

Time away from caring: Good practice in carer breaks

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INTRODUCTION

The Health and Wellbeing Alliance

The Voluntary Community and Social Enterprise (VCSE) Health and Wellbeing Alliance (HW Alliance) is a partnership between voluntary sector representatives and the health and care system. It is a key element of the Health and Wellbeing Programme, enabling the voluntary sector to share its expertise at a national level to improve services for all communities. Its purpose is to:

- Provide a coordinated route for health and care organisations to reach a wide range of VCSE organisations.
- Support collaboration between VCSE organisations and provide a collective voice for issues related to VCSE partnerships in health and care.
- Enable health and care organisations and VCSE organisations to jointly improve ways of delivering services which are accessible to everyone
- Ensure health and care decision-makers hear the views of communities which experience the greatest health inequalities.
- Bring the expertise of the VCSE sector and communities they work with into national policy making.

The HW Alliance is jointly managed by the Department of Health and Social Care (DHSC), NHS England (NHSE) and UK Health Security Agency (UKHSA) and is made up of 18 VCSE Members that represent communities who share protected characteristics or that experience health inequalities, and a VCSE coordinator. Through their networks, HW Alliance Members can link with communities and VCSE organisations across England.

The Carers Partnership

Carers Trust and Carers UK are members of the HW Alliance as the Carers Partnership. The Carers Partnership worked with DHSC, local carer support organisations, local statutory partners and fellow VCSE HW Alliance members to look at good practice in providing carer breaks.

The benefits of breaks

This project explores good practice in providing breaks to adult carers. Within the broad spectrum of carer breaks, the project also explores what works for carers from ethnic minority communities and LGBTQ+ communities – both of which are communities that face additional barriers. In addition, there is a focus on digital support and the barriers this may create for older carers.

From the good practice case studies, we have identified some common elements to help commissioners and providers establish a breaks provision that meets the needs of unpaid carers.

This document:

- Brings together evidence on the importance of breaks for unpaid carers – both empirical data and evidence collected as part of the project and Carers Trust's wider work with local carer organisations and carers
- Highlights good practice in providing breaks collected
- Give Top Tips to commissioners and providers on what steps they can take to ensure the carers they support have access to breaks.

ABOUT CARERS BREAKS

What are breaks?

Breaks are not defined in legislation, and good practice is that they are defined by what the carer wants.¹ NICE recommends that carers' breaks should "meet carers' needs for a break, for example in duration, timing, frequency and type of break" and "be arranged in a way that provides reliable and consistent support to the carer (such as avoiding last-minute changes that could lead to additional stress for the carer)"²

In their Carer Breaks Guidance, the Social Care Institute for Excellence (SCIE)³ set out that breaks are:

"...something that carers want to use for themselves. It should be planned, meaningful and positive. The arrangements need to work for both the carer and the person they care for to be beneficial and improve carer wellbeing."

There are a range of carer breaks and respite which can vary from a few hours to allow the carer to go for coffee with friends, to longer periods to allow the carer to, for example, go on holiday. The break or respite can be provided at a day-care centre, or a care support worker can provide care at home whilst the carer takes a break.

A break can be accessed in many ways including:

- day care centres
- homecare from a care support worker/replacement care
- short breaks for a few hours
- group activities including peer-to-peer support.
- a short stay in a care home
- getting friends and family to help
- respite holidays
- sitting services

¹ <https://www.scie.org.uk/carers/breaks/adults/introduction#definition-carers-breaks>

² <https://www.nice.org.uk/guidance/ng150/chapter/Recommendations#social-and-community-support-for-carers>

³ <https://www.scie.org.uk/carers/breaks/adults>

The benefits of breaks

Unpaid carers tell Carers Trust and Carers UK that they value breaks and respite very highly. Carers tell us that they find taking a break from caring is beneficial for their health and wellbeing. Carers UK State of Caring report in 2022 found that of the over 13,000 respondents, 47% of carers said they need more breaks or time off from their caring role.⁴ Similarly, a Carers Trust survey of over 2,500 unpaid carers found that 53% of respondents said a break from caring is what would make the biggest difference to them.⁵

Carer breaks form a key part of local authorities' commissioning programmes and local carer support organisations provide advice on breaks, facilitate engagement, and provide breaks directly.

The 2021 Census showed that there are approximately 4.7 million carers in England. Of these:

- 1.4 million carers in England provided more than 50 hours of care per week.
- 1 million carers provided over 20 hours of care,
- 2.3 million carers provided between 1 and 19 hours of care per week.⁶

The GP Patient Survey⁷ has shown that carers are more likely than those not in a caring role to have a long term health condition and to feel isolated. It also showed that the more intense a caring role is (in terms of hours of care provided) the more likely it is that carers have poorer health outcomes.

The Care Act 2014 and Carer Breaks

Under the Care Act 2014, Local Authorities must promote carers' wellbeing and prevent their needs from escalating.⁸ Breaks have a potentially crucial role in helping local authorities meet their Care Act duties.

Under the Care Act 2014, Local Authorities must⁹:

- **Prevent, reduce, and delay** – local authorities need to ensure the provision of preventive services. Carers play a vital role in preventing the need for other care and support for the people they care for and a wide range of services can contribute to preventing, delaying, or reducing the needs of carers, improving their lives by enabling them to continue to have a life of their own alongside caring.

⁴ <https://www.carersuk.org/media/p4kblx5n/cukstateofcaring2022report.pdf>

⁵ <https://carers.org/downloads/ct-report-i-feel-like-i-have-disappeared.pdf>

⁶ <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellbeing/bulletins/unpaidcareenglandandwales/census2021>

⁷ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/971115/Caring_as_a_social_determinant_report.pdf

⁸ <https://www.scie.org.uk/carers/breaks/adults/legal>

⁹ <https://www.scie.org.uk/carers/breaks/adults/legal>

- **Prevent carers from developing support needs is distinct from the duty to meet their eligible needs.** While a person's eligible needs may be met through universal preventive services, this will be an individual response following an assessment. Local authorities cannot fulfil their universal prevention duty simply by meeting eligible needs, and nor would universal preventive services always be an appropriate way of meeting carers' eligible needs.

Breaks and respite can potentially help carers maintain their health and wellbeing¹⁰¹¹, giving carers the chance to maintain their hobbies alongside their caring role and can help reduce the risk of carer breakdown.

Carer breakdown or carer burnout is when a carer reaches a point where they feel emotionally and/or physically unable to provide care. It can be caused by the pressures faced by carers due to their caring role and undertaking that role without the support they need.

The Social Care Institute for Excellence (SCIE) conducted a literature review of evidence about carer breaks and found¹²:

- Carers value breaks for a wide range of reasons – practical, emotional, social and psychological.
- For some, the break has value beyond the allotted time: 'to look forward to a break has the same effect as the break itself'.
- It's important to think about whole family approaches and breaks as a break from the caring routine', not just time away from the person. Some carers prefer a break that is about being with the person they care for, or as a whole family, but not having to do all the caring.
- Breaks can play a vital preventive role, sustaining the caring relationship and preventing carer stress, crisis and breakdown. There are key points where, if practical support and information had been provided, the impact of caring may be reduced.
- Breaks can reduce loneliness and isolation, enabling the carer (and the person they care for) to stay connected to family, friends and things they enjoy.

Public Health England's *Caring as a social determinant of health*¹³ report found that:

"Breaks from caring are essential in sustaining caring relationships and ensuring that carers have time for their own lives" and "[e]valuation of short-term effects of breaks indicates positive effects on health and wellbeing, and the ability to cope with the stress of caring".

¹⁰ <https://www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/carers-breaks-and-respite-care/>

¹¹ <https://www.scie.org.uk/carers/breaks/adults/evidence>

¹² <https://www.scie.org.uk/carers/breaks/adults/evidence#importance>

Operational context and environment

We want to offer a positive way ahead for how commissioners and providers can work together to ensure carers are accessing the breaks they need based on existing practice. However, it is important to set out the context in which commissioners and providers are working.

Funding for supporting carers

Analysis of Short and Long Term (SALT) data shows a decline in funding used to support carer breaks. According to an analysis by the Nuffield Trust, there were 24,000 fewer carers receiving breaks in 2020/21 than in 2015/16 – a decline of 42%¹⁴

Shortage of breaks and demand outstripping supply

We believe that more unpaid carers should be accessing breaks. In our engagement with providers, many told us that demand outstripped supply and this is borne out by the available data too.

Carers UK's 2022 State of Caring survey and report showed that¹⁵:

- 41% of carers responding to the survey have not taken a break from their caring role in the last year.
- Of carers responding to the survey, 31% had never used sitting services, 34% had never used other breaks services, 28% had never used day services, and 29% had never used care homes for short respite breaks.
- Only 11% of carers responding to the survey said they had access to appropriate support including respite and carer breaks.

The Personal Social Services Survey of Adult Carers in England, 2021-22¹⁶ found:

“In 2021-22, 13.3% of carers reported the person they care for used services that allowed them to take a break from caring for more than 24 hours, this compares to 19.6% of carers in 2018-19.”

¹³ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/971115/Caring_as_a_social_determinant_report.pdf

¹⁴ <https://www.nuffieldtrust.org.uk/files/2022-10/nuffield-trust-unpaid-carers-web-final.pdf>

¹⁵ <https://www.carersuk.org/media/p4kblx5n/cukstateofcaring2022report.pdf>

It should be noted that this is referring to the “respite care and other forms of support delivered to the cared for person” that has been arranged for the benefit of the carer within SALT data and therefore does not capture respite or breaks arranged through direct payments.

¹⁶ https://files.digital.nhs.uk/28/2342AD/PSS_SACE_Report_2021-22.pdf

Knowledge – unpaid carers are unaware of what is available.

One of the barriers to carers accessing breaks is carers being unaware of the support services available. Carers need good quality information and advice about breaks. 36% of carers responding to Carers UK's State of Caring¹⁷ survey said they did not know what services (including breaks) were available to them. This could be part of any carer's assessments that they have or through a carer support service. However, this relies on the identification of carers and the availability of those breaks.

Cost

Cost is also often a factor for why unpaid carers are unable to access breaks. Carers UK research found that of carers surveyed:

- 38% said they could not afford replacement care
- 34% said they were unable to afford any activities to do during the free time

When considering the cost to the carer of taking a break, commissioners and providers should be aware of two important factors.

- Care Act guidance¹⁸ strongly discourages charging carers for their own support. The guidance says:
 - While charging carers may be appropriate in some circumstances, it is very unlikely to be efficient to systematically charge carers for meeting their eligible needs. **This is because excessive charges are likely to lead to carers refusing support, which in turn will lead to carer breakdown and local authorities having to meet more eligible needs of people currently cared for voluntarily.** [Emphasis added]. As an example, work carried out by Surrey County Council found that if even 10% of people with care and support needs in families supported by carers presented to the council with eligible needs as a result of carer breakdown, the resulting cost would be 3 times the current total budget for carer support. The ADASS produced the Economic Case for Investment in Carers¹⁹, a short factsheet for local authorities to use in considering whether to put in place a policy of charging carers, **setting out the evidence that charging would be a false economy.** [Emphasis added].

¹⁷ https://www.carersuk.org/media/vgrlxkcs/soc22_final_web.pdf

¹⁸ <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#charging-and-financial-assessment>

¹⁹ <https://www.local.gov.uk/sites/default/files/documents/economic-case-investment--7a4.pdf>

- Continuing Health Care guidance²⁰ sets out that: “Where an individual is eligible for NHS Continuing Healthcare and chooses to live in their own home, the ICB is financially responsible for meeting all assessed health and associated social care needs. This could include: equipment provision (refer to Practice Guidance note 56), routine and incontinence laundry, daily domestic tasks such as food preparation, shopping, washing up, bed-making and support to access community facilities, etc. **(including additional support needs for the individual whilst the carer has a break).**” (Emphasis added)

Lack of replacement care and lack of trust in replacement care

Another major barrier to unpaid carers accessing a break for themselves is the lack of replacement care or a lack of trust in the quality of the replacement care available. Replacement care is care provided so that the carer can have a break. It is often provided by a domiciliary care provider who will provide care for the person with care needs. Carers UK research found that of the carers they surveyed, the reasons they gave for not having a break included:

- 25% said they are not wanting strangers looking after the person/people they care for
- 25% said replacement care was having a negative effect on the wellbeing of the person they care for
- 22% said there was a lack of availability of replacement care for the complex needs of the person they care for
- 19% thought the quality of replacement care that is available is not good enough

This points to issues around social care which are beyond the remit of this document, however, it is important to bear in mind regarding breaks is the importance of replacement care, and the importance of carers having trust in that replacement care. As is illustrated in some of the good practice case studies in this document – it is important that replacement care is provided, that the replacement care is of a good quality that takes into account the needs of the person with support needs and that the carer trusts the provider to provide that good quality care.

Better Care Fund

Better Care Fund

The Better Care Fund (BCF) programme supports local systems to successfully deliver the integration of health and social care in a way that supports person-centred care, sustainability and better outcomes for people – including unpaid carers.

²⁰ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/10_87562/National-Framework-for-NHS-Continuing-Healthcare-and-NHS-funded-Nursing-Care-July-2022-revised.pdf

The Better Care Fund (BCF) is a pooled budget between the NHS and local authorities, aiming to support local systems to deliver integrated health and social care, providing personalised support for people with care needs and unpaid carers. The pooled budget is a combination of contributions from across integrated care systems and local authority grants.

BCF Policy Framework

The 2023 - 2025 Better Care Fund Policy Framework sets out the aims of the BCF and certain conditions that local areas must adhere to.

- a jointly agreed plan between local health and social care commissioners, signed off by the HWB
- implementing BCF policy objective 1: enabling people to stay well, safe and independent at home for longer
- implementing BCF policy objective 2: providing the right care, at the right place, at the right time
- maintaining the NHS's contribution to adult social care (in line with the uplift to the NHS minimum contribution to the BCF), and investment in NHS commissioned out of hospital services

As in previous years, the NHS contribution to the BCF will include funding to support the policies introduced under the Care Act 2014, as well as funding earmarked for the provision of carers' breaks.

Supporting unpaid carers is one mechanism through which local areas can achieve the BCF objective of enabling people to stay well, safe and independent at home for longer. The 2023 - 2025 BCF Policy Framework continues to highlight how the money can be used to support unpaid carers and sets out that the way local areas work in partnership with unpaid carers is critical. Local areas will be expected to provide a brief overview in their narrative plans of how BCF funding is supporting unpaid carers in their area.

There is BCF support available to local areas. This is detailed briefly below and in more detail in the Top Tips: Integration and Better Care Fund section later in this document.

Better Care Managers

Better Care Managers sit within each of the NHS regions to provide support to local areas, work with stakeholders and partners as well as gather learning and coordinate support.

Better Care Fund support offer

The BCF national support programme, delivered by the Local Government Association in partnership with ADASS and Newton Europe, offers support to local areas so that they work towards improving integration between health, housing and social care services and delivering their BCF plans.

The programme will ensure responsive and comprehensive support is available to all systems that need it, as well as supporting the development of national tools and good practice guidance.

The Better Care Exchange

The Better Care Exchange is a collaborative social network for health, housing and social care professionals. It enables networking, information and knowledge sharing on good practice for delivering better integrated care and implementing Better Care Fund plans.

CARER BREAKS: WHAT GOOD LOOKS LIKE

There is no one way of providing breaks to carers. The case studies in this document illustrate how commissioners and providers can work differently in different local areas and still provide breaks which unpaid carers benefit from.

However, there are some commonalities at the heart of good practice which other commissioners and providers can hopefully learn from.

Flexibility and Personalisation

Providers and commissioners should adopt the Whole Family Approach when providing services, including carer breaks. The Whole Family Approach means working with both the carer and the person with support needs to ensure services meet both of their needs.²¹

The Whole Family Approach²² means talking to both carers and the person they care for to provide breaks that meet both their needs. The key element is to have conversations with carers and the person with support needs to ensure that both benefit from the break provision.

Flexibility comes in the form of breaks and respite services being able to adapt to the needs of the carer. For example, the carer may be in work, so needs a break outside of traditional work hours or may want to see friends who are at work during the week and needs a break over the weekend.

Personalisation means tailoring the break to the wishes of the carer and the person with care and support needs. As is borne out in many of the good practice examples, the activities undertaken during the break are not dictated by the service but rather chosen by the person with care and support needs if it is a sitting service, or by the carer(s) if it's an organised group activity.

As part of their Market Shaping duties under the Care Act, Local Authorities, in line with statutory guidance²³, are expected to:

“stimulate a diverse range of care and support services to ensure that people and their carers have a choice over how their needs are met and that they are able to achieve the things that are important to them.”

²¹ A Whole Family Approach to supporting adult unpaid carers may also entail identifying young carers (a carer under the age of 16) and referring them for a Young Carers Assessment. It should entail talking to the young carer about their caring role, and any support needs they might have – including the need for a break.

²² <https://www.local.gov.uk/sites/default/files/documents/care-act-and-whole-family-6e1.pdf>

²³ <https://www.gov.uk/government/publications/adult-social-care-market-shaping/adult-social-care-market-shaping>

Therefore, commissioners should ensure that there is a wide range of breaks available to carers. The services should be coproduced with carers, and providers to reflect the needs of the local population and be provided by a sustainable range of providers from across different sectors.

Services should offer carers genuine choice in the type of break they access, be open to everyone in the community including carers from communities who face health inequalities or barriers to accessing services such as carers from the LGBTQ + communities, and carers from ethnic minority communities. The services should also be adaptable and tailored to the needs of the individual.

One way of achieving flexibility and personalisation is through partnership working. A key benefit of partnership working is each organisation can “play to its strengths” and working together offer a more holistic, better rounded offer of support to carers than they would be able to act alone.

Good Practice: Wandsworth Carers Centre - Partnership with Blue Bird

Key lessons:

- Partnership working
- Giving individuals flexibility

Wandsworth Carers Centre has partnered with Blue Bird Care – a private care company– to give carers a break. Carers can access 52 hours of breaks over nine months free of charge.

This service is designed to enable carers to take short breaks away from their caring role by providing respite care. Carers can use the hours flexibly within the nine months and the service is accessible seven days per week, except for Bank Holidays.

The service is aimed at carers who may not have the financial resources to access private care and/or carers who do not have family or close friends nearby who can cover their care.

Carers are referred to the service through several channels, such as the Local Authority, GP Practices or other charities and can also self-refer. After referral, Wandsworth Carers Centre will talk to the carer about their needs and the needs of the person they care for. Wandsworth Carers Centre will then arrange a meeting between the carer, the person with care needs and Bluebird Care Wandsworth where there can be a further assessment of requirements and the details of the service can be discussed.

Carers can then book their short respite breaks. Care workers from Blue Bird Wandsworth will provide care for the person with care needs in the home or the community, whilst the carer has a short break away.

Top Tips: Partnership working

Partnership working is key to ensuring good quality, varied breaks provision. Partnership working cuts across all sectors and should be both strategic and operational. Organisations should be committed to working together to ensure unpaid carers have access to the breaks they need.

As shown in the good practice case studies, partnership working could be between Local Authorities and the VCSE, between the VCSE and the private sector or between several VCSE organisations in a consortium or coalition.

There is no one method of developing a partnership – they are often built up over time but there are some crucial steps that Commissioners and VCSE organisations can take to foster an environment where partnership working can occur.

Commissioners:

- Through contracts, commissioners should imbed partnership working as the default way of work.
- commissioners should try, where possible to ensure that breaks are free of charge and not means-tested
- Encourage providers from across the sectors to work both across sectors and within their own sectors. For example, Commissioners can encourage consortia of VCSE providers to be formed or seek to facilitate partnerships between the VCSE and the private sector.
- Should ensure that there is a range of options available including personal budgets to provide self-determined breaks.
- Partnership working, which is part of integration, should mean that services across health and care are aware of the support – including breaks provision – available to unpaid carers. There should be an easy referral route for unpaid carers to get the support they need – including access to respite breaks.
- Partnership working is built on codesign and coproduction. Commissioners should work directly with carers, including carers from communities who face additional barriers to accessing services, and with the local carer support organisations and the wider VCSE.
- Commissioners must make sure the services they commission are open to members of the communities – including carers from LGBTQ+ communities and ethnic minority communities. Work with local specialist organisations and with carers from those communities to ensure services are open and inclusive.
- Some carers from those communities may prefer services that are only for members of that community and provided by specialist organisations. Commissioners should ensure that as part of the mix of services available in their area, specialist services are available.

Providers

- Create partnerships with other VCSE organisations in your area and provide carer awareness training.
- Create two-way referral routes with other VCSE organisations to ensure unpaid carers can access the support they need at the time they need it through the organisation they choose.
- Work with specialist organisations who provide services you don't or can't provide. **This could be organisations specialising in supporting people from communities who face health inequalities or with organisations who provide domiciliary care.**
- Work with specialist organisations to make sure your services are open to all members of the community.
- Codesign your services with frontline staff and carers – including carers from communities who face health inequalities.

Good Practice: Local Solutions – MyTime

Key lessons:

- Partnership working
- Codesign
- Tailored to individual needs
- Flexibility in service provision

Local Solutions are commissioned to provide carer support in Liverpool. Their Mytime service offers carers a break from their demanding carer role. This is achieved through businesses and organisations offering complimentary leisure, cultural and educational activities.

Mytime work with unpaid carers to find out what breaks carers want and what they want from breaks. This work with unpaid carers is often talking to groups of carers and individual carers about their needs, and what they want from their breaks. Breaks and activities that Mytime offer include:

- Overnight stays in hotels and apartments.
- Theatre trips
- High-end restaurants
- Spa days
- Leisure activities such as sporting events or cultural activities
- Events for carers bringing carers together to socialise.

In 2019, carers benefited from 1600 donated breaks worth over £200,000. Carers report that breaks have a positive impact on their health and wellbeing, ability to cope with their caring role and their levels of isolation.

Following a Mytime break:

- 94% of carers reported an improvement in their health and wellbeing.
- 89% of carers felt better able to cope with their caring responsibilities.
- 85% of carers felt less isolated and more aware of where they can obtain support for their caring role.
- 78% felt more resilient in their role.

Top Tips: Tailored to individuals

When delivered, breaks should be tailored to individual needs – both of the person with care and support needs and the carer. These needs should be established through a conversation with the carer – this may be a formal statutory carer’s assessment or a separate conversation that is used to establish the carer’s needs.

Services should be based on the needs of the people using the service. Services must work with carers to develop a plan that meets their needs. Carer Breaks should always have a specific approach to working with people and putting them front and centre about what they want from life – what matters to them – that is at the core of the work.

Commissioners

- When commissioning services, prioritise services that highlight their person-centred approach.
- Work with local VCSE organisations and the local population to develop service specifications.
- Ensure the services available in the local area are wide and varied and can meet the diverse needs of the local population.

Providers

- When planning breaks, have conversations with carers and the person they care for about their preferences and what they want from the break.
- Asking the question “What matters to you?” is a good starting point as it will enable providers to identify what the carers’ priorities are for themselves.

Good Practice: Carers First - Men Do project

Key lessons:

- Partnership working
- Tailored to individuals
- Codesign

Men Do project

Aimed at male carers (and former carers) over the age of 50 in Lincolnshire, Men Do is one of Carers First's most successful projects. As men in caring roles are less likely to reach out for support and/or join standalone support groups, the project brings men together to do activities that they can enjoy. Activities include monthly breakfasts, visits to garden centres, pubs, film screenings and axe throwing.

The monthly breakfasts (known as Banter Breakfasts) happen at 7 different cafes across Lincolnshire on the first Tuesday of every month. Carers First had an average attendance of 72 male carers or former carers across the cafes. From Nov 2021-Oct 2022, the project supported 201 men.

Carers' feedback: "I feel more confident...I was a bit apprehensive about going but once I got there, I had one of the best days I've ever had. It has been good to make friends with men in a similar position to myself and of a similar age."

Carers First secured funding from a corporate partnership to offer male carers the chance to attend social activities. Initially limited to one area of Lincolnshire, carers and former male carers attended free events including meals out at local restaurants, a theatre trip, a visit to Woodhall Spa 1940s festival, a summer celebration BBQ, a day at a racecourse and a Christmas celebration.

After the success of the project, Carers First secured extra funding to expand the project across the whole of Lincolnshire. Men Do More has enabled carers to meet up with each other regularly alongside their caring roles. Without work, many of the male carers supported by Carers First have limited opportunities to meet their peers, relax, socialise, and take a break.

Because Carers First pays for the main expenses of the events, individual financial situations are not relevant. One carer said: *"This was part of why I joined Men Do More. We're all the same on the day, we're all just blokes there having a laugh, level pegging."*

The project benefits carers as they have the chance to come together with others in a similar situation and relax whilst undertaking a shared activity. The feedback from participants is positive:

- “I think this is great, it’s a reason to go out”
- “Today reminded me I’m not alone.”
- “This is something I’ve always wanted to do, but never had the opportunity.”
- “As a group, we have become more aware of each other’s situation and are able to support each other.”
- “One thing men miss when they leave work is camaraderie. They get this here.”

This service is aimed at men – a group of carers who are often more reluctant to seek help and advice, and less likely to access services.²⁴

Good Practice: Wandsworth Carers’: Parent carers with disabled children

Key lessons:

- Coproduction and codesign

At the beginning of 2021, Wandsworth Carers’ Centre carried out a consultation with carers about respite to find out if the needs of carers in the borough were being met, what was working well and if there were any gaps. An overwhelming response was from parents who had children with additional needs and disabilities who told us there was very little opportunity for them to take a break from their caring roles or to spend quality family time together.

As a result of that consultation, Wandsworth Carers applied for funding from Carers Trust to provide a parent and family respite service. They were able to provide formal respite, where care workers would look after the child with additional needs in the home and family trips, allowing families to have days out, and spending time together.

The project offered entry, travel and staff to support parents, to various places including Legoland, Woburn Safari Park and a day out in Brighton with full access to the pleasure pier. These trips meant that families were able to do things which they may otherwise not have been able to do.

Many of the parent carers who accessed this project had very limited means of support in their caring role. Many parent carers were not able to take a break from their caring role or take time for themselves as their caring role took all their time; This meant that Carers felt isolated. Carers who have accessed the project have

²⁴ <https://core.ac.uk/download/pdf/29472042.pdf>

told Wandsworth Carers' that it has been a lifeline for them, and that it has allowed them to take time to see friends and other family. Carers have also said how the project has introduced them to new friends who are in similar situations and understand the challenges of caring for a child with an additional need.

The project was a huge success and had a real positive impact, not just for the parents of the children but also for the children with additional needs and their siblings.

Feedback from families

"We would like to thank Wandsworth Carers for organising the fantastic day trip to Legoland Windsor. We are entirely grateful for this fantastic day out. My children had really enjoyed themselves and my special needs daughter felt special on the day as she had known for a short while that Legoland was meant for her. Thank you."

"Meeting other parents on the day made it easy for me to feel comfortable around them and when my daughter displays negative behaviour, everyone was understanding as we all face the same daily challenges. Thank you again for organising a lovely trip for the children and parents."

"Because of the complex needs of my son, it has been impossible for us to spend time with our other children but with the care worker coming to our home, we can spend time with our other children, knowing that our son is safe and happy. This service has been a lifeline to our whole family".

Top Tips: Coproduction and codesign

Coproduction is:

A way of working that involves people who use health and care services, carers and communities in equal partnership; and which engages groups of people at the earliest stages of service design, development and evaluation.²⁵

Coproduction recognises that people with lived experience, in this case, unpaid carers, are the best place to design the services that support them. Coproduction will help commissioners and providers ensure services are designed in a person-centred way, encouraging genuine involvement and engagement.²⁶

²⁵ <https://www.nationalvoices.org.uk/wellbeing-our-way/co-production>

²⁶ <https://www.nationalvoices.org.uk/wellbeing-our-way/co-production>

Local communities should be at the heart of service design with commissioners and providers working with unpaid carers to coproduce and codesign services. Doing this with carers alongside specialist organisations will ensure:

- Services are open to all members of the community including those who face barriers to accessing services and face health inequalities.
- There are specialist services available if the carer using the service wants or needs to access them.

Commissioners

- Coproduce services with providers – such as local carer support organisations and unpaid carers.
- Early engagement is key to good coproduction. Involve unpaid carers and local carer organisations early in the process and enable them to have a genuine opportunity to shape breaks' provision
- Develop processes and mechanisms which enable unpaid carers to shape the services they access.
- Make sure these processes and mechanisms enable you to hear from carers from communities who face additional barriers to accessing services.

Providers

- Work with your local commissioners and the unpaid carers you support to design services.
- Share your data and your insights to ensure breaks services are reflective of the needs of the local community.
- Facilitate carers' involvement and engagement in the codesign process.
- Enable carers to shape the services they provide.
- Engage with unpaid carers who face barriers to accessing services by working with other organisations who may be supporting them or by creating links with community organisations that these carers already access.

Useful resources for coproduction and codesign:

- [Health and Care Act Working in Partnership with People and Communities Guidance](#)
- [NHS England Carers Toolkit](#)
- [TLAP Making it Real](#)
- [SCIE's guide to co-production and co-design](#)
- [NHS England Guidance on partnerships with the voluntary, community, and social enterprise sector](#)

Integration, coproduction and codesign

Local areas should be providing integrated services so that carers can access the services they need at the time they need them, including breaks. Commissioners and providers should work together to ensure that health and care services are joined up and referrals that need to happen are as easy as possible for unpaid carers.

In the context of breaks provision, it is important that professionals can refer carers for breaks across different services – be that health or social care – and that unpaid carers themselves can easily navigate the health and care system for their own needs.

The Health and Care Act

The Health and Care Act came into force in June 2022. The Health and Care Act is a pivotal piece of legislation that will transform how local areas design and deliver health and social care.

Many of the provisions within the Health and Care Act will support – and in some cases require – local areas working more closely together, within services and with their local communities.

Under Section 25 of The Health and Care Act 2022, Integrated Care Boards (ICBs) have a legal duty to involve unpaid carers and their local representatives in the commissioning and designing of services that impact them.

NHS England and DHSC expect local areas to work with their local VCSE organisations to develop local strategies. In guidance for Integrated Care Systems (ICSs) on partnership working with the VCSE²⁷, NHS England set out that:

- “The VCSE sector is a key strategic partner with an important contribution to make in shaping, improving and delivering services, and developing and implementing plans to tackle the wider determinants of health”. And;
- “VCSE partnerships should be embedded in how the ICS operates, including through involvement in governance structures in population health management and service redesign work, and in system workforce, leadership and organisational development plans.”

ICBs have duties to involve communities in the commissioning and designing of services. This includes working with communities, VCSE and specifically unpaid carers. ICBs are also expected to promote this involvement of patients, service users, unpaid carers, and their representatives in the development of the integrated care strategy and consider how the strategy supports personalised care and support.

²⁷ <https://www.england.nhs.uk/ourwork/part-rel/voluntary-community-and-social-enterprises-vcse/>

The guidance sets out that:

“Commissioning VCSE organisations to lead engagement with the groups they work with supports investment in community assets and can secure wider benefits by strengthening local organisations.” [See Working in partnership with people and communities: Statutory guidance]

The Health and Care Act 2022 introduced a duty on ICBs to involve unpaid carers and their local representatives in the commissioning and designing of services that impact them.²⁸

In statutory guidance on Integrated Care Strategies, unpaid carers are specified as an example of a population group that may not fully benefit from a joint strategic needs assessment due to a lack of data or systemic barriers to accessing services.

The guidance also sets out that:

“The Health and Care Act 2022, amends the National Health Service Act 2006 to require integrated care boards to have regard to the need to reduce inequalities between persons, not just patients, concerning access to health services. The integrated care strategy should ensure that the needs of underserved populations are identified and met through the integrated care board, NHS England, or responsible local authorities exercising their functions.” [See *Groups who can be under-represented in assessments of need* section of Guidance on the preparation of integrated care strategies]

As set out above, ICBs must now involve people – including unpaid carers – in developing services. ICSs are expected to build on established mechanisms for involving people and organisations previously developed by local authorities and NHS bodies. It is expected that Integrated care Partnerships (ICPs) will explore which other local partners and stakeholders they will need to engage in the development of the integrated care strategy either directly or indirectly through other organisations.

Local carer support organisations could play a dual role locally – both working with local partners to shape the local strategy and helping and enabling local partners to connect with the unpaid carers they support.

²⁸ <https://www.england.nhs.uk/long-read/working-in-partnership-with-people-and-communities-statutory-guidance/#legal-duties-and-responsibilities>

Good Practice: Kirklees Council - Carer Breaks

Key lessons:

- Partnership Working
- Coproduction and Codesign
- Tailored to individual needs

Kirklees Council fund all its carer support services through the Better Care Fund, meaning it draws from both NHS and social care budgets. Kirklees Council has commissioned Carers Trust Mid Yorkshire, a CQC-registered domiciliary care provider, to provide carer breaks. Kirklees Borough Council and Carers Trust Mid Yorkshire developed the service to reflect the needs of local carers.

Carers access breaks after having a statutory carer's assessment undertaken by a council social care assessor. If the assessment finds that the needs of the carer include a break, they are referred to Carers Trust Mid Yorkshire's breaks service.

An important aspect of this is the assessment does not set out the length of break that the carer needs – only that the carer needs a break. Carers Trust Mid Yorkshire then meet the carer, and the Carer Support Workers have the autonomy to decide how the length of break the carer needs following that conversation.

The autonomy and freedom given to frontline workers mean the breaks are tailored to the needs of the carer. Following that conversation between the carer and the Carer Support Worker, a plan is put in place which reflects the needs of the carer and the person with care needs. As a home care provider, Carers Trust Mid Yorkshire can carry out domiciliary tasks whilst the carer has their break.

Top Tips: Integration and the Better Care Fund

Commissioners

The Better Care Fund (BCF) aims to improve the integration of local health and care services. There is support available from NHS England on how to best use the BCF.

The Policy Framework [can be found on this webpage](#).

BCF support is available to local areas, including:

Better Care Managers

Better Care Managers sit within each of the seven NHS regions to:

- provide support to local areas,
- work with stakeholders and partners
- gather learning and coordinating support.

The contact details for the regional Better Care Managers are on the NHS England [website](#) with a detailed list of regional breakdown also listed [there](#).

Better Care Fund support offer

The BCF national support programme, delivered by the Local Government Association in partnership with ADASS and Newton Europe, offers support to local areas so that they work towards improving integration between health, housing and social care services and delivering their BCF plans. The programme will ensure responsive and comprehensive support is available to all systems that need it, as well as supporting the development of national tools and good practice guidance.

The Better Care Exchange

The Better Care Exchange is a collaborative social network for health, housing, and social care professionals. It enables networking, information and knowledge sharing on good practice for delivering better integrated care and implementing Better Care Fund plans.

How to guide: the Better Care Fund technical toolkit

The BCF team has refreshed the how-to guides related to the integration of health and social care to reflect policy developments, as well as the development of integrated care systems and the publication of the NHS Long Term Plan. These guides are intended to provide practical steps and guidance on implementing BCF plans.

The exchange works as a learning hub that pools the knowledge and skills of leading organisations and professionals across the health, housing and social care sectors. The Better Care Exchange offers free, easy-to-access information to those involved in health and care, to help us work together more effectively and deliver better care to more people.

The exchange is free to use and will help you to:

- collaborate with and learn from colleagues in health, housing and social care through online discussions and communities of interest
- access good practice on better integrated and joined-up care
- keep up to date with the latest integration resources and products.

You can find these guides on the Better Care Exchange. To request access to the Better Care Exchange, please email england.bettercareexchange@nhs.net.

Providers

Integration will help providers support unpaid carers and ensure that services are reflective of the needs of carers in the area.

Providers should work together to ensure carers can access good breaks provision:

- Build, develop and maintain relationships with other local organisations. Once those relationships are established create two-way referral routes and ensure that staff are aware of the services available in the local area
- Share data on outcomes to build good breaks provision
- Within data sharing laws and rules, share personal data where this means providing personalised service to carers and the people they care for
- Share information with commissioners and partners to services and the impact of those services
- Get involved with coproduction and codesign opportunities.

Good Practice: Stockton Borough Council – Time Out

Key lessons: Tailored to individual needs

Stockton Borough Council provides carer support “in-house” – so, unlike many other local authorities, do not commission carer support to a third-party organisation.

The Carers' Hub offers a 'Time Out' service for unpaid carers who need time away from their duties. Time Out provides up to 8 hours of breaks a month free of charge. This can be a planned regular break or used on an ad hoc basis.

Referrals to the project can come from any professional in health and care or be a self-referral. The only criteria for accessing the services for both the carer and the person with care needs must be adults, and the service is not regulated and does not provide domiciliary care as part of the break.

When carers are referred to the service, a Time Out Coordinator will have an initial conversation with the carer, and the person with support needs to find out what their needs and preferences are. Based on this, the Time Out Coordinator will connect the family with a Time Out worker. The project aims to have the same Time Out worker providing the break each time.

Breaks are flexible and the Time Out worker can take the person with care needs into the community or sit with them at home. It is up to the person with care needs and the carer how the time is spent.

Time Out can often be a good first step into accessing carer support. Because carers do not require a statutory assessment to access the service, the service can act as an early intervention preventative measure and enable Stockton Borough Council's carer support team to engage with the carer and monitor if their support needs increase. If additional support is required, then carers can access other services that are provided by the Stockton Borough Council carers support team.

Carer's Story

Margaret's husband Michael was diagnosed with Parkinson's Disease in 2009. Margaret has been using the Time Out service for several years, using the opportunity to meet friends and family.

Karl, a Time Out worker, takes Michael out for walks and to the sites like Preston Park. A visit to a local museum sparked many memories for Michael who shared them with Karl.

Margaret said, "Karl has become a friend, he's like one of the family now. He treats Michael as his friend and it's as if we've known him for years. The support workers that take Michael out are really brilliant. They make him laugh."

Margaret added, "I don't think I could cope without the Time Out service now. They are really nice, trustworthy people. I would recommend the service to everybody."

CARERS FROM COMMUNITIES FACING HEALTH INEQUALITIES

Over the course of the project, we found limited evidence for specific breaks services for carers from ethnic minority communities, or LGBTQ+ communities. This may not be a surprise as carer breaks are often delivered to individuals, rather than groups. However, there are wider lessons for providers and commissioners to ensure carers from these communities are identified and referred for support in the first place as without that, these carers are less likely to access breaks.

As expanded on below, some carers from these communities do not feel that “mainstream” services cater for their needs²⁹³⁰ so whilst all services should be open to all members of the community, specialist support services also need to be in place.³¹³²³³³⁴

Carers from communities consistently tell us that whilst they want services to be open to them, they also want to be able to access services that cater to their own communities specifically.

Commissioners and service providers should engage with carers from across all communities. Carers from across all communities should be enabled to design services which provide the support they need. This requires early engagement from commissioners, service providers, and other local partners.

Commissioners and providers should ensure specialist services are available to support communities who face additional barriers if that is what those carers want. This specialist support could be provided through partnership working and co-design on the local level. Service providers must be able to refer carers for support to other local organisations that may be able to provide that specialist support.

This document aims to highlight good practice in ensuring all services are open to all members of the community and when it is appropriate and wanted, also highlights examples of where areas have provided specialist services to communities who face additional barriers.

²⁹ <https://www.nice.org.uk/guidance/ng44/resources/primary-research-report-1-community-engagement-approaches-to-improve-health-pdf-2368402382>

³⁰ <https://raceequalityfoundation.org.uk/wp-content/uploads/2022/10/REF-Better-Health-484.pdf>

³¹ https://www.stonewall.org.uk/system/files/lgbt_in_britain_health.pdf

³² https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/721704/LGBT-survey-research-report.pdf

³³ <https://raceequalityfoundation.org.uk/wp-content/uploads/2022/10/REF-Better-Health-484.pdf>

³⁴ <https://lgbt.foundation/canyousee>

Carers from ethnic minority communities

There is extensive evidence showing that carers from ethnic minorities face additional barriers to accessing carer support.³⁵³⁶³⁷³⁸ Part of this may be the difficulty many carers face in self-identifying as carers – instead of seeing caring for a family member or friends as “their duty.” Historically, services not being accessible to carers from ethnic minorities may be the result of carers from ethnic minorities, not perceiving services as “for them,” and services concluding that carers from ethnic minorities are not interested in accessing their services, therefore, do not do enough to reach out to those communities.³⁹ This is starting to change, with a recognition of the importance of reaching communities that face health inequalities and barriers to accessing services.⁴⁰

However, as some of the good practice examples highlight, these practices are changing – particularly in areas with a high proportion of carers from ethnic minority communities.

Good Practice: Camden Carers - Black Carers Collective

Following requests from Black carers they support; Camden Carers established the Black Carers Collective (BCC) in October 2020. The carers supported by Camden Carers wanted a group that catered to their needs in a culturally sensitive way.

The Black Carers Collective offers the chance for Black carers to come together and enjoy activities with other Black carers, whilst taking a break from their caring role. It is members of the BCC who drive the activities they undertake ensuring that it is tailored to their needs as individuals and as a group.

During Black History 2021 Camden Carers set up a virtual art exhibition featuring art created by members of the Black Carers Collective. Of the ten artists featured, only two had previously been involved with Camden Carers’ longstanding art group which is open to all carers. Many did not feel confident to join the established group but were delighted to be given an opportunity to celebrate their creativity in a culturally safe space. This highlights the need for more spaces that allow genuine expression from groups who may not otherwise engage in mainstream activities.

The BCC’s first anniversary was celebrated both virtually and in person. The in-person celebration took place at the Camden Arts Centre and featured Black artists throughout October.

³⁵ <https://raceequalityfoundation.org.uk/wp-content/uploads/2022/10/REF-Better-Health-484.pdf>

³⁶ <https://www.iriss.org.uk/sites/default/files/iriss-insight-7.pdf>

³⁷ <https://www.jrf.org.uk/blog/unpaid-carers-changing-systems-trap-them-poverty>

³⁸ <https://www.carersuk.org/media/3izluvum/cuk-black-asian-and-minority-ethnic-carers-good-practice-briefing.pdf>

³⁹ <https://raceequalityfoundation.org.uk/health-and-care/improving-health-and-social-care-support-for-carers-from-black-and-minority-ethnic-communities/>

⁴⁰ <https://www.gov.uk/government/publications/health-disparities-and-health-inequalities-applying-all-our-health/health-disparities-and-health-inequalities-applying-all-our-health#core-principles>

It was an opportunity for Black carers to meet in person, have a break from their caring role and celebrate a group that they hold dear.

One carer wrote, "I can have tea and cake any time, but a Black art exhibition is an extraordinary and life enhancing event for me. I was able to meet up with friends I'd met at the stand-up comedy event organised by the [Black Carers] Collective so that was a triple delight: a beautiful ambience, delicious refreshments and scintillating company. Who could ask for anything more"?

Good Practice: Your Voice in Health and Social Care - Carer's Short Breaks

Your Voice in Health and Social Care (YVHSC) is an independent organisation that gives people a voice to improve and shape services and help them get the best out of health and social care provision. YVHSC specialises in providing Health and Care services that offer effective engagement and involvement that impacts community wellbeing and development.

In the London Borough of Ealing, YVHSC is part of consortia, led by Dementia Concern, providing short breaks for carers via a befriending service. Carers and the person they care for are referred to the service, after which YCHSC has a conversation with both the carer and the person with care and support needs. YCHSC then connects a volunteer befriender for the person with care needs. This enables the carer to have a break from caring.

Befrienders receive training and will support the person with care needs for up to 3 hours at home, or in the local community – such as going to a café, or the local park. The activities that take place are set by the person with care needs, after a conversation between the YVHSC team, the carer, and the person with care needs.

YVHSC are starting to arrange group activities for people with care needs as another route for carers to get a break. The person with care and support needs and carers have a range of options open to them when accessing the service. These include:

- Carer Support Groups
- Respite breaks for carers
- Accessing Ealing Carer's hub services including a coffee morning, yoga, Pilates and arts and crafts sessions
- Music Therapy
- Exercise Groups

As part of the consortia, specialist organisations have deep links with ethnic minority communities. The Consortium includes partners The Asian Health Agency and the Centre for Armenian Information Advice both of whom can provide specialist services to members of the communities. If carers from these communities are referred to the project and want to be connected to that specialist support, they are referred. As it is a consortium, the Asian Health Agency and the Centre for Armenian Information Advice can also refer carers who present to them and want to access mainstream support alongside any specialist support.

Carers from Lesbian, Gay, Bisexual and Transgender (LGBTQ+) communities

There is lots of evidence that makes clear that LGBTQ+ people face additional barriers to accessing health and care services.⁴¹⁴²⁴³⁴⁴ These barriers include past experiences of discrimination, and service providers lacking the skills to provide high quality support for LGBTQ+ people. These two factors can combine to increase the reluctance of carers from LGBTQ+ communities to seek or access support; potentially meaning carers from LGBTQ+ communities are less likely to access services – including breaks.

To enable carers from the LGBTQ+ communities to access breaks, action needs to be taken to ensure carers from this community are identified and supported within services that they feel are open to them.

As breaks should be part of a suite of support services available to carers, to ensure breaks are accessible, providers and commissioners must first ensure that the wider support is open and accessible.

Good Practice: Wandsworth Carers – LGBTQ+ Carers Peer-to-Peer Support Group

Key lessons:

- Working with carers from communities who face health inequalities
- Coproduction and codesign

Wandsworth Carers Centre hosts support for LGBTQ+ carers. Alongside the peer-to-peer support group, the LGBTQ+ carers help codesign the services Wandsworth Carer provide them as carers from the LGBTQ+ communities.⁴⁵ One part of these services is day trips specifically for carers from LGBTQ+ communities to enable them to enjoy a break from caring alongside their peers.

41 [Wandsworth Carers Centre](#) [LGBTQ+ Carers Peer-to-Peer Support Group](#)

42 [Wandsworth Carers Centre](#) [LGBTQ+ Carers Peer-to-Peer Support Group](#)

43 [Wandsworth Carers Centre](#) [LGBTQ+ Carers Peer-to-Peer Support Group](#)

44 [Wandsworth Carers Centre](#) [LGBTQ+ Carers Peer-to-Peer Support Group](#)

45 <https://carerswandsworth.org.uk/specialist-support/lgbt/>

Wandsworth Carers' Peer Support and Wellbeing events are for LGBTQ+ Carers living anywhere in London. They allow carers to share lived experiences with other carers who understand what it means to be an LGBTQ+ carer.

They are an opportunity to meet other LGBTQ+ carers and are a safe space to enjoy activities which contribute to physical and mental wellbeing. They run in-person LGBTQ+ Carer peer support meetings (near Waterloo or Blackfriars Station), regular trips for LGBTQ+ carers and online group meetings too.

Wandsworth Carers Centre organised a trip to the Tate Britain for the LGBTQ+ Support Group, including a guided Tour of the gallery and a trip to a coffee shop. The group was made up of 7 Carers, 1 volunteer (who has been volunteering at the Peer Support Group since June) and a staff member. The feedback was that everyone enjoyed the trip whether or not they were very interested in the art itself. Some of the feedback received was:

- 'This group has been a lifeline for me.'
- 'Thanks for organising a fab afternoon of culture and caffeine!'
- 'Thank you for a really nice day'.

Wandsworth Carers organised a trip to Shakespeare's Globe Theatre for a Pride-themed, guided Tour. Once again, 7 Carers signed up for this trip. All carers who attended very much enjoyed the trip and asked if the Group could continue to have trips in the New Year. Some of the feedback received was:

- 'Thank you for organising The Globe tour. It was excellent and I thoroughly enjoyed it.'
- 'Thank you, Wandsworth Carers' Centre, I really look forward to your outings.'

Top Tips: Working with carers from communities who face health inequalities

Coproduction must work with carers from communities who face additional barriers to accessing services and health inequalities. This means:

- Working with specialist VCSE organisations who have established relationships with these communities.
- Going to where these communities are, and not expecting them to come to you. This could mean for example having focus groups in places where these communities already access support or socialise – rather than expecting members of these communities to attend meetings at a council building or similar.

Some carers from communities that face additional barriers to accessing services prefer receiving support from specialist organisations or services tailored to the needs of the communities they belong to.

- As set out above, commissioners should encourage partnership working between VCSE organisations to ensure the needs of all communities are met.
- Specialist services, or specialist programmes within services, should be available

- All information provided must be accessible and you should ensure support and information are provided in the way that services users prefer. For example, many service users will prefer face-to-face support, rather than online support.

CORONAVIRUS AND A SHIFT TO DIGITAL SUPPORT

The Coronavirus pandemic and the various lockdowns which were implemented severely limited carers' ability to access breaks and services outside of their home. Understandably many unpaid carers were reluctant to leave their houses or have others come into their homes, due to the fear of contracting the virus themselves, or the person they care for contracting it.^{46 47}

Research released for Carers Week in 2021⁴⁸ found that during the pandemic carers lost, on average, 25 hours of support a month they previously had from services or family and friends before the pandemic. 72% of carers responding to the survey have not had any breaks from their caring role at all. A Carers Trust survey during the pandemic found that one in six (16%) reported that lockdowns and closure of local services have forced them into caring for an additional 40 hours or more per week.

Carers UK found almost two-thirds of carers (64%) of carers responding to the survey have not been able to take any breaks from their caring role during the crisis.⁴⁹ ADASS reported that between February 2020 and April 2021, days services and community-based services decreased by nearly 50%, and home-based respite decreased by 15%.⁵⁰

Older carers, Coronavirus, and the switch to digital

During the pandemic, many services switched to digital providing a different range of services. For many carers, it provided a different type of break when there was no other. Some of these breaks and peer-to-peer support services have continued. Carers UK runs a regular Care for a Cuppa session (more below) for any members of Carers UK and more focussed Share and Learn sessions around particular topics. Similar services are offered by many local carers' organisations.

One group of carers who may have been potentially excluded from this switch to digital support are older carers as they are more likely to lack the digital skills to access it. The older a person is the less likely they are to be digitally skilled. An Age UK report⁵¹ during the pandemic found:

⁴⁶ <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/socialcare/articles/coronavirusandthesocialimpactsonunpaidcarersingreatbritain/april2021>

⁴⁷ <https://www.sheffield.ac.uk/news/caring-our-carers-report-calls-investment-digital-tech-support-unpaid-carers-lockdown>

⁴⁸ <https://www.carersweek.org/media/u4jby32a/carers-week-2021-research-report.pdf>

⁴⁹ <https://www.carersuk.org/reports/caring-behind-closed-doors-forgotten-families-in-the-coronavirus-outbreak/>

⁵⁰ <https://www.adass.org.uk/adass-activity-survey-2021>

⁵¹ <https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/active-communities/digital-inclusion-in-the-pandemic-final-march-2021.pdf>

- A large majority of 50-64 year olds (88%) and 65-74 year olds (75%) in England use the internet every day or almost every day, compared to under half (46%) of those aged 75+. Others use it less often, but among those aged 75+ more than two out of five (42%) do not use the internet.

Many organisations did face the issue of ensuring people who are digitally excluded due to their age still had access to these services. Some older people are digitally excluded because they lack the hardware (e.g., laptops or tablets) to access digital support whilst others lack the confidence and skills. We know of many organisations that tackled both – either by providing service users with a tablet or by building service user confidence in the use of that technology.

The Coronavirus pandemic and subsequent lockdowns meant support services switched to being provided online. There are numerous examples of classes such as yoga, Pilates, support groups and art classes switching to being delivered digitally. This was welcomed by many unpaid carers as – despite not being able to leave their homes – the online classes did allow them to stay connected to support and other carers.⁵²

Speaking to providers, as the country moves forward from the pandemic and lockdowns, many services are providing a hybrid model whereby some support remains online. This was based on feedback from carers who told services that the online classes and support were more convenient for them and is backed up by broader research.⁵³

We are likely to see a continuation of this hybrid model of service delivery. Online support for carers is convenient for many carers especially if that support is, for example, an hour long yoga session. It might be convenient for carers to access this support online as they don't need to leave the house – saving time and money on commuting – whilst still accessing support that is important to them.

However, face-to-face support must remain as we know how vital that interaction can be. Service providers and commissioners must be reactive to the needs and preferences of unpaid carers and ensure carers can access the support they need in the way that they want to.

⁵² <https://www.scie.org.uk/care-providers/coronavirus-covid-19/commissioning/impact-on-citizens#carers>

⁵³ <https://www.scie.org.uk/care-providers/coronavirus-covid-19/commissioning/impact-on-citizens#carers>

Good Practice: Carers First - Digital Support

Key lessons:

- Partnership working
- Coproduction and codesign

Carers First received funding through Carers Trust's Respite Support and Development Fund in September 2021 to run Breathworks sessions for different groups of carers. After speaking to carers about what support they would want, Carers First delivered thirteen 75-minute-long online Breathworks sessions during the day and evening. These sessions received great feedback and we have made Breathworks a part of our online programme.

A Carer's Story

"I am a working carer, aged 61, living in Essex with my husband and 2 adult sons. I care for my elderly parents, both aged 92, who live close by and have numerous health conditions, including sensory impairments and mobility issues. Recently, I've also supported my husband as a carer for his sister, who suffered a stroke in February and who lives 2 hours travel away.

Whilst we have lots of solutions in place such as care alarms and other equipment, click-and-collect online shopping, prescription delivery and benefits, it can still be a real challenge to balance lots of conflicting demands and can leave me feeling stressed and struggling to use my time to the best advantage.

I signed up for a Breathworks session, really out of curiosity as much as anything, but enjoyed the hour very much as our facilitator was very calm, and reassuring and gave easy-to-follow instructions. The exercises were simple but effective and I've used them on a few occasions since to take a break, clear my head, relax – and just breathe!"

Good Practice: Carers UK - Care for a Cuppa

Carers UK began delivering online meetups for carers at the start of the pandemic in April 2020. Carers UK's weekly 'Care for a Cuppa' sessions enable carers from across the UK to come together to share how they are feeling and discuss any challenges they are facing with other carers who understand and can empathise with their situations. Several 'Share and Learn' sessions are also held each week, which enable carers to maintain their wellbeing and develop their skills and knowledge. External facilitators provide sessions ranging from yoga, Pilates and mindfulness to creative writing, photography and singing. Carers UK has also hosted many music performances, poetry readings and interviews with authors who have written books about their caring experiences.

In January 2023, Carers UK delivered its 500th online meetup and over 7,000 carers have benefitted from these sessions, with 99% saying that they would or may recommend them to a friend or family member who is caring.

A Carer's Story

"Being able to access support through organisations such as Carers UK has been a lifeline. I have participated in over 30 Carers UK online Share and Learn sessions, ranging from craft workshops and community singing groups to mindfulness, yoga and creative writing. Not only have these sessions given me an opportunity to switch off and enjoy uninterrupted time for myself, I have also made new friends, gained new skills and established new support networks. I now feel more empowered, not only in my caring role but also as an individual in my own right."

Top Tips: Digital Support

Commissioners

- Ensure there is a digital element to carer breaks support – if that is what the carers in your area want
- Support carers to access digital support. Some carers may need support to have the hardware (laptop, tablet, etc) needed to access digital support, whilst others may need support with the cost of data.
- Provide digital literacy sessions to enable unpaid carers to gain confidence
- Some unpaid carers may still need replacement care whilst they are accessing online support as they would if they were accessing "offline" support – so make sure that offer is available where appropriate

Providers

- Offer services online where they are appropriate and there is demand
- Offer carers the support they need to become more digitally skilled.
- Some carers may need support to have the hardware (laptop, tablet, etc) needed to access digital support, whilst others may need support with the cost of data. Work with your commissioners and partners to try and secure that support.
- Provide digital literacy sessions to enable unpaid carers to gain confidence
- Some unpaid carers may still need replacement care whilst they are accessing online support as they would if they were accessing "offline" support – so make sure that offer is available where appropriate

HELPFUL LINKS AND RESOURCES

[Care Act 2014](#)

[Care Act Guidance](#)

[Health and Care Act 2022](#)

[Health and Care Act Working in Partnership with People and Communities Guidance](#)

[The Care Act and Whole Family Approaches](#)

[SCIE Carer Breaks Guide](#)

[NICE Supporting Adult Carers Guidance](#)

[NHS England Commissioning for Carers](#)

[NHS England Carers Toolkit](#)

[Supporting carers in general practice: a framework of quality markers](#)

[TLAP Making it Real](#)

[SCIE's guide to co-production and co-design.](#)

[LGBT Foundation's Pride in Practice](#)

[Wandsworth Carers' Centre LGBTQ+ Toolkit](#)

[Carers UK: Supporting Black, Asian and minority ethnic carers: A good practice briefing](#)

[Carers UK: Supporting LGBTQ+ carers: A good practice briefing](#)

ABOUT CARERS TRUST

Carers Trust is a major charity for, with and about carers. We work to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems. We do this with a UK wide network of quality assured independent partners and through the provision of grants to help carers get the extra help they need to live their own lives. With these locally based Network Partners we are able to support carers in their homes through the provision of replacement care, and in the community with information, advice, emotional support, hands on practical help and access to much needed breaks. We offer specialist services for carers of people of all ages and conditions and a range of individually tailored support and group activities. Our vision is that unpaid carers count and can access the help they need to live their lives.

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