

Carers
Information
Service



No one
should
have
to care
alone:



Carers
Support
Centre

caring and
loneliness in
Croydon

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Introduction

No one should have to care alone. That's the view of the Carers Support Centre, the one stop shop for Croydon's 33,000 unpaid carers.

In 2017, the Jo Cox Commission published *A Call to Action*, a national report exposing the impact of loneliness on Britain, particularly on some of the most vulnerable groups of people in our society. It urged individuals, organisations and the UK government to take swift and effective action. Yet despite increased levels of public awareness, loneliness is still too often a hidden experience that is unspoken of and unrecognised.

On a national level, eight in ten carers state that caring has made them feel lonely. This is a troubling statistic, particularly given the impact of inadequate social relationships on mental and physical health.

The Carers Information Service wants to see an end to carer loneliness. We wrote this report to raise awareness of how loneliness affects carers in Croydon and our current impact on carer isolation, whilst remaining aware that there is still much more to be done.

Loneliness is a very personal and sensitive experience, often hidden away and associated with shame and stigma. We have therefore given each individual's comments and personal stories a prominent position in this report. It is far better for carers to share their experience in their own words.

An end to carer loneliness cannot be achieved unless we work together. Our #CarerConversations campaign is encouraging the Croydon community to do more to help carers feel connected with their family, friends and local communities. By joining forces, we can ensure that no one has to care alone.

Executive summary

The Carers Information Service surveyed 124 adult carers who are currently caring for someone in Croydon about their experience of loneliness and isolation. We also undertook nine in-depth interviews with carers about their experience.

Our survey found:

- 64% of carers said that caring stopped them from socialising as much as they wanted to for most or all of the time.
- 45% felt lonely or isolated because of their caring role most or all of the time.
- 78% of carers who used the Carers Support Centre said it helped them feel less lonely and isolated.
- 53% said that increased access to respite breaks from caring would reduce their loneliness; followed by support for the person being cared for (52%); increased disability and carer awareness from professionals (44%); and the general public (37%).

The Carers Information Service would therefore like to see:

- Carers in Croydon being identified and directed to local support services such as the Carers Support Centre if they need help.
- Current respite provision for carers being reviewed based on carers' actual levels of need.
- Individuals and organisations using the #CarerConversations toolkit and Carers Week resources to reach out and support carers around them.

Background

What is loneliness?

Loneliness is an emotional, subjective feeling that is often hard to define. One report describes it as 'the unpleasant experience that occurs when a person's network of social relations is deficient in some important way, either quantitatively or qualitatively' (Perlman and Peplau, 1981, p. 31). Loneliness is therefore not necessarily the same as social isolation; it is possible to have a large social network and still feel disconnected from those around you.

A "social epidemic"

Loneliness in the UK has been referred to as a 'social epidemic' (https://www.huffingtonpost.co.uk/entry/loneliness-in-britain-uk_5a2cf4a8e4b069ec48adf8c5). In 2017, the Jo Cox Commission published *A Call to Action* revealing the rising levels of loneliness in the UK, particularly amongst certain groups such as older people, disabled people and carers. Since then, the UK government has responded by setting up a national strategy to reduce loneliness, including appointing a national minister for loneliness, Tracey Crouch MP.

How many people feel lonely?

According to the *Trapped in a Bubble* (2016) report by the British Red Cross and the Co-op Foundation, 18% of the UK population report high levels of loneliness- that's over nine million people. The Office of National Statistics (ONS) reached a slightly different figure, reporting that between 2016- 2017 one in twenty (5%) of adults in England 'often' or 'always' felt lonely.

Loneliness and carers

Carers report higher levels of loneliness than the general population. According to Carers UK, eight out of ten carers say they have felt lonely or isolated because of their caring role, and ONS research found that those with caring responsibilities were 37 times more likely to report feeling lonely. These findings are also supported by research at a local level; the Croydon Council Carers Survey 2016- 2017 found that 18% of carers reported that they have little social contact and feel socially isolated.

"[I]solat[i]on is a major issue for carers. Their caring commitments, the little support from family and friends and lack of respite, make their life difficult."

(D'Agostino, *Social Isolation and BME People in Croydon: Issues and Solutions*, 2018)

The cost of loneliness

Loneliness and social isolation do not only feel unpleasant; they are also harmful to health. Research shows that lacking social connections is as damaging as smoking 15 cigarettes a day (Holt-Lunstad, 2015). Being isolated is therefore worse for our health than obesity and inactivity.

As well as placing a strain on health, loneliness also costs the UK economy. *The Cost of Loneliness to UK Employers* report by the New Economics Foundation suggested that loneliness costs UK employers and businesses £2.5 billion a year, including increased sickness absence, reduced productivity and increased staff turnover.

Our survey

The Carers Information Service ran an online survey in March 2018 asking carers questions related to loneliness and social isolation. The survey consisted of nine questions and was collected via the online survey programme SurveyMonkey.

A total of 124 responses were received from carers in Croydon. 18 further responses were unable to be included in the final report (three did not give permission for inclusion and 15 were not carers in Croydon).

104 comments were received in response to the question, 'Please write any further comments on the impact caring has or has had on your relationships with others.' An additional 61 comments were received in response to the question, 'If you have any further comments on the difference the Carers Support Centre has made to your life and your relationships with others, please write them here.'

The Carers Information also interviewed carers who are frequent users of the service about the impact of caring on their relationships with others and the impact of the Carers Support Centre on their loneliness. A selection of these interviews have been recorded as case studies in this report. Names have been changed to protect individual privacy.

Key Findings

A rapidly diminishing social life

For the majority of carers who took part in our survey, caring has a profound impact on their social life. 64% said that caring reduced their ability to socialise as much as they would like for all or most of the time, with a further 33% stating that caring restricted their social life some of the time. This issue is clearly of importance to carers; just under 29% of the comments we received on the impact of caring on social relationships referred to restricted social opportunities.

Carers frequently referred to a lack of time to socialise with family and friends. Many carers juggle multiple demands and responsibilities, and spending quality time with friends, family and/or a partner is often pushed to the back of the queue. This carer's comment is unfortunately fairly typical:

'Caring for my parents especially my mum with dementia has taken most of my time. I used to socialise or have "me time" on my days off from work but my caring role has taken over this. My life is now [so] centred between work and caring that I rarely see friends anymore and can no longer have holidays with my partner and I'm afraid this role is putting a strain on my relationships- with others, with myself as well as with my parents who [I] care for.'

Such restrictions can lead to a vicious cycle. For example, having to reject social invitations due to caring commitments can cause future social opportunities to dry up, leading to a rapidly diminishing social life: ***'Some friends understand because they find themselves in a similar situation. Others have no idea and after you have to say no to their invitations a few times, they stop asking. It's hard to maintain some friendships and a social life.'***

As well as a lack of social opportunities, carers also reported a subjective sense of loneliness. 45% of carers reported feeling lonely or isolated all or most of the time and a further 43% felt lonely or isolated some of the time. This is far higher than the 5% prevalence of high levels of loneliness reported by the general population (ONS, 2018).

For some carers, the loss of freedom and social connections can be devastating. As one carer stated, ***'[I am] starting to feel like a prisoner in my home.'***

'People don't always understand your role as a carer.'

Carers often felt that family and friends did not understand the practical realities of caring and the intense pressures of their role, placing strain on these relationships. This was particularly the case for those who cared full-time, often behind closed doors:

'Family members don't realise that it's a 24 hour job. They think it's all over at bed time, or that Mum can sit and watch TV or go in the garden. These things undoubtedly help but caring is constant.'

'[I] have to pretend our lives are alright as most do not understand the real condition... [I experience] constant worry about our future...'

Such lack of understanding can even end friendships altogether, placing carers at risk of social isolation: **'[I have] lost friendships due to lack of understanding or time.'**

To counteract this lack of understanding, many carers identified a need to be able to discuss their situation with people who have personal experience of caring, and can therefore empathise with their difficulties:

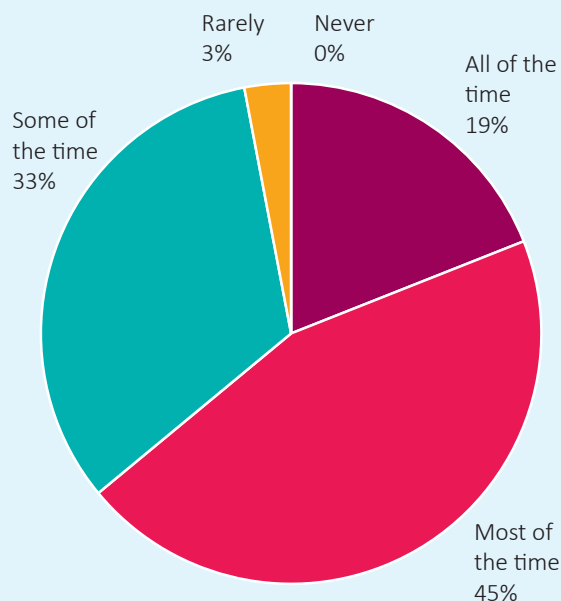
'Other people aren't able to understand the pressures and terrible worries when in a caring role. You need to be able to talk to and share with those who are in a similar position. This is what causes a lot of the isolation - people not understanding.'

It is important to note that not all comments were negative. A significant minority made positive comments about the willingness of friends and family to be supportive and stay in touch, which carers highly appreciated:

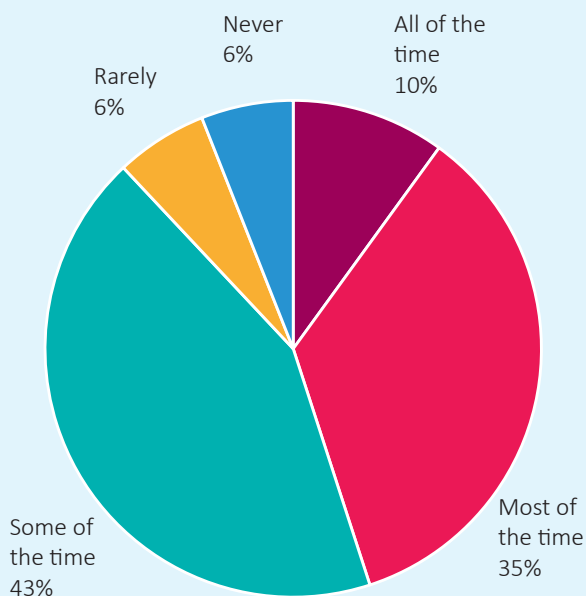
'I feel lucky that I have lots of friends and ex work colleagues who keep in touch and still want to meet up. Facebook and texting is helpful to me too.'

'Friends and family have been lovely along with the support services in Croydon.'

My caring role stops me socialising as much as I want to



I feel lonely or isolated because of my caring role



Eric's story: 'Friends don't wish to know the stark details.'



Eric is a former carer for his wife with dementia. He cared for his wife at home until she died. Looking back, Eric describes his caring role as intensive: '[It was] onerous, but I did not feel it was onerous at the time. I did it out of mutual love and affection.' Eric is sure that his wife would have done the same for him if he had become ill. 'We had [many] years of excellent marriage and nothing can take that away.'

Whilst caring was never a burden or a duty, it was all-encompassing. 'Caring subsumed my life in the end.' Opportunities to go outside the home were limited, and evening social events the couple previously enjoyed were impossible. Eric did not generally invite people to the home and found friends came to visit less frequently. 'My wife was the friendship-maker, the friendship-builder. Without her, things tended to wither away.'

Eric dislikes the world isolated and is keen to stress that he possessed a close network of family and friends. However, he did experience loneliness. 'Life was lonely.' He generally did not share details about his caring role with others, and kept the tone of conversation light-hearted and superficial. 'Friends don't wish to know the stark details.'

'[Caring] has affected my relationship with my children and makes it very difficult to spend any regular, quality time with them or my grandchildren.'

Social exclusion

As well as having less time to spend with loved ones, carers reported friends and family visiting less frequently, often causing resentment. The Carers UK *Alone and Caring* report (2015) found that 57% of carers have lost touch with family and friends. This trend is particularly concerning for carers who struggle to leave their homes, as it leaves fewer opportunities for meaningful face-to-face social contact with someone other than the person they care for:

'Many so called friends stay away, which I find very upsetting!'

'Friends and family don't visit much now.'

Some carers felt excluded from social events by friends who made presumptions about their ability to attend or were unwilling to make the necessary adjustments:

'People either exclude me now from social events because they think I won't have the time to come or because of how they are feeling. [They] ignore my caring role.'

Even when friends tried to be understanding and include carers in social events, the demanding nature of the caring role can still leave carers feeling left out:

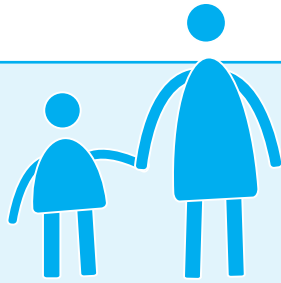
'I often have to leave socialising early to care for my mum, or can't attend plans in the mornings/evenings because of this. My friends are understanding but then have experiences and build in-jokes without me.'

As well as the impact on their own social lives, carers were also worried about the impact caring had on close relatives, particularly children: **'My daughters are sometimes reluctant to bring friends home because of their brother's psychosis and autism...I see a lonely old age beckoning.'**

'Many so called friends stay away, which I find very upsetting!'

Hannah's story:

'The world's going on around me and I'm not able to tap into it.'



Hannah cares for her young adult son with a learning disability and multiple health conditions. Hannah describes her caring role as 'full on', as he is 'not independent.' She supports and prompts him with daily activities such as bathing, dressing, taking his medication and preparing and cooking meals, as he would be unable to do these things by himself. He attends college but cannot travel alone, so she needs to take him and pick him up.

Hannah describes her son as 'a joy'; 'I wouldn't change him.' Yet his needs mean her caring role will not come to an end now he has reached adulthood: 'It's relentless.' As well as supporting her son, Hannah also cares for her husband, who has a health condition, and her elderly mother, whose care is shared with other family members. She visits her mother two to three times a week to make sure she is safe and well.

Due to her caring role, Hannah is unable to go out in the evenings. 'I can't remember the last time I went out with my husband.' She says she feels OK about this, but it does make it harder to stay in touch with friends and she sometimes feels like she is missing out. 'I feel quite sad about it sometimes. The world's going on around me and I'm not able to tap into it.' But even when she's with other people, Hannah sometimes feels lonely: 'You can feel lonely in a room with 20 people. They haven't got a clue what your life is like.'

Hannah first came to the Carers Support Centre three years ago. 'I wish you were here 15 years ago,' she says. 'I received support I'd never received before, mentally and physically... nothing is too much trouble... It gives me confidence that if something happens, you can go and ask someone... [they're] here to listen.' Hannah enjoys health and wellbeing activities at the Centre but says that even just being able to come in and have a cup of tea makes a difference. 'It's a bit of a lifeline.'

Planning ahead

'You have to prepare or organise in advance for visits to friends and sometimes family depending on the ability or disability of the person you care for.'

For carers, social visits often require a great deal of forward planning in order to happen at all. This can be due to a number of factors, including difficulties arranging alternative care, problems with transport and concerns about the health of the person they care for. The strain of organising such events can create a reluctance to socialise in the first place:

'You definitely can't be spontaneous, everything has to be planned way ahead and then you half expect that something will happen to scupper that plan so sometimes when you do have something to look forward to you're reluctant because of all the work involved or you fear something will happen to prevent it so you don't raise your hopes. Often you can't give a definite yes and people get frustrated because you can't commit.'

Shrinking horizons

Carers were also concerned about the reduced quality of their relationships. For many, the constant demands of their caring role left them with little to talk about other than the person they care for:

'Being isolated. Having nothing to talk about except about the person you care for.'

'It limits one's horizons / opportunities therefore one's experience is limited which in turn affect conversations / interactions with other[s]'

'Some friends are quite shocked at the deterioration [in the person I care for], resulting in a different kind of conversation, different from the light hearted fun it used to be.'

'[T]he topic of conversation when we do socialise with friends always turns to dementia and that is a turn-off subject for most people. Without going out as often your world becomes less interesting and you wonder if friends find you less interesting, i.e. your confidence does go down.'

Christian's story: 'You adapt, you get used to it.'



Christian cares full-time for his disabled wife. He is the primary carer, though his wife currently receives some support from paid care workers. His role involves personal care, helping her get up, washed and dressed, administering medication, taking his wife to appointments and liaising with nurses and other health professionals. This takes up the majority of his daily life.

When asked if his caring role affects his ability to socialise, Christian says, 'It does, big time.' He explains that he often cannot leave the house at all and may have to cancel any social plans at the last minute if he can't find someone else to care for his wife whilst he is out. This used to happen a lot, so he usually stays at home. He goes out when he can during the day but going out in the evening is 'virtually impossible.' 'I miss going out at Christmas, it's nice to go out.'

Christian's social isolation causes him a lot of stress, but he tries to have a stoical attitude: 'You adapt, you get used to it.' He notices that his friends no longer visit and call less often. 'You don't realise until you look back and think, we've had no visitors for a year. If you don't visit, [people] don't visit you.' His wife no longer wishes to go out and Christian sometimes finds this frustrating. 'We used to go [to a support group] but she doesn't want to go now.'

Christian now finds companionship at the Carers Support Centre. 'You meet people in the same situation.'

He identifies that guilt has been a big issue for him. 'It took me a long time to accept that I need to stop feeling guilty and have some fun. It's hugely important. You get in a vicious cycle. You don't go out because you feel guilty and become stressed and short-tempered, which doesn't help.'

Despite the many challenges of his caring situation, Christian now finds that the Carers Support Centre now provides him with some relief: 'It's been a positive thing.'

Relationship pressures

Being in a positive and stable relationship or marriage is associated with greater life satisfaction, reduced stress, lower blood pressure and improved heart health (Mental Health Foundation, 2016). Yet according to national research, 49% of carers have experienced difficulties in a partner relationship because of their caring role (Carers UK, 2015).

In our survey, carers stated that they often went for long periods of time without being able to enjoy activities with their partner, especially if there was a lack of alternative care:

'I have a very limited social life, I can only go out if my husband is home. We have not been out together for four years as one of us is always needed to care for our child.'

'My partner and I are unable to go out together on a date, as we have no family nearby to offer childcare.'

'My husband and I have not been able to enjoy our retirement and worry that we may be too old when the caring is over.'

As well as time spent with their partner, the time and emotional pressures of caring can also lead to stress and arguments, placing a strain on the relationship:

'I cannot go to after work dos [and] I take my frustration out on my partner by arguing. I don't see friends or have time to do things for myself.'

'Caring for both parents in their home puts a strain on my relationship. Trying to juggle both roles is stressful.'

In several cases, the impact of caring has led to complete relationship breakdown:

'Killed my last five relationships.'

'I will be separating from my partner.'

'My mother and sister needed more specialised care than could be provided so I took on the responsibility. This caused the end of my 44 year marriage.'

Health

'You don't want to overburden the same people with your thoughts or troubles, but you find yourself stuck - only certain people understand (former carers), and you keep going to them for support. You feel guilty. You feel guilty spending time away from the 'cared for' person. Guilty for going out to work, but it keeps you sane. You feel isolated and distant - you miss out on conversations because you haven't watched programmes, films, news etc. You think you're becoming boring! You most probably are before you realise it...'

A national survey of over 3000 carers found that 87% of carers felt caring had a negative impact on their mental health (In Sickness and In Health, Carers UK, 2012). This is reflected in carers' responses; carers frequently commented that they regularly experienced 'stress', 'guilt' and 'worry' because of their caring role. Such emotions were often combined with sleep deprivation, which is linked to poorer physical and mental health (Public Health England, 2017):

'Stressful, feel selfish/guilty, irritated, annoyed.'

'Stopped work, started antidepressants, don't sleep, anxious, worried about my child, stopped voluntary work, etc, etc.'

'Weight gain (myself). Lack of sleep. Less time for other family members. Fatigue. Reduced output at work.'

For some carers, the stress, frustrations and anxieties created by their caring role prevented them from engaging in meaningful social interactions, placing strain on existing relationships with friends and family. One person noted that the intense demands of caring left them feeling too drained to even attempt to socialise: ***'I have become more aggressive and stressed! I am too tired to speak to people a lot [of] the time.'***

For others, a lack of social engagement in itself leads to poorer mental health: ***'Normal life seems to shrink when caring for a loved one because of the restrictions placed upon both of you as a result of illness - which cannot be helped but which has a depressing effect nonetheless.'***

This is sadly unsurprising. National research shows that loneliness has a 'profound and detrimental

effect on mental health' and that healthy social relationships are closely linked with greater happiness and wellbeing (Mental Health Foundation, 2016). The strains of caring can put these relationships into jeopardy, leaving carers at risk of poorer mental health. As one carer put it, ***'I feel very depressed and lonely.'***

As well as mental health, Carers UK research found that 83% of carers stated that caring affected their physical health. Disability and long-term health conditions have been linked to increased risk of loneliness and isolation; a 2017 report by Scope found that 67% of disabled people have felt lonely in the past year and 45% of working age disabled people are chronically lonely.

Some carers were concerned about the impact of their health on their ability to socialise. One carer looking after multiple people explained that her intense and difficult caring role had left her in poor health, so that even the very little time to spend with friends and family was impacted by pain:

'I have no time to speak to anyone on the phone or to visit galleries with a precious friend. My daughter longs to go away with me because she wants to spend time with me but I have no time. She came round to see me yesterday but I had such a blinding migraine I could not even speak to her. She was heartbroken to see what state I'm in.'

'A national survey of over 3000 carers found that 87% felt caring had a negative impact on their mental health.'

Employment

Around 11% of the comments we received referred to the impact of employment on their social relationships, either due to the stress of trying to combine work and caring on other relationships, or the feelings of loneliness and financial stress caused by a lack of employment.

Being in employment has been linked with improved health and wellbeing (Royal College of Psychiatrists, 2008). Yet over two million people have given up work and three million have reduced their working hours nationally because of a caring role (*Facts About Carers*, Carers UK, 2015).

Deciding whether to continue, reduce or give up employment altogether is a difficult choice for many carers. For some carers, work is in and of itself a form of respite from the caring role:

'...work... keeps you sane...'

Yet for others, juggling the multiple responsibilities of work and caring can severely reduce their quality of life:

'I have to work compacted hours to build free time to devote to caring so my days are extra-long and combined with 3.5 hrs commute, often exhausting. I travel to Newcastle every other weekend to care for my Mam so I lose that free/personal time too and have to spend the weekends I do have catching up on my life or more often sitting still just recovering. I have no time to look after my finances or health except at a basic level. I exist...I don't live.'

'It is extremely limiting in terms of job prospects. Not having access to proper care facilities where a very vulnerable child can be left with knowing she is going to be safe and happy puts a lot of pressure. Other relationships suffer because of the continuous cycle of either working to make ends meet or to take care of the child. The uncertain future does hinder the long-term planning process.'

For carers who do decide to give up work, there are further pressures on finances and reduced social contact, increasing the risk of loneliness. Several carers commented that they wished to return to work, but a lack of replacement care and/or flexible working hours meant that they were unable to:

'I had to stop working due to caring for my son. Now he is in a special school, but the hours don't allow me to go back to my career. During the daytime I am extremely lonely.'

'I would love to be able to get a part-time job as money is really tight, but I can't leave mum for any longer than an hour...'

'...over two million people have given up work and three million have reduced their working hours nationally because of a caring role.'

'I had to stop working due to caring for my son... During the daytime I am extremely lonely.'

Making connections: our impact on carer loneliness

Restricted social opportunities and emotional feelings of loneliness are clearly a pressing issue for a substantial number of carers who responded to our survey. As we have already explored, causes of carers' loneliness are linked to a wide range of factors, including a lack of alternative care, poor understanding from family and friends, relationship breakdown, financial pressures and inflexible or non-existent employment.

Given the complexity of these issues, it is impossible for one solution or service to resolve the problem. As the *Trapped in a Bubble* report suggests, 'there is no one ideal service for people who are feeling lonely... a mix of support for different stages of loneliness is needed.'

Despite these complexities, the Carers Support Centre has a noticeable positive impact on those who access the service. Of the carers who reported using the Carers Support Centre in this survey, 78% told us that the service helps them feel more socially connected.

Carers who responded positively to this question were asked which services specifically improved their social connectedness:

If yes, which Carers Support Centre services have helped you feel more connected with other people?	Percentage
Newsletter	45%
Advice Worker	27%
Volunteer or Staff Member	26%
E-bulletin	26%
Support Group	23%
Workshop	23%
Carers Week Activity	20%
Carers Café	18%
Advice Surgery	18%
Not Used the Carers Support Centre	17%
Lunches	13%
Massage	12%
Other Health and Wellbeing Service Activities	10%
Pilates	7%
None	7%
Dance	3%
Singing	3%

These results show that the newsletter (45%) is the most frequent way that the Carers Support Centre reduces carer loneliness and isolation, followed by speaking to an Advice Worker (27%). This result may be skewed by the data collection method, as carers who receive emails may be less likely to use face-to-face services. However, it is positive to see that those who cannot access the Carers Support Centre in person can still feel more socially connected through the newsletter and, to a lesser extent, the e-bulletin.



Information and advice

When asked to provide further comments, carers were highly positive about the impact of the Carers Support Centre. Carers primarily highlighted the Centre as a source of specialist information and advice in one centralised location:

'It is reassuring to know that there are people who understand, and have answers to my questions.'

'It's great all these services are under one roof...'

'The centre and its staff has given me valuable information and advice on the help that's available which I never knew existed.'

'A place for you'

Many carers were grateful to have a place that specifically catered to carers. One carer explained that an off-chance visit had a long-lasting impact:

'I shop every Saturday in Croydon, and always passed by the Carers Support Centre. I happened to have a Friday off, during my Dad's illness. I think I blubbered there and then. I was sorted out with an appointment for a counsellor and a Carers' Pack. That kind of kindness went a long way. We knew about benefits, coping strategies, and you had a place for you, if only for a half-hour, but it was for you. Thank you.'

'It's great all these services are under one roof...'



Simon's story: 'It's like an extra room to my house'

Simon cares for Alan, who has a severe learning disability and a health condition which affects his mobility. Alan lives independently but needs additional support. Simon provides social, emotional and practical support for Alan, such as getting and delivering his shopping and taking him on trips out. His caring hours vary, but Simon usually sees Alan for a few hours three to four times a week.

Simon says he gets a lot out of caring for Alan, seeing him as 'almost like a brother', but he requires a lot of time and attention. 'You can't just pop in for a cup of tea; he'll want you to stay for quite a long time.' His caring relationship with Alan takes priority over other friendships. 'If Alan calls me, I'm likely to drop everything to help.'

Simon considers himself a very sociable person and highly values his friendships with other people. However, he experienced a period of chronic loneliness in the past when his father died. Whilst he no longer feels continuously isolated, he does experience 'bouts of loneliness'. These generally occur once he has finished his caring visits to Alan. 'I move from an intense friendship to living alone. The contrast accentuates the loneliness.'

Simon realises he would prefer to live with other people, as he does not always deal well with being in his own company for too long. He does not know any of his neighbours and family live far away. 'We live in isolated communities,' he says. 'Sometimes after I finish visiting Alan in the evening, I get home at nine and go straight to bed. That or put the TV on. The noise is like something happening.'

When Simon first saw the Carers Support Centre, he thought it was a careers centre! 'It took

weeks to come in and ask [what the Centre was all about].’ Since coming to the Carers Support Centre, there has been a noticeable difference: ‘It’s lovely to be able to come in here and have a cup of tea and chat with other carers.’ Simon uses the Carers Café in particular to ‘relax’ and ‘switch off’ from his caring role. ‘I like to sit and gather my own thoughts. I do better here rather than at home. The background conversations of people help.’

As well as spending time reflecting, he also values the chats he has with other carers, and has taken part in several workshops and wellbeing activities at the Centre. ‘I found them very uplifting’. He feels very much at home in the Centre, often staying longer than intended. ‘It’s like an extra room to my house. Sometimes I don’t want to leave!’

‘A sympathetic ear’

Emotional and listening support from a person who understood was also seen as highly valuable, particularly for carers who were experiencing loneliness:

‘A sympathetic ear does wonders on the ability to cope when tired and alone.’

‘They are a lifeline for carers of all ages.’

‘It’s just great knowing that the carer’s centre is there. You can walk in and see familiar faces or have a coffee and someone is there to listen.’

One carer particularly appreciated having someone outside their family situation to speak to. Since using the service, their social isolation has significantly reduced and they feel more confident to continue in their caring role:

‘To be honest the caring role has got better since I walked into [the Carers Support Centre] because I was unable to talk to family and friends as it was family member’s personal information and for them to disclose not me. So I was dealing with a lot of things and not being able to talk to no one. I felt isolated and alone a while ago but it has got better with being able to access service/workshops talk and meet others via Carers Centre so has had a massive positive impact on myself and which has allowed me to be better at supporting the person I care for and to understand feelings better.’

Donna’s story: ‘I always feel included’



Donna has a part-time caring role for her older parents. Her role primarily involves sorting out issues, providing advice and speaking up on their behalf. Her caring role can fluctuate from the very minimal to several days’ worth of support, and she is on call 24/7 if there are any problems.

Donna feels that her caring role doesn’t cause much loneliness or isolation at the moment, but her support network at the Carers Support Centre makes a difference. Unlike other places in her life, Donna can talk about her caring role in confidence and finds useful advice and support through workshops. But most importantly, Donna values the fact that the Carers Support Centre simply exists. ‘You don’t have to make a justification for being here. You can just come in and have a cup of tea and a laugh.’

For Donna, the Carers Café is a place where she can enjoy the company of other people without feeling judged or dismissed. ‘It goes beyond just being carers. There are so many different people, you can talk about anything. I always feel included, even if I’m only listening.’

As well as seeking support for herself, Donna finds a great deal of satisfaction in being able to support and help others in a similar situation. ‘If [a carer feels] lonely, I invite them for coffee, call, visit or send a message. It helps people who can’t get to the Centre. If you can do something to help someone else, it’s good. It’s mutual thing; you all benefit.’

Donna says she wouldn’t know where else to find help if the Carers Support Centre didn’t exist. ‘It covers all I need.’

'Just knowing it's there'

Even for carers who weren't regular users of Carers Support Centre services, simply knowing that the Centre is available was of key importance:

'Just knowing it's there and that there is a point of reference for information is reassuring.'

'Simply knowing there is somewhere to contact/ go to both on bad days and on good, and always receiving a warm and unconditional welcome.'

'Knowing the support is there if things get too much is a great help.'

'Meet people in the same boat'

In addition, carers commented that opportunities to meet others with a caring role helped them feel more socially connected:

'Meeting people in similar circumstances makes you feel less alone and the NAS (National Autistic Society) support group gives great advice.'

'It's allowed me to meet people in the same boat and for us to exchange our thoughts and feelings about our caring role, sometimes it's helped for me to put things in perspective and to realise things are not as bad as I feel.'

Some carers even made lasting friendships which they maintained beyond the Centre:

'I have made some very good friends at the Centre with whom I am in e-mail contact and who attend events at other locations...'



Connor's story: 'If you help someone else, you will help yourself.'

Connor has had a range of caring roles. He previously cared for his wife who died in 2016, and now provides a caring role for a couple he met through his work before he retired. His caring role is currently part-time, and caring responsibilities fluctuate from a half hour visit to more intensive support.

Now retired, Connor is very conscious about looking after his health, keeping active and maintaining his social life. He used to play golf three times a week, but this stopped due to the pressures of his previous caring role. Though this caring role has now come to an end, he now has some health problems which prevent him from playing golf, and he misses it a lot. 'I didn't appreciate that giving up physical activity would lead to body deterioration.'

Connor first came into contact with the Carers Support Centre through another voluntary organisation. He went to the Carers Café and made connections straight away, meeting a fellow former member of the Merchant Navy. He now attends twice a week and looks forward to his visits.

The Carers Café is particular important to Connor. 'I like to listen to other people.' Through speaking to fellow carers at the Carers Support Centre, Connor was able to find out about a product to support his back pain. He now walks two to three miles a day and takes regular exercise, which reduces the pain and helps him look after his health.

Connor very much sees himself as having a helping role, passing on useful information to others in the Café and those around him. 'If you can make people aware, you have the satisfaction of seeing their immediate situation going in the right direction.' He describes his attitude to life with a quote from Sarah Ferguson: 'If you help someone else, you will help yourself.'

Overcoming barriers

Unfortunately, not every carer is able to access the Carers Support Centre; 29% of carers surveyed said they had not yet accessed the service. When asked why, several stated that this was due to a lack of time or alternative care. Improved respite provision would allow these carers to access support and meet other carers at the Carers Support Centre, which could potentially reduce their isolation.

Further issues raised included opening times, a lack of confidence to use the service due to social anxiety, the need for improved telephone support, lack of awareness of the service and high demand for wellbeing activities. The Carers Support Centre will investigate this feedback in conjunction with the comments provided in the recent Croydon Carers' Strategy.

'Very important service but not easy for me to make use of due to little free time.'

Wider solutions to loneliness

The desperate need for a break

Due to the high demands of meeting the needs of the person being cared for, it is unsurprising that 53% of carers stated that the most important solution to their loneliness was regular breaks from caring, closely followed by increased support for the person they cared for (52%). This reflects the findings of Carers UK's 2015 *Alone and Caring* report, where 54% of carers stated that more caring breaks would help. Yet according to the national 2017 *State of Caring* report, one in four carers have gone without a day off in the past five years:

'It is difficult to go out for any period of time unless someone else is available to help my daughter if needed.'

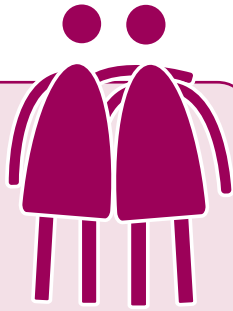
'It's difficult to go out socially because of finding someone else to take over the caring role. So social events are turned down.'

'[It is hard] to arrange support for my wife if I wish to play golf or be away for more than 2/3 hours.'

'In general terms I am unable to go out of the house unless someone is available to be with the person for whom I care. This is not easy to arrange.'

'Unable to leave my husband to go out and socialise.'

Given the overwhelmingly pressing need to offer carers more breaks from their caring role, it is essential that current provision is reviewed to ensure carers do not experience the damaging impact of chronic loneliness and/or social isolation.



Isabella's story: 'Even though you're going through hell, it's made a difference'

Isabella is a full-time carer for her sister with a learning disability and a mental health problem. Her sister's needs can be very complex and she requires intensive care, including help with eating, bathing and dressing; emotional support; keeping her safe; and speaking to professionals on her behalf.

Isabella transitioned to being her sister's full-time carer last year and in order to make this shift, Isabella decided to leave her job. 'It wasn't an easy choice. But I didn't want her to go into a care home.'

Due to the intensive nature of her caring role, Isabella finds it very difficult to socialise without her sister. Most of her friends are understanding of her situation, but Isabella has missed out on social occasions because of her caring role, and it's rare for her to even find time to sit down for a minute and relax. On the few occasions she does get out, she is always clock watching, as her time is limited.

The biggest issue for Isabella is a lack of respite. The service her sister previously used was cut, and has not been replaced as she'd hoped. 'I just want to go to a few social events a year.' The difficulties are still ongoing, but Isabella tries to remain hopeful. She has recently gained some limited respite support, and she intends to make the most of the little bit of 'me time' she gets.

Whilst friendship matters most to Isabella, she feels that caring has impacted her ability to seek a partner. 'I've sacrificed opportunities to go out and meet others.' Yet despite the difficulties, Isabella takes the long view. 'Like most people, I want love in my life, but I accept that it will take longer to get.'

Since coming to the Carers Support Centre, Isabella has felt the change: 'This place has been a godsend.' She's attended several workshops,

finding them helpful and informative, and visits the Carers Café when she can.

Isabella recognises the benefits of meeting other carers at the Centre. 'Everyone is understanding and sympathetic. We're supporting one another.' As an unofficial ambassador for the Centre, she is always suggesting that other carers visit when they need help. 'A neighbour mentioned she'd got help at the Carers Support Centre and I felt quite chuffed.'

Isabella describes the Carers Support Centre as 'crucial' for carers. 'Even though you're going through hell, it's made a difference.'

Raising awareness

In addition to further practical support, carers also wanted increased understanding. Carers highlighted that better carer and disability awareness from professionals (44%) and from the general public (37%) would decrease their loneliness. Several carers in our survey expressed frustrations with public services that were meant to support them as carers, and felt that liaising with unsympathetic professionals and complicated bureaucratic processes took up a great deal of their time:

'Trying to deal with agencies, health services, social services and Department of Work and Pensions makes me feel like I am going mad. It is all about the money and who can avoid paying for what. The person, my loved one is completely disregarded. The only people who understand this feeling of madness are going through it themselves and [they] have their own burdens. It can't really be talked about. This makes me feel even more isolated even when with friends. It occupies my mind but cannot be spoken. Other things seem trite.'

Other carers felt that the public also needed to be more understanding and accommodating of caring and disability:

'I think there is still a massive gap with the local community understanding the role of a carer and what it is like for someone to look after a child with disabilities.'

'Parenting two kids with disabilities is hard. Constant parent bashing and being offered parenting courses is not helpful.'

Matthew's story: 'The first step is recognising you are a carer.'



Matthew cares for his elderly mother in her late nineties. He lives very close by and visits his mother almost every day for several hours. He is the primary carer, as other relatives live further away and are less able to help. Even when not visiting his mother, he always 'on call'. Matthew sums up his role as 'running another property and keeping a 96-year-old safe.'

Matthew experienced chronic loneliness and isolation in the past, which affected his mental health. His isolation contributed to severe depression and he was taking medication for a while. 'It's like being in a big dark hole. You can see the light but you can't climb a ladder to get out.'

It was during this time that Matthew first discovered the Carers Information Service and the Carers Support Centre. 'It's brilliant. I can drop in to the Café whenever. You meet so many new people... It's amazing for self-esteem, I've made so many friends and contacts, plus the wonderful help and advice the Centre can give.'

Matthew particularly appreciates the atmosphere of the Carers Support Centre. 'It's a welcoming place, you feel so safe. You know you will be treated with compassion, that you won't be criticised, that you will be accepted for who you are.' He enjoys meeting other carers in the Carers Café. 'Everyone acknowledges and respects that you're a carer. People understand each other - there's a common bond. People come in and say, oh I remember you! It's nice to be remembered by somebody.'

Matthew is now very conscious of the importance of looking after his own needs as well as keeping his mother safe and well. 'You have to make time for yourself and your wellbeing. If you let [your caring role] dominate you, it's a slippery slope to being socially isolated.'

Despite the gains he has made personally, Matthew is concerned about those who

are missing out: 'There's a very big need for awareness. Carers can become very socially isolated. There needs to be as many opportunities as possible for carers to meet socially.'

'Many people don't recognise that they are carers. It's a big problem. The first step is recognising you are a carer.'

When asked where he would be without the Carers Support Centre, Matthew says, 'I would be in a very dark place. It's truly been a lifeline.'

Accessible and affordable activities

'Keeping myself as busy as I possibly can for my own good.'

To reduce loneliness, 35% of carers stated that they needed more information and advice on accessible activities and 32% needed more financial support to access them. Particular issues raised included concerns about cuts to after-school activities for children with autism and a need for subsidised transport:

'Help with travel costs so I could afford to socialise.'

Disabled people and those who care for them are at particular risk of financial hardship and even poverty. A 2018 survey by Scope found that the average disabled person spends £570 extra a month due to the extra costs of their disability or condition, and the 2017 *State of Caring* report by Carers UK found that nearly four in ten carers are struggling to make ends meet. One carer expressed that a lack of funds and fears around the stigma of claiming welfare benefits left them virtually housebound:

'[I] very rarely go out not only because of caring but due to lack of funds... Very few friends outside of those with similar situations... [I am] always made to feel that I am a strain on the benefit system... always having to jump through hoops to get help and support from professionals and the benefit system.'

Increased financial support and subsidised leisure activities would allow carers on a low income to access social opportunities and remove a further barrier to social inclusion.

Conclusion

Carer isolation is a serious issue

The majority of the carers in this survey have a severely or completely restricted social life, and almost half of carers stated that they experience chronic loneliness. Given the previously mentioned health risks of a lack of meaningful social connections, the impact of caring on loneliness is of concern and should be addressed with urgency.

The Carers Support Centre can help carers feel less alone

The vast majority (78%) of carers in our survey who used the Carers Support Centre said the service helps them feel more socially connected. It's therefore important that carers are made aware of the service and are not left to struggle alone.

Short breaks from caring are urgently required

Due to the high demands of meeting the needs of the person being cared for, it is unsurprising that 53% of carers stated that the most important solution to their loneliness was regular breaks from caring, closely followed by increased support for the person they cared for (52%). Given the overwhelmingly pressing need to offer carers more breaks from their caring role, it is essential that current local provision is reviewed to ensure that carers do not experience social isolation.

Carer awareness still requires improvement

Despite the increased recognition of carers in society and in legislation, 51% of the British public say that they do not know a single friend or family member who cares for someone (Carers UK). Carers highlighted that better carer and disability awareness from professionals (44%) and from the general public (37%) would decrease their loneliness. Increasing public and professional awareness of carers and the issues that affect them would go some way to helping carers feel less alone.

A need for accessible, affordable activities

Promoting accessible activities would ensure that all carers can take part in social and leisure activities that meet their needs and the needs of the person they care for. Whilst affordability was less frequently raised by carers, financial support and subsidised leisure activities would also allow carers on a low income to access social opportunities.

We all have a role to play in reducing carer isolation

Whilst the Carers Support Centre has a broadly positive impact on carer loneliness in Croydon, it cannot work in isolation. Carers in our survey raised a wide range of issues which impacted their relationships with others, and these cannot be resolved through one service.

Family and friends, employers, businesses, schools, health and social care professionals and local and national decision makers all have a role to play in helping carers feel connected in their communities. Our #CarerConversations toolkit gives individuals and organisations tips and resources so they have the confidence to reach out and support carers around them: www.carersinfo.org.uk/whats-on/carers-week-2018

References

Abdallah, S., Jeffrey, K. and Michaelson, J. *The Cost of Loneliness to UK Employers*. <http://neweconomics.org/2017/02/cost-loneliness-uk-employers/>
London, New Economics Foundation, 2017.

British Red Cross and Co-op Foundation. *Trapped in a Bubble*. London, British Red Cross and Co-op Foundation, 2016.

Campaign to End Loneliness. (n.d) "The Facts on Loneliness." *Campaign to End Loneliness*. <https://www.campaigntoendloneliness.org/the-facts-on-loneliness/> Accessed 20 April 2018.

Campaign to End Loneliness. (n.d) "Loneliness Research." *Campaign to End Loneliness*. <https://www.campaigntoendloneliness.org/the-facts-on-loneliness/>
Accessed 20 April 2018.

Campaign to End Loneliness. (n.d) "Threat to Health." Campaign to End Loneliness. <https://www.campaigntoendloneliness.org/the-facts-on-loneliness/>
Accessed 20 Apr. 2018.

Carers UK. *Alone and Caring: Isolation, Loneliness and the Impact of Caring on Relationships*. London, Carers UK, 2015.

Carers UK. *Facts About Carers*. London, Carers UK, 2015.

Carers UK. *State of Caring 2017*. London, Carers UK, 2017.

Carers UK. (24 Nov. 2017) "Unpaid Carers Missing Out on Vital Support as 'Public is Unable to Recognise Friends and Family that Care'" *Carers UK*. <https://www.carersuk.org/news-and-campaigns/press-releases/unpaid-carers-missing-out-on-vital-support-as-public-is-unable-to-recognise-friends-and-family-that-care>
Accessed 23 May 2018.

Carers UK et al. *In Sickness and In Health*. London, Carers UK, 2012.

Croydon Council. *Carers Survey 2016- 2017*. Croydon Council, London, 2017.

D'Agostino, Anna. *Social Isolation and BME People in Croydon: Issues and Solutions*. Croydon BME Forum, London, 2018.

Jo Cox Commission on Loneliness. (2017) *Jo Cox Loneliness*. <https://www.jocoxloneliness.org> Accessed 23 April 2018.

Jo Cox Commission on Loneliness. *A Call to Action*. London, Jo Cox Commission on Loneliness, 2017.

Kennedy, S. and Reeves, R. "Loneliness in Britain Has Escalated From Personal Misfortune into a Social Epidemic." *Huffington Post*. https://www.huffingtonpost.co.uk/entry/loneliness-in-britain_uk_5a2cf4a8e4b069ec48adf8c5
Accessed 20 April 2018.

Mental Health Foundation. *"Relationships in the 21st Century: the Forgotten Foundation of Mental Health and Wellbeing."* London, Mental Health Foundation, 2016.

Office for National Statistics (ONS). "Loneliness- What Characteristics and Circumstances are Associated with Feeling Lonely?" *Office for National Statistics*. <https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/articles/lonelinesswhatcharacteristicsandcircumstancesareassociatedwithfeelinglonely/2018-04-10>
Accessed 20 April 2018

Perlman, D., & Peplau, L. A. (1981). "Toward a Social Psychology of Loneliness." *Personal relationships 3: Personal relationships in disorder*, edited by R. Gilmour and S. Duck, London, Academic Press, 1981, pp. 31-43.

Royal College of Psychiatrists. *Mental Health and Work*. London, Royal College of Psychiatrists, 2008.

Scope. "The disability price tag." *Scope*. <https://www.scope.org.uk/campaigns/extra-costs/disability-price-tag>
Accessed 23 April 2018.

Tran, Anh. *What is the Impact of Poor Sleep on Physical and Mental Health? What is the Evidence on the Individual Interventions to Improve Sleep?* London, Public Health England, 2017



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