Breaks from Caring

“I’m sitting here with tears in my eyes hoping that this can bring about real change. ...I am utterly exhausted and no longer feel I’m giving my best because I’m just so worn down with never getting a break.” NCO Right to a Break Survey 2021

Background
Research tells us that having planned, regular good-quality breaks is vital to carers’ health and wellbeing but despite the evidence of the benefits, and the duty on local authorities to meet eligible needs, only a small proportion of carers receive regular breaks from their caring role. We also know that for carers and their families the challenges of accessing breaks from caring, only to find this is unavailable, unaffordable, or they are ineligible, causes considerable suffering and hardship. The COVID pandemic and the suspension of many respite care services has of course magnified these challenges and placed significant additional financial, practical, and emotional pressure on carers.

Access to Breaks
In 2018, Carers Scotland reported that only 18% of carers said they had managed to have a break in the past 12 months, and in a 2019 survey less than a third of carers said their need for a break was sufficiently considered as part of their Adult Carer Support Plan. According to the government’s own data, as few as 3% of unpaid carers currently receive support for breaks from caring.

There is significant variation in the availability of breaks across Scotland and carers’ experiences of accessing breaks can be very different due to a variety of factors. Carers consistently report these key concerns - frustrations with sourcing information; complicated and stressful referral pathways; shortage of suitable and accessible provision; loss of short breaks at transition points; lack of personalisation; issues relating to the cultural sensitivity of services; and cost.

Variations have also been evident with approaches to Self-directed Support during COVID, where many carers were not informed that SDS could be used more flexibly if, for example, their normal care and support services were unavailable.

Recent progress in strengthening carers rights through both legislation and policy development has clearly not produced the consistency or scale of improvements expected. Consequently, for carers, there is a gaping divide between policy intentions and everyday reality.

1 Bangor University/Shared Care Scotland, (2019), Short breaks for carers: a scoping review
2 Carers Scotland, State of Caring Survey, 2018
3 Carers Scotland, State of Caring Survey, 2019
4 Scottish Health Survey (The 3% statistic for carers supported by short breaks and respite care comes from the Scottish Health Survey and has stayed much the same for several years. The wording of the interview question does not confine support to “statutory” sources, and the 3% may include support from other family members, or voluntary organisations.)
6 Shared Care Scotland, (2020), ‘Regular & Meaningful Breaks’, Annual General Meeting discussion
7 SDS during the pandemic: experiences of unpaid carers in 2021, COCIS & SDS Collective, 2021
Recent Developments
The 2021 Independent Review of Adult Social Care (IRASC)\(^8\) also highlighted this ‘implementation gap’, and in relation to breaks from caring recommended that carers’ access to regular breaks should be guaranteed through a new ‘right to respite’. IRASC also recommended this new right should be developed alongside greater efforts to increase the availability and choice of short breaks, on the basis that a right to a break is of little value if there are insufficient levels of suitable provision in place to enable carers to exercise this right.

The Scottish Government has made a commitment to improve access to breaks and to introduce the legal right to a break from caring. Proposals will be brought forward shortly taking into account the IRASC recommendations and responses to the recent consultation on the ‘right to a break’, which was part of the wider National Care Service (NCS) consultation. However, given the extreme pressures facing carers now, we cannot afford to wait until legislation is enacted, or the NCS is established, before acting to address the high levels of unmet need.

Break from Caring and the National Carers Strategy
The preparation of a new National Carers Strategy provides an opportunity to set out how the conditions will be created to provide more, better, and improved access to short breaks. In doing so the aim should be to give carers access to the regular, meaningful breaks that enable them to thrive, to live happy and fulfilled lives, and to maintain the quality of care they want to, and can, provide.

A National Carers Strategy should therefore strongly reinforce:

- The necessity and importance to unpaid carers of having access to regular, meaningful breaks from caring;
- The wellbeing that accrues to carers and the whole community from the provision of short breaks;
- The value of involving carers in shaping strategy and delivery plans;
- The importance of ensuring that both national and local strategic and delivery plans are explicit in describing how provision will be made for planned, regular and crisis short breaks;
- The importance of making financial provisions that take account of short breaks provision that focuses on both the family and home and the wider community, national and local interests;
- The longer-term financial gains of investing in short breaks; and
- The importance of any system of entitlement facilitating and not getting in the way of access to short breaks.

Recommendations

**Phase 1 (COVID Recovery)**

- Ensure that carers and their families are involved in, and informed of, plans for COVID recovery and the remobilisation of short breaks and respite care services.
- Ensure that that both national and local COVID recovery plans are explicit in describing how provision will be reinstated for planned, regular as well as crisis short breaks, and ensure priority is given to the re-opening of social care services and services which provide breaks from care.

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• Increase funding to expand the availability of non-statutory, flexible approaches to delivering short breaks, such as those supported through the Short Breaks Fund (Creative Breaks, Better Breaks, Time to Live & Take a Break Scotland)
• Commission research to ascertain the present status and ongoing sustainability of statutory funded day-based and overnight short break services (that provide replacement care).
• Make the COVID Self-directed Support (SDS) Guidance\(^9\) permanent and ensure it is applied consistently across Scotland, enabling carers to use SDS budgets as flexibly as possible, including to access breaks from caring.
• If individuals have been unable to spend their SDS budgets due to COVID restrictions, then maximum flexibility should be offered to allow supported people and carers to use unspent budgets to address any unmet needs as a result of the pandemic.

**Phase 2 (Carers Strategy)**

• Commission research to understand the demand for, use of, and preference for different short break options. This intelligence should inform the prioritisation of national resources and determine how and where provision should be planned, identify what gaps exist and how these might be addressed by new investment and other means.
• Use the development of the Carers Strategy as an opportunity to set out a clear and compelling vision and improvement plan for short breaks provision across Scotland.
• Ensure that both national and local strategic and delivery plans are explicit in describing how provision will be made for planned, regular as well as crisis short breaks, and how improvements will be measured.
• Improve choice and personalisation by building the capacity and skills of Carers Centres to support carers to identify and access personalised breaks through, for example, providing short breaks brokerage, and by expanding Respite and community-based and micro enterprise-led solutions.
• Support innovation, learning exchange and capacity building by moving the third sector Short Breaks Fund from an annual to a five-year funding cycle, and by increasing the funding available to support more short breaks development.

**Young Carers**

Regular access to recreation and leisure opportunities is also vitally important to young carers and therefore a National Carers Strategy must address the equally important but perhaps different needs of young carers. Further recommendations relating to breaks for young carers have been provided in a separate NCO paper.

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