

# A Manifesto for Unpaid Carers and Young Carers



National Carer Organisations

2021



## About carers

Unpaid carers provide care and support to family members, friends and neighbours. The people they care for may be affected by disability, physical or mental ill-health, frailty or substance misuse. A person does not need to be living with the person they care for, or providing a certain number of hours of care, in order to be considered a carer.

There are an estimated 729,000 unpaid carers in Scotland. This includes 29,000 who are under the age of 18. However, research<sup>1</sup> published in June 2020 showed an estimated 392,000 additional people in Scotland have become unpaid carers a result of the Covid-19 pandemic. This brings the total number of carers in Scotland to 1.1 million.

## About this manifesto

This manifesto has been developed by the National Carer Organisations, in consultation with unpaid carers across Scotland. We are Carers Scotland, Carers Trust Scotland, the Coalition of Carers in Scotland, Crossroads Caring Scotland, MECOPP, Shared Care Scotland, and the Scottish Young Carers Services Alliance. Together we have a shared vision that all Scotland's unpaid carers will feel valued, included and supported as equal partners in the provision of care. The NCOs aim to achieve this through the representation of carers and giving them a voice at a national level.

We believe we can deliver more for carers by working together to share our knowledge and experience, and by focusing our collective efforts on achieving improvements in areas of policy and practice that are of greatest concern to carers.

This manifesto has been developed in two sections: section one outlines recommendations for change for all unpaid carers; and section two sets out more direct considerations for young carers and young adult carers.

# SECTION 1: All carers

## Support

Key to supporting carers is ensuring that services are available when they need them and are designed to meet their needs and outcomes. However, help from social care services remains limited, with restricted eligibility criteria and lack of choice. Too often carers have little choice but to take on care because services and support are simply not available, particularly at the start of their caring journey.

Carers need support so they can sustain their caring role as well as having a fulfilling life outside caring. This is essential to carers accessing their human rights and being able to participate as active citizens. They should be fully involved in decisions on the future of social care and should always have timely access to the information they need to make an active and informed choice about the level of care, if any, they are willing and able to provide.

Carers are the largest workforce providing social care in Scotland, vastly outnumbering those employed in both NHS and social care across sectors. Their needs must be fully considered and addressed as part of any future social care reform programmes.

Key areas for carers include:

- Full implementation of the recommendations made by the Independent Review of Adult Social Care.
- Additional investment in social care, expanding access to social care support and investing in prevention.
- A right to respite, with the development of a range of options for respite and short break services enabling carers to look after their own health and wellbeing and have a life outside their caring role.
- Human rights at the heart of social care and the recognition that carers require support to access their human rights and participate as active citizens.
- Existing and future legislation, including the Carers Act, fully resourced and implemented, bridging the gap between promise and reality. Where people are not able to access their rights they must have rapid access to an effective complaints system and to redress.

- ▶ Social care afforded the same priority of esteem as health care, with support fully integrated to ensure that unpaid carers and those they care for do not “fall between the cracks”.
- ▶ Both health and social care provision delivered without charge, with all social care charges scrapped.
- ▶ The vital role of the third sector and community supports fully recognised. This includes ensuring that carers centres and young carers services have increased, sustainable resources with funding ring-fenced for this purpose. Carers centres and young carers services should be allocated a preventative budget to respond quickly to carers’ needs to prevent crisis.
- ▶ In order for the social care system to be successfully reformed those who use services and their carers must be fully involved as equal and expert partners in care. This includes strengthening the role of carer representatives on Integrated Joint Boards (IJBs) and supporting carer involvement in decision making at all levels, including at Board level on any potential new structures, such as the National Care Service.

### Health and wellbeing

There is significant evidence that caring impacts upon the physical and mental health and wellbeing of people providing care. This has been exacerbated by the coronavirus pandemic, resulting in many carers having to significantly increase the hours of care they provide and nearly 400,000 people taking on a caring role for the first time.

Carers should be supported to maintain their health and wellbeing and parties should commit to providing dedicated support for unpaid carers to do so.

A national programme for improving carers health and wellbeing should be developed, with sufficient funding for NHS Boards, Health and Social Care Partnerships (HSCPs), local councils and other partners to ensure that there is consistent provision across each area of Scotland. We recognise that service provision will vary from area to area, however levels and a core “offer” should be consistently applied and monitored. This programme should include:

- ▶ Implementation of social prescribing for carers in all areas including, for example, free access to leisure, health and wellbeing activities to unpaid carers, alongside the introduction of a national carer discount card, with similar benefits to the Young Scot card.

- the introduction of health checks for carers and flexible appointments to ensure that carers can access national screening programmes. This should include a commitment to invest in providing an occupational support system for carers delivering fast track access for carers to physiotherapy and counselling and similar services, in the same way that staff have access to this through their employers.
- the introduction of dedicated mental health support for carers of all ages, including providing funding for local carer and young carer services to offer counselling services alongside their longstanding provision of emotional support services. For carers providing care to someone with mental health problems, it is vital that Triangle of Care is implemented across mental health services in all NHS boards. The Triangle of Care approach encourages partnership working in mental health services with carers at all levels of care from the individual to overall service planning in line with carers' rights under the Carers (Scotland) Act 2016.”

## Employment

One in five carers has to give up work to care and carers often miss out on promotions or have to take lower paid jobs to fit around their caring role. The pandemic has increased risks to carers of losing employment, with many support services that enable carers to remain in employment reduced or suspended.

Carers should have a right to reconcile caring with paid employment of their choice and, whilst employment law remains reserved, parties should commit to supporting carers to remain in employment using the levers available in Scotland.

A Carers Employability Strategy should be developed and funded as part of the Fair Work Agenda. This should include:

- Local HSCPs should be required to ensure that dedicated funds within social care are available to provide replacement care to enable carers to work or to study to update their skills. This investment should be viewed in the same way as investment in childcare.
- Consideration of carer's access to employment should be a routine part of all Adult Carer Support Plans.
- All public bodies and organisations receiving public funding (either through grants or contracts) should be required to become Carer Positive employers.
- The UK Government is proposing to introduce unpaid statutory leave for carers but, recognising the significant impact of caring on finances, all public bodies and those organisations seeking public contracts should be required to provide a minimum of 10 days paid leave.

- ▶ A dedicated employability programme should be introduced for carers, including supporting carers to build skills and experience to enable them to return to employment. Specific employability support should be developed for young adult carers who may experience additional disadvantage in accessing employment. This should include access to modern apprenticeships and extending the Job Grant to young carers in receipt of Carers Allowance.

### Economic wellbeing

Many unpaid carers face significant financial hardship because they care. Financial hardship is often exacerbated by low paid roles, or leaving employment in order to care. As a result, unpaid carers often struggle to make ends meet, choosing between food and heating, and facing debt and poverty well beyond when caring ends.

All parties should commit to reforming Carer's Allowance and increasing levels of benefits and to extending passported benefits to support unpaid carers.

This includes:

- ▶ Committing to a full reform of Carer's Allowance, in order to better support people to care, including those in employment or education. The new Scottish Carer's Assistance should be available to carers who care for 20 hours or more each week; evidence shows that caring for 20 hours or more is the point at which impact starts to be felt on employment, health and more. The new benefit should consider how to address the "overlapping benefit rule" that disadvantages carers on the state pension. At a minimum, a Carer Recognition Payment for carers in receipt of State Pension, similar to the Carers Allowance Supplement should be introduced.
- ▶ Until Carer's Allowance is fully reformed, opportunities should be sought to make changes to the current benefit including changing the earnings threshold and removing the cliff edge. This could include, for example, aligning the threshold to, at a minimum, 16 hours at the Real Living Wage. The 21 hours/full time study rule should be removed completely. When caring comes to an end, the timeframe for Carer's Allowance continuing to be paid should be extended from the current limit of 8 weeks to at least 6 months. Eligibility for this "run on" should be extended to those whose caring role has ended when the person they care for has gone into full time care. Although disability benefits cease after 4 weeks on admission to hospital, carers should continue to receive Carer's Allowance as currently they lose this vital financial support, even though they continue to support the person during their hospital stay.

## SECTION 2: Young carers and young adult carers

Similarly, to adult carers, the numbers of young people providing unpaid care during the pandemic has increased, as has its impact upon them.

Even before the outbreak of Coronavirus, young carers and young adults were already spending significant amounts of time providing unpaid care in addition to the time they needed to spend on education, work and time for themselves. Coronavirus has significantly increased those pressures. Recent research undertaken by Carers Trust Scotland found that 45% of young carers and 68% of young adult carers that participated said their mental health was worse as a result of Coronavirus, and 58% reported that their education is suffering. Additionally, almost 80% of young carers and young adult carers that responded were worried about their future and 42% of young adult carers said they were unable to take a break from caring as a result of Coronavirus.

### Support

Key to supporting young carers and young adult carers is ensuring that age-appropriate services are readily available when they need them and are designed to meet their needs and outcomes. Young carers and young adult carers often have little choice but to take on unpaid care because services and support is simply not available, particularly at the start of their caring journey.

Young carers and young adult carers must have support in place to protect them from undertaking inappropriate caring roles. Support should also allow them to make an active and informed choice about the level of care, if any, they are willing and able to provide and ultimately ensure that they have a fulfilling life outside caring.

### A cross cutting action plan

Young carers and young adult carers should be supported first and foremost as children and young people. Significant work is needed to ensure that young people with caring responsibilities do not face exclusion or disadvantage simply because they are caring. The urgency for action has been heightened by the pandemic and its impact on young people, and without action the impact on young carers and young adult carers may be felt well into their futures.

All political parties should commit to developing a new cross cutting action plan for children and young people with caring responsibilities, with clear actions that can be delivered at pace.

This should include:

### Identification

- ▶ Requiring local authorities to report annually on how many young carers are identified and the number of these young people who received a Young Carer Statement, in order to track progress and communicate impact. Local young carer services should be provided with preventative budgets to enable them to provide direct support to young carers who do not meet the local threshold for support.

### Action in schools

- ▶ Requiring all schools to record identified young carers as having an additional support need on SEEMiS (Scottish Educational Management Information Software). Statutory Guidance for the Education (Additional Support for Learning) Scotland Act 2004[i] clearly highlights that young carers may have additional support for learning needs. However inadequate identification, support and recording of young carers in education is putting their studies and future opportunities at risk. All schools should be identifying young carers and ensuring they have access to the support that they need to have a fair chance to be successful in their studies.
- ▶ Introducing compulsory Young Carers' Awareness training for all teachers and education professionals as part of Professional Learning. This should include specific training for those providing counselling and mental health support in schools and the community. School staff members are vital and ideally positioned to identify young carers early and initiate support. Understanding unpaid caring and being able to identify young carers is essential to offering them much needed additional support so they can successfully engage, achieve their own potential in education and live their own life outside caring.
- ▶ Ensuring that all schools have a Young Carer Champion; a member of staff who is the main point of contact for young carers, raising awareness in the school and building external partnerships with relevant stakeholders (such as health, social care and voluntary sector).



- ▶ Developing specific guidance around using Pupil Equity Funding to include young carers and supporting their attainment goals to help close the poverty related gap that young carers may experience.

### Action on further and higher education

- ▶ Committing to work with UCAS to move forward with identification of students on UCAS application forms and publish data on student carer applicants. UCAS are well positioned to identify student carers through applications to higher education. This would alert education institutions that an applicant has caring responsibilities and could help initiate the process for a potential contextualised offer to their course. This would also help facilitate for the institution to connect with the unpaid carer applicant to inform them of what support is available during application stage and, if accepted, when they arrive on campus.
- ▶ Requiring all colleges and universities receiving public funding to become Going Further/Going Higher for Student Carer Recognition Award institutions and develop Student Carer Support Policies to ensure they are following good practice models and holistically supporting student carers.
- ▶ Encouraging colleges and universities to introduce and develop more flexible course structures which enable more ‘carer friendly’ courses – allowing for flexible attendance and engagement without impact on course completion and finance.

### Action to support health and wellbeing

- ▶ Ensuring that young carers have access to “Out of School Care” services and activities, free of charge. Having a carer role can affect young carers’ abilities to form friendships and take part in leisure activities. Evidence shows that young carers are at a higher risk of experiencing bullying and having or developing mental ill-health. Free access to “Out of School Care” services and activities including short breaks may reduce isolation and reduce negative impacts on their health and wellbeing. Young carers providing care for a person in receipt of/or eligible for a disability benefit should be exempt from being charged for “Out of School Care” services and activities that they may access.

Young carers should not be penalised in any way due to non-attendance at “Out of School Care” services as a result of their caring responsibilities impacting their ability to attend.

It is equally important to remove financial barriers for young carers to take part in activities and services, including short breaks, that require families to purchase materials or equipment for example sports/club kits, art materials or purchasing/hiring musical instruments etc.

- ▶ Providing sufficient ringfenced funding for third sector local carer services to support and develop tailored and age-appropriate services for young carers and young adult carers, creating opportunities for short breaks, socialisation, building their confidence, improving their wellbeing and to find out about other support that they are entitled to.
- ▶ Prioritising young carers for the Coronavirus (COVID-19) vaccines if they become medically approved to be administered to children and young people under 16. Young carers should be listed in the initial priority groups to be offered these as they may be providing unpaid care to people who are particularly vulnerable or at risk.

### Action to provide financial support

- ▶ Amending the Young Carer Grant regulations so that multiple young people can be eligible for the grant for providing care for the same cared-for person. When more than one young carer meets all of the other required eligibility restrictions, they are currently penalised from receiving the Young Carer Grant because another young carer has received a grant for caring for the same person. If this restriction is not removed, then there may be young carers who are entitled to wider unpaid carer support who will not be identified.

Wider consideration is needed on how the immense contribution of young carers that are not eligible for Young Carer Grant because their cared-for person is not in receipt of a qualifying disability benefit is recognised. For example, young people caring for someone with mental health problems or an addiction who may not receive a qualifying disability benefit, may be most at risk of not receiving support although they could have intense caring responsibilities.

### Action to support employability for young carers

- ▶ Developing a specific employability programme to support young adult carers who may experience additional disadvantage in accessing employment and who are at higher risk of not being in education, employment or training (NEET) compared with their peers who do not have caring responsibilities. This wider programme should include access to modern apprenticeships and extending the Job Grant qualifying eligibility to include young adult carers in receipt of Carer's Allowance.

## Equalities

Across all the actions, it is vital that the needs of ALL unpaid carers of all ages are addressed. This means that the Scottish Government and partners must assess all activity intended to support unpaid carers to ensure that it will meet the needs of unpaid carers with protected characteristics. Measurable actions must be developed, in partnership with unpaid carers, to address any gaps and to respond to specific needs.

This should include:

- ▶ community languages being accorded the same status as BSL, particularly in relation to emergency public health messaging as evidenced by the disproportionate impact of the coronavirus on BAME carers and cared for people
- ▶ consideration of a Carers Impact Assessment across all policy areas to ensure that policy developments are assessed against actual and potential impact on Scotland's carers



National Carer  
Organisations

## Further information

For more information contact:

Fiona Collie, Carers Scotland  
Email: [fiona.collie@carerscotland.org](mailto:fiona.collie@carerscotland.org)

Claire Cairns, Coalition of Carers in Scotland  
Email: [coalition@carersnet.org](mailto:coalition@carersnet.org)

Kate Hogarth, Shared Care Scotland  
Email: [kate.hogarth@sharedcarescotland.com](mailto:kate.hogarth@sharedcarescotland.com)

Paul Traynor, Carers Trust Scotland  
Email: [ptraynor@carers.org](mailto:ptraynor@carers.org)