



## Discussion Paper on Life Leaving Lockdown

The NCOs have produced a discussion paper outlining some of the measures that we believe need to be implemented to support unpaid carers and the people they care for as restrictions are eased. This is not intended to look at the broader future but rather actions that need to be considered at each stage of lockdown easing. This paper has been informed by the many comments and issues raised by carers during the pandemic to the NCOs, carers centres and young carers services. Unless directly specified “unpaid carers”, refers to unpaid carers of all ages.

### Background

The COVID19 pandemic has not affected everyone equally. People with disabilities, those with long-term conditions, older people and of course their unpaid carers have been significantly more impacted than the rest of the population. For those at extremely high risk (“shielding”) or who are very high risk but not “shielding” and their unpaid carers this has confined people to their homes, without a prospect of end. This impact has been on all aspects of individual lives – finances, paid employment, education, availability of care services and support, access to food and medicines, mental and physical health. For many, extreme isolation has been a day to day reality.

Yet, the debate on easing lockdown has so far focused not on this critical group, but instead on economic factors with little nuance on the very real challenges that “restarting the economy” will mean for people of all ages who are at increasing risk from coronavirus and their unpaid carers.

In Scotland “Caring Behind Closed Doors”<sup>1</sup> found that a staggering 78% of unpaid carers in Scotland are having to provide more care for their loved ones during the coronavirus outbreak. Reduced care and support services, and paid care workers isolating meant many unpaid carers in Scotland had, and still have, no choice but to care round the clock for loved ones with complex health conditions and disabilities - without any hope of a break. Nearly 4 in 10 (39%) of unpaid carers are providing more care as a result of local services reducing or closing.

This has had a devastating impact on their health and wellbeing, with more than half (53%) of unpaid carers saying they felt overwhelmed managing their caring responsibilities during the outbreak and worry about burning out. And, it should be remembered that for many unpaid carers, the strain of the coronavirus pandemic only adds to intense caring roles and reinforces the inequalities they face on health, work, education, finances and more.

In a survey<sup>2</sup> of their 5000 members by Glasgow Disability Action (GDA), they found that coronavirus has “supercharged existing inequalities already faced by disabled people” with 40% of disabled people they spoke expressing worries about food, medication or money. This is also the case for unpaid carers, for example, around 1 in 5 unpaid carers also talked about similar problems, including accessing food, with 80% reporting seeing extra costs for food and more than half (53%) for other household bills. Almost 40% said they were worried about their financial situation.

*“My savings that I have spent 30 years trying to build up for retirement are now vanishing to pay the bills.”*

<sup>1</sup> Caring Behind Closed Doors: Forgotten families in the coronavirus outbreak, Carers UK April 2020. Unless otherwise referenced; all other statistics noted are from this report.

<sup>2</sup> GDA’s Covid-Resilience Engagement and Response, Interim Report April 2020

22% of unpaid carers were either furloughed or were on unpaid leave due to current social distancing rules. A small percentage (2%) reported having had to give their jobs up entirely. And, for the 41% of unpaid carers that have been able to work at home, managing caring and working from home can be extremely challenging. Unpaid carers face both the emotional impact of not being able to take a break, trying to work and providing care.

*“Working from home has increased my stress levels because I am no longer able to use going to work as respite from my caring role.”*

In GDA’s survey, 72% of disabled people said isolation is a major worry. This reflects a similar situation for unpaid carers. More than 80% of unpaid carers in “The World Shrinks”<sup>3</sup> were already saying that they were lonely or socially isolated. Coronavirus is exacerbating this, with many unpaid carers speaking of feeling alone and forgotten.

Information was also critical to unpaid carers. Unpaid carers spoke about the lack of clear guidance targeted at them as being a barrier. 56% of respondents said that clearer and specific guidance from the Scottish Government for unpaid carers would help them. For many unpaid carers, digital exclusion exacerbates not only this but access to online supports that have been developed.

### Young Carers

For young carers, as well as the challenges of caring and lack of breaks, many worry about the impact of coronavirus on their future. With young carers already experiencing educational disadvantage because of their caring role<sup>4</sup>, they are real concerns that decisions on their exam results may affect their future educational and career opportunities.

*It is extremely frustrating that the exams have been cancelled due to this pandemic and I know that I would have gotten much better grades in my exams. If it wasn't for my home life, I know I would have done a lot better in my prelims and since then I have been working really hard for my exams. I hope that the SQA takes into consideration how difficult this year has been for me and I hope that I get decent expected grades for most of my classes but it is out of my hands now.*

### Carers with Protected Characteristics

Many of the issues set out above have particular resonance for unpaid carers with one or more protected characteristics. Historically, unpaid carers within these communities have been distanced from mainstream carer support and a significant proportion continue to experience difficulties in accessing services due to problems associated with both the accessibility, and appropriateness of available support. Reduced care and support services may disproportionately impact on communities already struggling to access help which is culturally appropriate, further contributing to both physical and emotional strain.

Limited literacy in some communities, both written and spoken, coupled with digital exclusion further compounds the information gap for some of Scotland’s most vulnerable people. Social isolation for communities which have a cultural tradition and reliance on more communal forms of living have contributed significantly to increasing levels of stress and anxiety. We urge that the principles and accompanying actions

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<sup>3</sup> The world shrinks: Carer loneliness: Carers UK and the Jo Cox Foundation, 2019

<sup>4</sup> 27% of young carers (aged 11–15) miss school or experience educational difficulties. This figure is 40% where children care for a relative with drug or alcohol problems (Dearden & Becker 2004).

set out below are taken forward with equality considerations in mind to avoid further exacerbating existing inequalities.

### **Moving out of lockdown for unpaid carers – a discussion**

The next section of this paper, aims to outline key principles that should underpin ongoing support for carers as the wider community moves out of lockdown, alongside suggestions on activities and actions that

#### **Principles -**

##### **Unpaid carers as equal and expert partners in decision making.**

Unpaid carers of all ages and those they care for **must be at the heart of decisions that affect them**, involved and consulted about what matters to them and what support would help them at this time. Decisions must be based on evidence and balance risk of the harms of COVID19 versus the known harms that isolation can and is causing unpaid carers. Individuals should be supported to make decisions based around their circumstances and good information is needed to support this.

This partnership must be a key part of the development and review of social care, including future funding. Carers voices must be at the heart of this and opportunities should be developed to ensure that they can be fully involved.

##### **Unpaid carers rights must be reinstated and reinforced**

Unpaid carers rights must be reinstated at the earliest available opportunity, including their right to an Adult Carer Support Plan and Young Carer Statement.

#### **Wraparound Support for those shielding and at high risk**

- First and foremost, for those for whom lockdown will remain a reality for much longer than the rest of the population, a range of services and supports must be introduced to provide holistic support that encompasses improving and support all aspects of their lives (wraparound support). This must go beyond those who are shielding and include those who are at higher risk and their unpaid carers. This should be developed *with* those affected.

#### **Information**

- Information must be made available in a variety of formats and, whilst social media and digital messages are useful, this provision must be far wider to reach directly into peoples' homes.
- Although it will be challenging to produce different information for different groups of people, dedicated information must be produced for people who may have to remain at home for longer and their unpaid carers. This should include information that enables unpaid carers and unpaid young carers, disabled and older people to make risk based decisions.
- Specific information must be published and widely broadcast on face coverings, alongside the existing messages on handwashing and physical distancing. Any information published should include accessible versions.

#### **Services**

- Carers centres and other support services have worked extremely hard to try and ensure continuity of support during the lockdown period, often by moving some services online. However, many services have

been suspended, especially respite care and in-home support, and these vital forms of support need to be reinstated as soon as is practical. Services must be given access to practical information on infection prevention and control measures so they can make necessary preparations, and they must be assured of sufficient, ongoing supplies of appropriate PPE for staff. Unpaid carers must be included in any planning for resuming services, and must be given the information they need to assess any risks involved.

- The principles of person-centred and outcome focussed practice should be upheld as services are reinstated.
- Risk assessments of services must be undertaken – including community services - outwith the home. Some services, including young carer services, may be able to restart with changes e.g. with less people attending to allow for physical distancing, strict cleaning protocols pre and post activities, and appropriate PPE for all staff.
- In the interim before services are fully reinstated, other options must be made available for those individuals who cannot have people providing services in their own home and for those who have had external services withdrawn. This includes grants that can be used, for example, to purchase equipment or broadband to help people stay connected with friends and family, or for exercise equipment, audio book subscriptions , or anything else that will help unpaid carers have some time-out from their caring responsibilities. We have already seen the huge impact that relatively small grants have made to make lockdown a little less stressful for both unpaid carers, and also those they care for. Access to technology is though vital for all carers who wish it, as is assistance and support to use that technology.
- Sustainable funding must be made a priority for carers centres and young carer services, along with additional funds to enable them to provide other services to carers. This could include grants for items that will support unpaid carers' wellbeing or to enjoy activities and crucially to expand and sustain the staffing of telephone and online emotional support for all unpaid carers. One solution would be to allocate a percentage of Carers Act funding directly to third sector carer and young carer support services.
- There are additional challenges in supporting the estimated 400,000 new carers who have taken on a caring role during the COVID pandemic. These carers will not be registered with services e.g. carers centres and will not know their way around the system. Before the pandemic, the Scottish Government had planned a carer awareness campaign and this could be revisited, adapted to take account of current circumstances.

### **Self-Directed Support**

- Self-Directed Support should be made as flexible as possible and guidance published in May 2020 must be reinforced across every local authority. It is not enough simply to have guidance, this must be consistently implemented with unpaid carers and those they care for trusted to make decisions about what their budgets could be spent on not only to meet outcomes but also to ensure that their wellbeing is supported effectively at this difficult and challenging time.
- This flexibility should extend to enable, for this period, close family members to be employed through a direct payment in place of traditional service, in all cases where the service user **and** unpaid carer would like this to be an option.

## Practical

- Enable those who are caring for someone with vulnerable health who is not on the shielded list to also be able to register for food boxes and priority shopping slots. These food boxes should be enhanced to ensure that they provide nutritious varied food and food suitable for a variety of diets. Ensure that shopping deliveries prioritise those who cannot leave the home. Specific guidance and protocols should be put in place to address challenges unpaid young carers are experiencing in accessing shopping.
- Where the household does not have this available, government funded and arranged broadband should be provided for all shielded households. IT suitable for the individual should also be provided. This could be through the SCVO Connected Scotland scheme but other routes could also be considered.
- Unpaid young carers should be included in the disadvantaged children and young people list to have access to the £30 million announced by Scottish Government to provide laptops etc to help unpaid young carers to be able to learning effectively at home.
- As stated above, grants should be available for subscription television services, e-books or magazine subscriptions to help unpaid carers stay connected and have some time-out.
- Local councils should restart library book delivery and mobile library services in their area, using their support services to enable individuals to set up an account. Books could be delivered utilising local community support networks.

## Employment

- The Scottish Government should work with the UK Government to extend furlough for unpaid carers and those who have to shield. Extend this to ensure that all those who have to remain at home because of either being shielded or supporting someone with vulnerable health are paid a minimum of 80% of wages. Carers have also highlighted the need for the commitment by the UK Government to bring in statutory carers leave to be expedited and for this leave to be paid, to recognise the impact both employment and finances of caring.
- Local health and social care partnerships should seek to ensure that replacement care is reinstated to enable unpaid carers to return to work if they cannot work from home.
- The Scottish Government should provide guidance for employers on supporting carer employees during this period to continue to support home working, furlough or special leave whilst they are needed to provide care.
- Employers should provide home working allowances or support unpaid carers to claim tax relief available for home working expenses.

## Finances

- Financial support should be provided to unpaid carers where there has been an impact in their income and/or an increase in their household costs. The extra payment of CAS is welcome, but this does not apply to all unpaid carers, including those with an underlying entitlement. Additional routes to support unpaid carers must be considered and, when available, widely promoted.

- In relation to those who do not benefit from the Carers Allowance Supplement and the additional coronavirus payment, there is a need to recognise the needs and financial impact of caring on older carers. These carers cannot be paid Carers Allowance because of the overlapping benefits rule (with the state pension in this instance) and an older carers grant, developed similarly to the young carers grant, would offer both some financial assistance but also recognition of their caring role.
- Further additional hardship funds or non-monetary schemes should be identified for unpaid young carers. The Young Carer Grant is only available once per year and due to eligibility restrictions only to a small number of unpaid young carers. We welcome the additional funds provided to Young Scot to extend the Young Carer Package of the Young Scot Card. Further activity in relation to hardship should be revisited, taking account of this support and in conjunction with work around returning to school, college and university and in assessing the ongoing impact of coronavirus on young carers. What approach is needed to alleviate the impacts can be assessed alongside these areas of work.

## **Health and Emotional**

- There should be recognition that coronavirus has exacerbated the already significant impacts of caring on physical and mental health. Carers face a triple isolation – through existing caring, through the impacts of coronavirus and, for some, being cut off from new means of using technology to replace services such as emotional support.
- A dedicated resource, including access to counselling should be made available to any unpaid carer who needs it. This should be over and above the very welcome wellbeing hub.
- Specific mental health support in supporting carers to manage “the new normal” is required. There is a sense that supporting carers to have a life alongside caring has been lost as carers struggle to manage the impacts of coronavirus.
- Tailored bereavement support should be developed for carers and families who have lost a relative in a care home. This should recognise not only dealing with the loss itself but some of the specific aspects of losing someone during coronavirus e.g. not being able to visit or arrange a funeral in the normal way, alongside issues such as powerlessness to affect the outcome and pre-existing guilt at placing a relative in a care home.
- Consideration should also be given to providing access to counselling for carers centre staff and volunteers. This could be through enabling these staff to have access to these services via local public sector routes available to staff or in funding centres to purchase employee assistance as required.
- Every Health and Social Care Partnership (HSCPs) needs to ensure that full funding from the Carers Act is passed on to carer and young carer services to deliver emotional and other support.
- Health Boards and HSCPs should explore the potential to introduce remote health checks for unpaid carers to assess and address the impact of caring on their health.
- The campaign to encourage people to use their GPs when they need to should be expanded and backed up with online health resources e.g. through NHS Inform, with targeted information for unpaid carers and those they care for.

- Arrangements must be put in place for transport to routine healthcare appointments. Primary and secondary care need to consider what might need to be in place to enable unpaid carers and those they care for to be able to attend physical appointments; avoiding public transport.
- When the situation allows, funds should also be made available to offer unpaid carers a proper break of a week or at least a weekend where they are completely switched off from their caring role – a recognition of the huge emotional and physical toll many have faced because of coronavirus

### **Testing and Vaccination**

- Antibody testing for unpaid carers and those they care for should be prioritised within the planning for its adoption and roll out.
- Specific guidance for unpaid young carers on testing and vaccination (if/when it becomes available) routes should be produced.
- Whilst recognising priority that may be given to people who work in health and social care, vaccination (when it becomes available) should prioritise shielding people, those who qualify for a flu immunisation and unpaid carers. They should be vaccinated in the first wave and before any consideration of “vaccination for the economy”. Those at most risk MUST be prioritised before the general population.

### **Young carers’ education and support for disabled children and young people returning to school**

- Schools will eventually return but the needs of unpaid young carers and disabled children and young people must be prioritised in planning. Much more work is needed to ensure that there is equity.
- National guidance must include unpaid young carers and explore the options, risks – both from coronavirus and educationally – and set out a way forward for local education authorities.
- Detailed local and individual school plans must be developed for supporting children and young people who are most at risk of coronavirus, including those who are shielding and those who live in a household with someone most at risk. This includes individual conversations with parents, children, young people and unpaid young carers.
- All unpaid young carers undertaking any level of remote learning should have access to the necessary digital equipment and resources to ensure that they have equal opportunities to learn.
- For those unpaid young carers learning remotely, we encourage for all schools in Scotland to introduce mandatory health and wellbeing check-in meetings weekly.
- All schools should signpost identified unpaid young carers to local young carer services and sustain their professional engagement with these services even when young carer services are unable to have a physical presence at the school.
- All teachers in school should be required to undertake Young Carer Awareness Training to help them to identify and support unpaid young carers both in the classroom and those learning remotely.
- Transport to school – consideration of what might need to be in place to enable unpaid young carers to attend school in person.

- Further and Higher Education Institutions should consider the impact of cancelling the examination diet may have had on the exam results of unpaid carers. Scottish Government should promote further and higher education institutions to make enhanced contextualised admissions for those that have narrowly unmet conditional offers for study.

## Analysis

- Steps should be taking to analyse all trends of carer experiences during the Coronavirus pandemic. This includes identifying the key impacts on different groups e.g. parent carers, carers caring for more than one person, carers with protected characteristics etc.
- Identify and measure what has worked to support carers and utilise this to roll out formally and for the future in service and support provision, alongside more traditional service provision.

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