



National Carer
Organisations

- 1. Please briefly describe how your organisation's work is connected with Shielding. (i.e. are you involved with one or more of the specific clinical categories? Or a specific demographic of people within the shielded group? What kinds of support do you provide?)**

The National Carer Organisations are widely recognised by the Scottish Government and COSLA as the primary national reference group for carers. They are Carers Scotland, the Coalition of Carers in Scotland, Minority Ethnic Carers of Older People Project (MECOPP), Carers Trust Scotland, the Scottish Young Carers Services Alliance, Crossroads Caring Scotland and Shared Care Scotland.

Our role includes ensuring unpaid carers have a voice in the national and local development of policy and legislation.

Some of the national carer organisations provide direct advice and information to unpaid carers, including those providing care for someone shielding, or indeed who are shielding themselves. This can be on a variety of things including accessing support for food deliveries, linking them with their carers centre to arrange PPE, grants or emotional support and online information.

- 2. Do you have any data or information about the sociodemographic make-up of your shielding client group? (We are particularly interested in numbers of people likely to return to work; numbers of shielding children or families with children in the household; numbers of people living alone; numbers who may rely on carers for support.)**

We do not have any data or information relating specifically to carers looking after shielded people. However, in relation to the demographics of the carer population as a whole, two of the main sources of information are the census and the Scottish Household survey.

It is however fair to assume that a large proportion of people in the shielded category are likely to be receiving some form of support from family members in the same household as them, acting as their unpaid carers.

It is also worth noting that around 20% of carers have a disability or long term condition and around 100,000 are older carers so within the shielding population, there will be people who are both shielding and caring.

- 3. What challenges are your client group likely to be experiencing as a result of shielding (physical health, mental health, wider social and economic challenges, etc.)?**

There are many impacts on carers and young carers looking after people who are shielding, or self-isolating because they are in the vulnerable category. This has affected carers' health and wellbeing, their finances, their education and their ability to work. It has had a particular impact for carers with protected characteristics, such as those from black and minority ethnic communities.

Since lockdown the National Carer Organisations have been collating information about the impact of Covid-19 on carers and young carers and there have been several research pieces published by Carers UK. Below we have brought together some of the findings from these sources. Unless otherwise indicated any statistics have been taken from Carers UK survey, 'Caring Behind Closed Doors: Forgotten families in the coronavirus outbreak' published in April 2020

Additional Caring responsibilities

Many social care services are currently not operating due to Covid-19 and those that are operating have often had to scale down their level of provision or change their model of support. This has had a severe impact on many carers who have had to step in to replace the care that was previously provided by social care and community services. It has also meant that some people are taking on a caring role for the first time

- 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 400,000 additional people in Scotland caring for older, disabled or seriously ill relatives or friends since the Covid-19 pandemic, bringing the estimated number of unpaid carers in to 1.1 million in Scotland.¹

Practical Issues

Since lockdown carers have reported struggling with several practical issues, including being able to access vital supplies such as food and medication and accessing support which has primarily shifted online

- 1 in 5 unpaid carers have said they have had issues with accessing food
- 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.

Finances and Employment

Caring is known to impact on people's finances, including their ability to work. The financial impact of caring has been magnified by Covid-19

- Household expenses have risen for carers during this time 80% reporting seeing extra costs for food and more than half (53%) for other household bills. Almost 40% said they were worried

¹ Getting carers connected, Carers UK, June 2020

about their financial situation.

- 22% of unpaid carers who responded to the survey are either furloughed or are 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.

Loneliness and Isolation

Caring has a known impact on people's feelings of loneliness and isolation and ability to contribute as active citizens to their local communities

- Before Covid-19 more than 80% of unpaid carers were already saying that they were lonely or socially isolated. Coronavirus is exacerbating this, with many unpaid carers speaking of feeling alone and forgotten. ²
- On average, carers in Scotland reported that their life satisfaction was over a third (39%) lower than the population of Scotland as a whole (4.7 compared with 7.7) and that their anxiety levels were almost twice as high (5.5 compared with 2.8).

Health and Wellbeing

The culmination of all these factors has had a significant impact on the health and wellbeing of many carers. This is exacerbated by the reduction or cessation of some non-essential health care services at this time, which would normally promote self-management and wellbeing.

- More than half (53%) of unpaid carers have indicated that they feel overwhelmed managing their caring responsibilities during the outbreak and worry about burning out.
- At the recent Carers Cross-Party Working Group on the 9th June it was reported that the levels of exhaustion, anxiety and isolation are extremely high amongst carers over 70 who have been self-isolating since the beginning of March. They have not been eligible for Carers Allowance Supplements which has fed into a feeling of being invisible.
- Carers are also reporting that the suspension of some primary health care services has had an impact on their health, or the health of the people they care for. For example, both access to Vitamin B12 injections and drug and alcohol support services have been highlighted as being problematic at this time

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, there are real concerns that decisions on their exam results may affect their future educational and career opportunities.

Carers with Protected Characteristics

Many of the issues set out above have particular resonance for unpaid carers with one or more

² The World Shrinks, Carers UK and the Jo Cox Foundation, 2019

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.

The needs of carers and those shielding should be included within the recently announced Expert Group considering the impact of COVID19 on BME communities. This includes ensuring that accessible information is available for BME people shielding and their carers, tailored to individual conditions and the specific additional risks for BME people may face from the virus.

4. What support needs do you think your client group will have as lockdown eases?

We would like to start by setting out the following two key principles in relation to carer support as lockdown eases

1. That 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. In line with the First Minister's announcement of information tailored for different conditions within the shielded group, additional information should be developed for carers to support them in continuing care and in understanding the risk to the person they care for.
2. Unpaid carers rights must be reinstated at the earliest available opportunity, including their right to an Adult Carer Support Plan and Young Carer Statement.

In addition, we believe the following measures need to be put in place to address the support needs of carers as lockdown eases

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 provision must be introduced to deliver 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

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.
- 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.

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 Support

- Those who are caring for someone with vulnerable health who is not on the shielded list should 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.
- 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 Covid-19 payment of Carers Allowance Supplement 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.

Health and Emotional

- 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 wellbeing hub.
- 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.

5. Do you think your shielding client group would welcome increased flexibility in the shielding guidance so that they could better decide for themselves which measures to follow?

Yes, 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.

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.

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