

# Life After Death: supporting carers after bereavement

Policy proposals by Sue Ryder, Marie Curie and  
Reform Scotland, July 2020



Care and support  
through terminal illness

reform  
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palliative,  
neurological  
and bereavement  
support

## A growing need for change

Every year it can be estimated that around 40,000-50,000 carers in Scotland are bereaved<sup>1</sup>. In 2020 and 2021 we suspect that the number of bereaved carers will be even higher as a result of the additional deaths because of the Covid-19 epidemic in Scotland. National Records of Scotland (NRS) has shown that around 90% of people who died with Covid-19 had an underlying health condition, such as dementia (over 30%) and the vast majority were over 75, suggesting that they are likely to have been supported by a family carer.

For many when their caring role ends so does the vital support they receive from benefits and tax credits, peer support, and even their identity as a carer, as well as their purpose. This can have a significant detrimental impact on their physical and mental wellbeing, but there is currently limited support for carers once their caring role ends and our organisations believe this needs to change.

We know that as Scotland's population ages that more and more people will live into older age with multiple health conditions. Emerging trends have shown that more and more people are spending time at home in the period before they die and that more and more people will be dying at home<sup>2</sup>. This means greater pressure on those family members and friends in caring roles.

A recent report by Carers UK Scotland has found that nearly 400,000 additional people in Scotland are now caring for older, disabled or seriously ill relatives or friends since the Covid-19 pandemic<sup>3</sup>, and this too is likely to lead to more people needing support if those caring roles come to an end. If there is a second wave or future waves of Covid-19 outbreaks, then there is potential for the number of carers in Scotland to continue to grow.

Over 15,000 people have died of all conditions during the COVID epidemic in Scotland leaving behind a significant number of bereaved people<sup>4</sup>. Many of these people will have had carers and family members supporting them, and a lot of these carers will have needed support during their caring role and will need further support following the death of the person they have been caring for<sup>5</sup>.

We are calling on the next Scottish Government to commit to the following key actions:

- a Carers (Bereavement Support) (Scotland) Bill early in the next Parliament to provide information and a plan to support carers following the end of their caring role;
- a new fund to support training and education for carers returning to work/seeking employment;
- a new Post-Caring Support Payment to help carers struggling financially following the end of their caring role.
- to extend eligibility for the Carer's Allowance and Carer's Allowance Supplement for up to 6 months after the person's caring role comes to an end (from the current 8 weeks).

<sup>1</sup> Grande, G., Stajduhar, K., Aoun, S., Toyne, C., Funk, L., Addington-Hall, J., . . . Todd, C. (2009). Supporting lay carers in end of life care: current gaps and future

<sup>2</sup> Finucane, A.M., Bone, A.E., Evans, C.J. *et al.* The impact of population ageing on end-of-life care in Scotland: projections of place of death and recommendations for future service provision. *BMC Palliative Care* **18**, 112 (2019).

<https://doi.org/10.1186/s12904-019-0490-x>

<sup>3</sup> <https://www.carersuk.org/scotland/news/covid-19-pandemic-392-000-become-unpaid-carers-in-scotland-in-a-matter-of-weeks>

<sup>4</sup> National Records Office Scotland

<sup>5</sup> Harrop E , Byrne A , Nelson A . "It's alright to ask for help": findings from a qualitative study exploring the information and support needs of family carers at the end of life. *BMC Palliat Care* 2014;13.doi:10.1186/1472-684X-13-22

## Support for the carer when their role ends

*“No longer a carer’ for me is very real following my husband’s death. I honestly believe that if there had been post carer support around me at this time, the deep self-destruct feelings I have would have been alleviated. Someone who could have said “these feelings are normal”, someone who could have listened without judgment. Someone you felt safe to admit your feelings too. You can’t share these feelings with friends or family for fear that they think you are a selfish monster. Someone who allows you to talk about no longer being a carer”.*

- carer for someone who had dementia, supported by TIDE – Together in Dementia Everyday

The role of being a carer has a huge impact on the life of the person they are caring for. The value and role of being a carer was recognised by Scottish Government with the introduction of the Carers Scotland (2016) Act, which introduced and formalised a number of provisions for carers, with the most fundamental change being that carers are entitled to an Adult Carer Support Plan (ACSP) or Young Carers Statement (YCS) from their local authority. These plans ensure that a carer’s information, wishes, plans and goals for caring are captured. It can also lead to further statutory support such as respite care or direct payments to support the person in their caring role.

Recognising the financial burden of caring, some carers are eligible for the Carer’s Allowance, and Carer’s Allowance Supplement in Scotland.

Once the caring role comes to an end it can have a significant impact on the carer’s wellbeing, their financial position, relationships and virtually every aspect of their life. Much of the support provided to them while they were a carer is withdrawn following the death of the person they were caring for.

## Financial impact of being a carer and a former carer

Carers rely on a number of sources of income to help support them and those they are caring for.

The carer may receive benefits themselves depending on their age and employment status, but most carers will rely on the Carer’s Allowance and the Carer’s Allowance Supplement in Scotland. They could also be eligible for additional financial support following the death of the person they are caring for. A list of supportive benefits that carers might be eligible for are set out in Appendix A.

Carers qualify for Carer’s Allowance if they spend at least 35 hours a week caring for someone, if they are 16 or over, if they not in full-time education or studying for 21 hours a week or more and do have an income of less than £128 a week. The person being cared for must already get one of a range of benefits for the carer to be eligible for the allowance. Although there is no upper age limit to receive Carer’s Allowance, you cannot receive it and the state pension at the same time. As a result, the vast majority of recipients are of working age.

According to Government Expenditure and Revenue in Scotland (GERS) 18/19 data, Carer's Allowance amounted to £266m in 2018/19, up by 31% on £203m in 2014/15. The £266m for Carer's Allowance accounts for 8% of devolved social security expenditure.

Carer's Allowance figures Scotland<sup>6</sup>

- There were 76,597 carers in receipt of this payment in Feb 2019, an increase from 73,913 in Feb 2018
- 46,025 carers are entitled to the support but not claiming it (this may be due to being entitled to other benefits, as well as those not claiming, but would likely receive the benefit).
- 69% of carers were women
- 31% of claims last between 2-5 years
- 38% last over 5 years

For those carers living with the person they are caring for may also see household income increase with support from a range of benefits received by the person they are caring for, such as Personal Independence Payment (PIP).

However, many carers struggle to make ends meet with the level of financial support they receive. *Caring for your future - The long-term financial impact of caring* by Carers UK<sup>7</sup> showed that:

- Unpaid carers' finances worsen the longer they're caring for a loved one
- Half of people caring for more than 15 years and struggling financially are having to cut back on food or heating
- The number of carers in debt because of caring increases from 12% of people caring for a year or less to 19% of those caring between five and nine years. The proportion rises steeply to 25% of those who have been caring for over 15 years.

So, what happens when the person they were caring for dies? Although the Carer's Allowance payment continues for eight weeks, however, our organisations believe that this is not long enough for people to grieve, find a job and adjust to their new circumstances.

Indeed, this is recognised by the UK Government which will not impose a 'work search requirement' on someone whose spouse or child has died for 6 months after such a bereavement. However, this is not always matched with additional financial support.

The loss of the Carer's Allowance income may also be in conjunction with the loss of other incomes that the person they were caring for may have been in receipt of, such as PIP. This could have a considerable impact if the carer and the person they were caring for shared a house and it was all considered as part of one household income.

**We believe that the Scottish Government should extend eligibility for the Carer's Allowance and Carer's Allowance Supplement for up to 6 months after the person's caring role comes to an end (extending from the current 8 weeks).**

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<https://www2.gov.scot/Topics/Statistics/Browse/Social-Welfare/SocialSecurityforScotland/CASApr2019>

<sup>7</sup> [http://www.carersuk.org/images/News\\_and\\_campaigns/Carers\\_Rights\\_Day/CUK-Carers-Rights-Day-Research-Report-2018-WEB.PDF](http://www.carersuk.org/images/News_and_campaigns/Carers_Rights_Day/CUK-Carers-Rights-Day-Research-Report-2018-WEB.PDF)

## Bereavement Support Payment

Bereavement Support Payment (BSP) was introduced in 2017, replacing three former payments. The payment, which is reserved to the Westminster Government, is based on the deceased's National Insurance contributions. A bereaved spouse under State Pension age is entitled to a lump sum followed by 18 monthly payments. The amount received is based on whether the spouse and deceased had dependent children. If so, there is a first payment of £3,500 followed by monthly payments of £350. If there are no children, the first payment is £3,500 followed by monthly payments of £100. As with the three former payments, only couples who are married, not cohabiting, are entitled to the payment.

**We believe that this benefit should not be limited to married couples only but should include all couples regardless of their marital status. The High Court ruled in February 2020 that denying BSP to unmarried parents breached human rights. The UK Government confirmed it would not appeal this decision but as yet has not changed eligibility criteria in line with this ruling. We would urge the Scottish Government to make representations to the UK Government to have this changed immediately.**

## Return to employment

One in five (19%) employees aged over 45 expects to quit their job to care for an adult relative full time, according to research from Aviva<sup>8</sup>. Many ultimately find it difficult to return to the labour market following the end of their caring role.

The longer someone has been caring, the longer they are likely to have been out of the labour market and potentially isolated from the networks they had before becoming a carer. Support, counselling and retraining may be required. The more that can be done to help these individuals back into work, the better it is for them and for our communities and wider society.

As the statistics demonstrate, carers are also overwhelmingly more likely to be women. Women already face other barriers to work, something that the Scottish Government is trying to address with other policies. Helping women after the end of their caring period can help contribute towards this wider goal as well.

That has a significant impact on someone's ability to train, find or maintain employment. For many, working and caring, especially if they also have other caring responsibilities, will simply be incompatible.

This support for carers would be of particular importance now to help support the economic recovery following the Covid-19 epidemic, where many carers may be looking to return to the labour market following the loss of a loved one during this period. It may also be a much more competitive market for employment with the economic slowdown leading to less jobs being available. Any action the Scottish Government take with regarding retraining programmes as part of the broader recovery have to take account of the needs of carers trying to re-integrate back into work.

**We believe that specific support to enable those carers who wish to return to employment should be set out as part of the development of a person's Post Carer Support Plan (see below).**

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<sup>8</sup> <https://www.personneltoday.com/hr/working-carers-quit-work/>

**We also believe that the Scottish Government should look to create a fund that carers can access to specifically support training and education to enable them to return to work or to support a carer re-enter employment following a period of caring.**

### **New Post Caring Support Payment**

The Scottish Parliament has the power to create new benefits covering devolved areas. The financial impact of caring and the financial impact faced by carers following the death of a loved one can be severe, as set out above. Our organisations believe that Scottish Government should consider introducing a new payment aimed at supporting carers after the death of the person they have been caring for to help meet the gap created by lost income. We believe that this should be offered alongside the extended Carers Allowance and Supplement.

The length of time that the payment applies for would be linked to the length of time someone has been caring. If someone has been caring for an individual for over five years, while their grief and loss may be no greater than someone who has been caring for an individual for only a few months, their practical ability to rebuild connections in their local community and/or the work place will be considerably more difficult and that should be recognised. This new benefit would be an 'earned payment', based on the length of time spent caring and would, therefore, also be a recognition of the "job" or "unpaid work" the individual has undertaken, a contribution to wider society that is not always recognised. Entitlement would be based on the length of time the individual had previously been in receipt of Carers Allowance.

The payment could be offered alongside the proposed Post Carer Support Plan (see below).

**We believe that Scottish Government should give consideration to a new Post-Caring Support Payment to help carers struggling financially following the end of their caring role.**

### **Achieving better outcomes bereaved people whose caring roles have come to an end**

There is a considerable amount of research<sup>9,10</sup> which identifies factors associated with poorer bereavement outcomes:

- Dying in hospital
- Socio-demographic disadvantage
- A perceived lack of access to bereavement support and resources
- Closer relationship to the cared-for person
- Fairly immediate loss of the health and social care structure when the person dies
- Reluctance to access bereavement support
- Physical health, post death exhaustion, lack of sleep, poor eating
- Constructing a new identity post caring
- Renewed sense of their own mortality
- Caregiving experiences perceived as burdensome or overly stressful

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<sup>9</sup> Roulston, Campbell, Cairnduff, Fitzpatrick, Donnelly, Gavin. Bereavement outcomes: A quantitative survey identifying risk factors in informal carers bereaved through cancer. *Palliative Med.* 2017 Feb;31(2):162-170. doi: 10.1177/0269216316649127. Epub 2016 Jul 10.

<sup>10</sup> Burns, E., Prigerson, H.G., Quinn, S.J., Abernethy, A.P. and Currow, D.C., 2018. Moving on: Factors associated with caregivers' bereavement adjustment using a random population-based face-to-face survey. *Palliative medicine*, 32(1), pp.257-267.

- Caregiving impacted on existing relationship and social circle
- Negative interactions with health and social care professionals
- Being from the LGBTQ+ community
- Potentially stigmatised illness (eg HIV/AIDS)

There is also a significant amount of evidence that identifies factors that improve bereavement outcomes between one and five years after the person's death, including:

- >65 years (less competing demands, more experience of caring and death, expecting death)
- Caring for a parent rather than spouse
- Feeling well prepared for the death
- Gender – being female
- Patients having no preference for place of death
- Carers remaining in employment pre- or post-bereavement
- Systematic assessment of need and support (CSNAT) – this is a tool used to support the carer during their caring role and before the cared for person has died.
- Connecting with life again – aided by good informal support networks and good relationship with professionals
- Feeling proud of being a carer
- Renewed sense of their own mortality
- 'having done their best'
- Good communication between families and caregiver and receiver
- A positive good-bye

There will be many informal carers who as well as needing financial support following the death of the person they are caring for, will also need information, support and guidance. Often the help they require is available, usually provided by the third sector, but many people will not know what help exists and how can they access it. There can be additional challenging when someone is bereaved and grieving.

**We believe that the next Scottish Government should introduce legislation to create a Post-Carer Support Plan for carers who need and want one following the death of the person they are caring for or following their move into a care home or elsewhere.**

A Post-Carer Support Plan would be based on the current Adult Carer Support Plan (ACSP)/ young Carer Statement (YCS) model. It would be available to all those who were in a caring role, even if the person wasn't previously identified as a carer and didn't have an ACSP or YCS.

The carer would be given the chance to set out their needs and concerns and it would be an opportunity to identify information and services to support someone following the end of their caring role. This could include bereavement support, information and advice on financial support/benefits available, as well as identifying any services locally or online to support a return to work. For those not looking for work, it is just as important that they are helped to rebuild connections and not left feeling isolated.

"I have no family left and no friends as I gave everything up to look after both parents."

– Sue Ryder online community user

To allow someone to start dealing with their 'living grief' before the person they are caring for dies, this process should start while they are still in their caring role. This would also limit the gap between any services and support being withdrawn when their caring role ends and the start of any new support.

Different agencies and charities could be responsible for completing the forms and enabling carers to get support, with lead responsibility, i.e., management of the new system and ensuring carers get the support they need, resting with the local Health and Social Care Partnership.

### **A dedicated information and support toolkit for carers before and after a bereavement**

"I had moved in with her for the last 2+ years as her live in carer [...]... I feel SO LOST ... even tho there is the house of 64 years 2 clear... sort & sell!"

– Sue Ryder online community user

Clear and consistent information is essential to support those when their caring role comes to an end, as well as knowing where to access that information. We propose the development of a specific toolkit of information and support that should be given to every carer of someone with a terminal or long term condition where often the carer may be struggling with living grief as they see the cared-for person's health decline. This information could be given to all health and care practitioners, carer centres and be made available to information and support services such as those run by Sue Ryder, Marie Curie, Citizen's Advice Scotland and Cruse Bereavement Scotland.

### **Signposting and support**

There needs to be a better signposting system where key individuals, such as GPs, social care staff or community nurses are able to point people to the organisations where they can get support. A pack could be put together setting out the different organisations and entitlements that people could use. This could also highlight the Bereavement Support Payment and the financial support offered by the Scottish Government, such as the funeral payment and potentially, the Post Caring Support Payment.

**These proposals reflect the principle behind the Bereavement Charter for Scotland, which has been developed by a range of cross-sectoral organisations. It may be that for the proposals outlined above to be taken forward there will need to be new legislation introduced to Parliament. Our organisations would support the introduction of a Carers (Bereavement Support) (Scotland) Bill following the 2021 Scottish Parliament election.**

# Appendix A

## Benefits available to families/carers following the death of a person

### Bereavement Support Payment

BSP was introduced in 2017, replacing three former payments. The payment is based on the deceased's National Insurance contributions. A bereaved spouse under State Pension age is entitled to a lump sum followed by 18 monthly payments. The amount received is based on whether the spouse and deceased had children. If so, there is a first payment of £3,500 followed by monthly payments of £350. If there are no children, the first payment is £3,500 followed by monthly payments of £100. As with the three former payments, only couples who are married, not cohabiting, are entitled to the payment.

### Covid-19 death in service

As a result of the Covid-19 pandemic, the UK and Scottish Governments introduced death in service benefits to help those whose loved one died from Coronavirus as a result of being a front-line health worker<sup>11</sup>.

Bereaved family members receive a lump payment, generally equivalent to twice the staff member's annual earnings.

The payment in Scotland applies to all NHS front line staff, regardless of whether they are a member of the pension scheme. The Scottish Government has also set out proposals for social care staff to qualify for a death in service award on the same basis as those working in the NHS.

### Funeral Support Payment

This payment is administered by the Scottish Government, having been devolved in 2016, and replaced the Funeral Expenses Payment operated by Westminster. It can be used to help cover funeral costs for a baby, child or adult. This includes babies who were stillborn. It usually will not cover the full cost of the funeral, but it should help pay for some costs. The claimant has to be in receipt of certain benefits and be responsible for a funeral in order to claim.

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<sup>11</sup> <https://www.gov.uk/government/news/new-guarantee-on-death-in-service-benefits-for-frontline-health-and-care-staff-during-pandemic>; <https://www.gov.scot/news/new-benefit-for-all-health-service-staff/>