address individuals’ loneliness and social isolation.

# Conclusions and policy and practice implications

There are few studies that explore loneliness among ethnic minorities in the UK. This research work presented here, carried out by the Centre for Loneliness Studies, University of Sheffield, which was commissioned by the British Red Cross and Co-op partnership, makes an empirical, qualitative contribution to an issue which has been gaining recognition in recent years as being of major societal importance.

The research demonstrates that the pathway to loneliness is unique for each individual and, while there are often common aspects, this unique set of issues relates to factors such as the persistency of experiences of loneliness, multiple triggers to its causation, the impact of the breakdown of family and friendship networks, the importance of meaningful relationships, and the level of reliance on support services for social contact. The research also explored the importance of the role of place, and sense ofbelonging in experiences of loneliness. Regardless of ethnicity, gender, and age, and across different localities, interviewees mentioned various ‘places’ which were significant for them and which provoked a sense of belonging. Often interviewees said they felt ‘comfortable’, and ‘at home’, in these places meaning that, although they were often *alone* in those places, they did not feel *lonely*. Such places included places of worship such as Mosques and Churches, sporting venues, parks and other small open spaces, certain cafes or shops, and people’s own homes.

The research also identified various physical and psychological barriers to social connections that affected interviewees. Amongst these, particularly salient were factors which related to leaving the home, accessing transport, engaging in physical activities, sustaining social connections, completing everyday activities in the home, psychological issues, stigma, and language.

The research also identified various gaps in existing services relating to bereavement and health conditions among BAME communities. In particular, two key factors emerged here: a *lack* of services for people who had been bereaved; and a lack of *culturally sensitive* support for members of BAME communities.

It was recognised that dealing with sensitive issues of bereavement and health requires creating a *safe* and *sensitive* environment for individuals who use services and require support. It is important, therefore, for support services to understand the different cultural aspects of how diverse individuals may cope with health and bereavement issues. Some service providers argued, therefore, that it was important that services were co-produced by people from BAME communities: this ensured that they are listened to and heard in relation to developing services.

# There are a number of different ways in which the experiences of, and barriers to, connection experienced by people from the BAME and the White British communities at the two specific life transition points – bereavement, and experiencing a long-term health condition – intersect. These intersections relate to multiple factors compound experiences of loneliness, amplification of confidence issues, and the requirement of longer-term strategies with the requisite depth of support.

Some people experience combinations of physical and mental ill-health, physical ill-health and bereavement, mental ill-health and bereavement, or all three conditions simultaneously, and this presented additional difficulties in terms of their ability to engage in social connections. Moreover, this intersection of factors amplifies low confidence that many have when either attempting to engage in everyday life activities outside of their home, or when attempting to engage with support services. In turn,

creates challenges for individuals in accessing existing services.

Although social research usually looks for commonalities across different people experiencing a similar phenomenon, a key complicating factor in the analysis of loneliness is that each person affected by it faces a unique set of issues which relate to variations in the persistency of experiences of loneliness; multiple triggers, such as both physical and mental ill-health, multiple bereavements, or ill-health and bereavement; the breakdown of family and friendship networks; the existence or otherwise of

meaningful relationships; the extent of reliance on support service for social contact.

In terms of the impact of ethnicity on causes of loneliness, or on the impact of alleviation services, there are little appreciable differences that can be ascertained, although the issue of stigma may render the whole subject taboo, and some of those experiencing poor health which may be contributing to loneliness may hide their conditions, exacerbating the situation. Not wanting to be seen as being in need of support is another common factor amongst some ethnic groups, and barriers caused by language are another common factor. The need for long term support is another key issue that emerged.

The uniqueness of the pathway to loneliness for each individual precludes the prescription of a set of policy recommendations that could be created which would be efficacious in a generalised sense. Instead, a set of principles that should inform policy can be distilled from the research. Firstly, in an ideal world in which there was no limit to resources that can be allocated to the task, there would be a holistic approach focusing on the particular needs of the individual affected. Secondly, support would be provided to those that need it on a long term basis. Thirdly, support would be provided in a culturally-sensitive way, preferably by support workers equipped through training to be able to respond effectively to different cultural needs. Fourthly, the importance of the creation of places and spaces that are conducive to the development of meaningful relationships needs to be given an emphasis: at a minimum, these need to be areas that are comfortable, non-threatening, and supportive.

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