Carers Scotland is a charity led by carers, for Scotland’s 657,000 carers - our mission is to make life better for carers. Amongst other activities, we give expert advice, information and support through our dedicated advice line for carers and campaign together for lasting change.

Carers Scotland welcomes the opportunity to provide input to the Committee on social isolation and caring. Earlier this year, we produced a report “Alone and caring: Isolation, loneliness and the impact of caring on relationships” which highlighted the significant levels of isolation that unpaid carers face. We have submitted a copy of this report alongside this summary.

This revealed that 8 out of 10 carers in Scotland feel lonely or isolated as a result of looking after a loved one and over a third feel uncomfortable talking to friends about being a carer.

Lack of understanding from friends, colleagues and family, inadequate care services and financial pressures leave millions of people in Scotland caring for older, sick or disabled loved ones struggling with feelings of loneliness and isolation.

Over half of carers (58%) have lost touch with family and friends as a result of their caring role and half admitted to experiencing problems in their romantic relationships due to caring for their partner or another family member or friend.

The new research, revealed as Carers UK enters its 50th anniversary year, shows that:

- 8 out of 10 carers (82 per cent) in Scotland feel lonely or isolated due to their caring role
- 58 per cent have lost touch with family and friends as a result of their caring role
- Over a third (34 per cent) feel uncomfortable talking to friends about caring, adding to feelings of loneliness and social isolation
- 51 per cent have experienced difficulties in their relationship with their partner because of their caring role

The survey also found that 56 per cent of carers felt that they were unable to get out of the house due to their caring responsibilities and 42 per cent could not afford to take part in social activities.
Isolation and loneliness is something that many people face as a result of their caring responsibilities for a disabled, older or seriously ill loved one. Carers may feel isolated or lonely because, by putting the person they look after first, they no longer have the time to see other friends and family. They may feel unable to talk to colleagues about their caring responsibilities or have to leave work altogether. The extra costs of caring, and fall in income many carers face, can mean they cannot afford social activities. Or it can just seem like no-one understands their situation.

*Carers UK Chief Executive Heléna Herklots, in an essay for the Campaign to End Loneliness, explores how when you become a carer “you can find that your relationships become increasingly transactional rather than affirming and sustaining. For many carers, the world simply shrinks. Your role can become one of providing and co-ordinating care, taking your loved one to medical appointments, going to the chemist, liaising with care workers. You can feel invisible, as you fade into the background and the needs of the person you are caring for take centre stage.”*

Carers can also face very particular challenges. They often feel responsible, sometimes solely responsible, for the person that they are looking after – something that it may be difficult for others to fully understand.

Carers told us that they feel lonely or isolated for a range of reasons, including that they cannot get out of the house much or are uncomfortable talking to friends about caring

“*Not having anyone to talk to and express how I’m feeling [makes me feel lonely].”*

Carers talked about having too little time to participate in social activities or simply being unable to afford them.

“I sometimes feel so worn out after sorting everything out for my son that I don’t have the energy to have an outside interest.”

“We can’t afford to go out much together as our finances are tight so we have to sacrifice that to pay bills and for food and heating.”

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1 Herklots, Heléna (2014) ‘Caring alone’, *Alone in the crowd: loneliness and diversity*, Campaign to End Loneliness and The Calouste Gulbenkian Foundation
Significantly, carers also pointed to the effects of public perceptions of and response to disability and that this contributed to their isolation.

“People have often verbally abused my son and me because of his autistic behaviour.”

The financial impact is of particular relevance. We know from our Caring and Family Finances Inquiry\(^3\) that carers in Scotland face high levels of poverty, With carers reporting difficulties in meeting the costs of essentials such as utilities (40%) and rent/mortgages (20%) and cutting back on food and heating (38%) it is little surprise that the cost of social activities can take a back seat.

The availability and costs of replacement care services is also a contributory factor. Carers often find that the type of services they would like to use are either not available, not sufficiently flexible or are simply unaffordable. Problems such as these can mean that many carers are unable to take a break away from caring to socialise, catch up with other friends and family, pursue their interests or meet new people. 2 in 5 (41%) carers cite the lack of practical support with caring as a factor that makes it difficult to maintain relationships.

“It is difficult to be flexible or spontaneous as needs of the person I care for must be met before making social arrangements.”

Loneliness, isolation and caring can have an impact on carers’ health. We know that carers are already a third more likely to be in poor health than non carers (and in some areas more than twice as likely) and isolation can further exacerbate this.

Approximately 1 in 6 people over 65 are carers and in previous research\(^4\) three quarters of older carers said that caring had a negative effect on their physical health. As well as facing isolation and loneliness carers also report missing out on vital health support including cancelling a treatment or operation for themselves because of their caring responsibilities\(^5\).

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\(^5\) Ibid one third of older carers reported cancelling a treatment or operation for themselves. This is similar for all carers – see submission to Health Committee by Carers Scotland (2014) [http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Inquiries/Carers_Scotland_-_Access_to_Services.pdf](http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Inquiries/Carers_Scotland_-_Access_to_Services.pdf)
In our Alone and Caring report, we found that the experience of isolation and loneliness as a consequence of their caring role was broadly similar for all carers, with older carers reporting a range of impacts on their health including high levels of depression (50%), stress (80%) and other impacts on their health and wellbeing. All older carers in our survey said that they had reached breaking point because of caring at some point.

**What can make a difference?**
As part of our work to highlight our campaign\(^6\) that “No-one should have to care alone” we made a range of recommendations to policy makers across all sectors to help reduce isolation and loneliness.

In the first instance, an improvement in the financial support available to carers and their families is needed to prevent poverty, hardship and subsequent isolation. Carers Allowance is the lowest benefit of its kind – just £61.35 and available only to those carers caring for a minimum of 35 hours of care per week. Most older carers, apart from those on a very low state pension, cannot claim the benefit because of the overlapping benefits rule. As noted, finances have a significant role to play in limiting carers’ access to social opportunities. Simply put, many carers cannot afford to take part in the social and leisure activities that could help reduce isolation.

Delivering sufficient and sustainable funding of care and support services to meet the needs of carers and the people they care for, would assist in reducing isolation. In particular, regular breaks from caring could enable carers to enjoy activities outwith the home. Moreover, for carers still in the workplace, reliable and flexible care can support them to sustain employment and maintain and support their friendships with colleagues and wider networks of family and friends.

Isolation and caring can and does have an impact on the health of carers. As noted earlier, carers are more likely to be in poor health and the strains of caring and isolation can contribute to stress, depression and reaching breaking point. We believe that there should be a duty on NHS and integration bodies to identify carers and promote their health and well-being. We therefore welcome the inclusion within the national health and wellbeing outcomes for integration bodies of a specific outcome for carers which aims to support carers health and sustain their caring role.

However, this should go further to ensure that all health and social care professionals identify carers and support them to maintain and improve their health and wellbeing. This could, for example, include providing more access to counselling services, ensuring that carers are referred to appropriate support services and fostering support networks through housing, planning and welfare policy and to ensure carers are able to remain close to those networks.

The provision of information and advice is vital in ensuring carers can access the right information at the right time and are provided with essential emotional and practical support. We welcome the Scottish Government’s intention, as part of the forthcoming Carers Bill, to

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\(^6\) Carers UK (2015) No-one should have to care alone. [http://www.carersuk50.org/appeal-2/](http://www.carersuk50.org/appeal-2/)
ensure that all local authorities have in place appropriate information and advice services for carers. We hope this will build on and support the capacity of local carer and condition specific support services.

Finally, as isolation can often be about feeling unable to talk about caring and disability with friends, family and colleagues, our recommendations also include raising public awareness about care and caring. Everyone has a role to play in bringing about a cultural shift towards a society that recognises and understands caring, ageing and disability better. Caring is part and parcel of everyday life – more people openly talking about caring responsibilities would reflect this and allow everyone to understand caring better.

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About Carers Scotland
Across Scotland today, more than 660,000 people are carers, supporting a loved one who is older, disabled or seriously ill.

That’s 1 in 8 adults who care, unpaid, for family and friends. Three in five of us will become carers at some point in our lives and, within our lifetime, there will be 1 million carers in Scotland.
Every day 500 people in Scotland become carers. Many don’t know how or where to get help. It can be frightening and very lonely.

Caring is such an important part of life. It’s simply part of being human. Carers are holding families together, enabling loved ones to get the most out of life, making an enormous contribution to society and saving the Scottish economy £10.3 billion each year.

Yet many are stretched to the limit – juggling care with work and family life, or even struggling with poor health themselves – and finding it difficult to make ends meet.

**Carers Scotland** is a charity led by carers, for carers – our mission is to make life better for carers.

- We give expert advice, information and support
- We connect carers so no-one has to care alone
- We campaign together for lasting change
- We innovate to find new ways to reach and support carers

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