



# Portsmouth

## CITY COUNCIL

### HOUSING AND SOCIAL CARE SCRUTINY PANEL

### REVIEW OF THE PROVISION OF BREAKS/RESPITE FOR INFORMAL CARERS, PARTICULARLY THOSE WHO CARE FOR SOMEONE WITH DEMENTIA

Date published: 22 March 2023

Under the terms of the Council's Constitution, reports prepared by a Scrutiny Panel should be considered formally by the Cabinet or the relevant Cabinet Member within a period of eight weeks, as required by Rule 11(a) of the Policy & Review Procedure Rules.

## PREFACE

In the last few years social care has increasingly come under the spotlight and has never been more pressing than now. The pressures it faces became even more prominent during the Covid pandemic.

News headlines show how social care and health are strongly linked and in turn how formal social care is linked to informal (unpaid) social care. The pandemic increased the demands on informal carers and perhaps one consequence is growing awareness and recognition of informal carers, who have often been "the ghost in the room."

There are 11.5m people in the UK who give unpaid support (five times the number of posts in the health and care system) which saves £193m annually. At the Carers Count event in November 2022 delegates heard that these informal arrangements are "the glue that holds society together" and the NHS would "absolutely collapse" without informal carers.

Wider issues of social care reform and its relationship with health services, and the status of care work in society, are outside the scope of this review, which aims to give a view of the local situation and informal carers' experiences of caring.

The panel would like to thank Andy Biddle (Director of Adult Care), Clare Rachwal (Deputy Head of Service, Market Development & Community Engagement), Ben Muller (Assistant Team Manager, Carers' Centre), Solent Mind and the Brunel Carers' Group for providing information, responding to members' questions and arranging meetings with carers.

The panel would like to thank residents who participated in the review by sharing their experiences of caring.

I would like to thank all the panel members who have taken part: Councillors Stuart Brown, Graham Heaney, Ian Holder, Leo Madden, Scott Payter-Harris and Linda Symes.

Councillor Kirsty Mellor  
Chair, Housing and Social Care Scrutiny Panel.

Date: 22 March 2023

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## **Purpose**

The purpose of this report is to present the Cabinet with the recommendations of the Housing and Social Care Scrutiny Panel's review provision of breaks/respice for informal carers, particularly those who care for someone with dementia.

## **Background**

On 25 July 2022 the Housing and Social Care Scrutiny Panel (henceforth referred to in this report as "the panel") met informally with the Director of Adult Care, Andy Biddle, to discuss ideas and topics for a review in the 2022-2023 municipal year. In view of the timescale and so that the review could be completed within the municipal year it would be fairly limited in scope and more in the nature of a "temperature check." However, it could highlight aspects that may merit more in-depth investigation.

The panel learnt that Adult Social Care had identified gaps in respice provision for carers caring for people living with dementia who exhibit behaviours that can be challenging and that there are limited options for overnight respice for them. Therefore, the panel decided that the review's title should be "The provision of breaks/respice for informal carers, particularly those who care for someone with dementia." The topic was formally approved by the Scrutiny Management Panel at its meeting on 16 January 2023.

The review applies to carers who are over 18 and care for people over 18; care for children, and children who are carers themselves, are covered by the Education & Young People Scrutiny Panel. Local health services and Adult Social Care report regularly to the Health Overview & Scrutiny Panel.

The panel met formally on 23 September 2022 to hear from Andy Biddle, Director of Adult Care, and Clare Rachwal, Deputy Head of Service (Market Development & Community Engagement). The three representatives from the Residents' Consortium were present as well as panel members and participated in the discussion. Officers gave a brief introduction to the national situation and then an overview of the current provision for informal carers locally. They answered questions from the panel and the Residents' Consortium.

On 24 November 2022 the Chair of the panel and Democratic Services attended the Carers Count event at the John Pounds Centre to talk to informal carers about their experiences.

On 5 January 2023 Democratic Services attended one of the regular meetings of a group run by Solent Mind in Cosham for carers for people with dementia.

On 20 February 2023 panel members and Democratic Services attended one of the regular meetings of the Brunel Carers' Group who are carers for people with dementia.

The review was started by the Housing and Social Care Scrutiny Panel which comprised:

Councillors    Kirsty Mellor  
                      Stuart Brown  
                      Graham Heaney

Leo Madden  
Scott Payter-Harris  
Linda Symes

Standing Deputies were Councillors Dave Ashmore, Abdul Kadir, Lewis Gosling, Ian Holder and Gemma New. At Full Council on 6 December 2022 Councillor Holder became a full member and Councillor Brown became a standing deputy.

The minutes of the panel's formal meetings are published on the council's website at [Browse meetings - Housing & Social Care Scrutiny Panel Portsmouth City Council](#)

### **Background - national picture**

Recruitment and retention of care staff is a local and national issue so the panel felt it would be helpful to have some information on the care workforce to help put the role of informal (unpaid) carers into context.

Social care has increasingly become the subject of national debate, particularly who should pay for it and how it should be funded. It also has a complex relationship with health services and recent developments such as the Integrated Care Systems aim to deliver more joined up services. For both health and social care the Covid pandemic exacerbated existing pressures caused by staff shortages, winter flu, the economic situation and the ageing population. In addition, low pay for domiciliary carers (those who care for people in their own homes) has further increased shortages as other sectors offer better pay and conditions.

The shortages in the care workforce means more demands on unpaid or informal carers. Shortages also affect health services as patients cannot be discharged even when they are medically fit for discharge, ambulances cannot hand over patients; these delays mean other patients cannot be treated.

The social care workforce comprises people who work in nursing homes, residential care homes, day services, respite services, supported living and domiciliary care providers.

Key findings from Skills for Care in summer 2022 were:

- The total number of posts in adult social care in England (including filled posts and staff vacancies) was 1.79m as at 2021/22 (this was 0.3% higher than in 2020/21).
- The number of filled posts was estimated at 1.62 million and the number of vacant posts was 165,000.
- The number of filled posts has decreased by around 3% (50,000) between 2020/21 and 2021/22; the only annual decrease since records began in 2012/13.
- Over the same period the number of vacant posts has increased (by 55,000 or 52%) which shows that the decrease in filled posts is a result of recruitment and retention difficulties rather than a decrease in demand for care staff.
- The decrease in filled posts and corresponding increase in vacancies across adult social care comes as the wider economy has reopened following the height of the Covid-19 pandemic.
- The number of full-time equivalent (FTE) filled posts was estimated at 1.17 million and the number of people working in adult social care was estimated at 1.50 million.

- An estimated 17,900 organisations were involved in providing or organising adult social care in England as at 2021/22. Those services were delivered in an estimated 39,000 establishments.

In the 12 months since 2020/2021 there were the following changes:

- Between 2020/21 and 2021/22 the majority of the decrease in filled posts was in the independent sector (down by 45,000). Filled posts in local authorities remained broadly the same (up by around 1,000).
- In residential services, the number of filled posts fell by 13,000 in care only homes (4%) and 15,000 in care homes with nursing (5%).
- For non-residential services, the number of filled posts fell by 19,000 (3%).
- In terms of job roles, the majority of the decrease in filled posts was for direct care providing roles (down 55,000 and 4%). Registered nurse filled posts also decreased by 4.5% (1,600 posts).

The NHS Confederation published a [report](#) "System on a cliff edge: addressing challenges in social care capacity" in July 2022, which urged the government to take action on the social care workforce crisis. Some key points were:

- There is unsustainable pressure on health and care services, driven strongly but not exclusively by the severe capacity challenges affecting social care. Like the NHS, the sector faces steep vacancies and is struggling to recruit and retain staff desperately needed to keep people well at home and support them to leave hospital safely.
- 99 % of healthcare leaders responding to our latest survey agreed that there is a social care workforce crisis in their local area. Almost all agreed it is worse than a year ago and expect it to deteriorate into this winter.
- These pressures are impacting the whole health and care system's ability to deliver care across community and acute settings. For instance, 85 % of those surveyed agreed that the absence of a social care pathway is the primary cause of delayed discharge of medically fit patients.
- Almost three-quarters (73%) said a lack of adequate social care capacity is having a significant or very significant impact on their ability to tackle the elective care backlog. Over 80 % said it is driving urgent care demand.
- Although health and care are inextricably linked and interdependent, social care is not just about helping to alleviate pressure on the NHS. The care delivered by social care services is critical to the wellbeing of the nation.

### **Background - local picture**

Local and regional data that covers the period 2020/21 is available [here](#) split by varied comparisons. Portsmouth data can be found by going [here](#) and selecting South East as the region and Portsmouth as the local area.

As at autumn 2022 the data gave the following picture for Portsmouth.

Including the local authority, NHS and independent sector there were 4,300 filled posts in Portsmouth with 1,800 working in residential care, 200 in day care, 1,600 in domiciliary care and 600 in the community.

- Turnover rate in 2021/2022 was 27.6% (or 900 leavers), up from 26.2% in 2020/2021.

- Vacancy rate in 2021/2022 was 7.62% (275 posts).
- 54% of staff had full-time posts, 46% had part-time. 31% staff were on zero-hours contracts (equivalent to 1,100 filled posts).
- 82% staff are female and 18% male.
- Average hourly pay rate in the local authority sector was £14.08 in September 2021. Average hourly rate in the independent sector was £10.38 in March 2022.

## **INFORMAL CARE**

### **Who is an informal carer?**

Informal carers provide a wide range of care; their support can be personal care, practical or emotional support. People may not always consider themselves a carer but if they do something like get someone out of bed and dressed, take them to appointments, help with applying for benefits, or manage their medication, that makes them a carer. Carers are responsible all day, every day, and their roles include being nurse, secretary, pharmacist, activities co-ordinator, advocate, just to name a few. The Portsmouth Plan for Carers defines a carer as "Anyone who provides unpaid care or support to someone who would not manage without that help."

### **Identifying informal carers**

#### ***"The ghost in the room"***

One of the residents at the meeting on 23 September 2022 felt that sometimes there is a stigma on being and needing a carer. The perception needs to be worked on to make it less taboo to discuss. ASC tried to take the approach of asking "Do you look after someone? Do you help someone in your daily life?" and tried not to label people but it was very difficult. The Carers' Centre has just developed a quiz "Are you a carer?" National media has done much for carers but there has not been much coverage on carers who are family and friends. Many felt unseen, even before the Covid pandemic, and that they are "the ghost in the room." If a broader range of professions is encouraged to ask if people look after someone and if they need help that will have a bigger impact.

The Carers' Centre is quite well-established and is working with about 1,000 to 1,500 active informal carers. There are a lot of consultations though that can lead to "consultation fatigue." The Carers' Centre can target carers but the difficulty is targeting those who are not known to services. They could be reached by social media or word of mouth. ASC is trying to improve data. The vaccination programme used a flag to identify informal carers on the record system that is shared by ASC and primary care so visibility and data are improving. Officers agreed that carers who need help the most are probably the hardest to contact. According to a recent survey about 93% informal carers have seen a GP but only 7% have been identified as carers. Health services have a greater part to play but awareness has improved, especially with greater integration of health and care. Officers said some carers might not want to be identified but there is a societal shift to more acknowledgement of carers.

Carers do not exist in a vacuum so may be known through family, friends, neighbours and informal networks. Carers can be reached via the Carers' Centre's

newsletters, voluntary leader network, the Hive, Healthwatch and health services. The Carers' Centre has used Zoom and Teams to hold virtual sessions with carers who may not be able to leave their homes.

Carers are also known via employers as many are working age. About a third of public sector staff are estimated to be carers. Employers need to understand their workforce's needs. There could be about 7,000 carers in Portsmouth and as employers make it easier to work more flexibly it will enable carers to be more easily identified when they combine caring with work. A Private Members' Bill on unpaid leave for carers was going through Parliament in 2022 and was supported and formally endorsed by the council's Cabinet on 27 September 2022. About 50% council staff live and work in Portsmouth and as the council becomes more enlightened as an employer it makes it easier to support carers.

### **Current support**

Adult Social Care offers a range of support for informal carers.

- One-off annual payment of £150 that can be put towards anything that constitutes a break, for example, equipment for a hobby, gym membership or going out for a coffee.
- The sitting service provides up to six hours' respite per week (when carers go to someone's home) with no charge but this depends on having the right people who can give this type of support.
- ASC has block purchased two respite beds in a local nursing home for planned overnight breaks (most homes will not take future bookings). However, this is not always the best setting for people with dementia, particularly where someone is mobile, and with adults their wishes have to be taken into account, depending on their capacity to make decisions. Prior to Covid the two respite beds were pretty fully booked. They did not admit people during Covid and now there is almost nil demand. Bookings have been slow to grow and are then cancelled because of illness or outbreaks of Covid or other viruses. In addition, younger adults may not want to go to a nursing home. The beds are sometimes used now for Continuing Healthcare admissions but their use needs reviewing.
- The Carers' Centre offers a range of activities such as peer support, groups, training and time out.
- ASC considers fairly regularly the issue of training people so they can be a carer in the short-term to prevent delayed hospital discharges. However, there may be concerns with insurance and the capacity of the proposed carer. In the past some occupational therapists have helped provide safe care, for example, moving and handling.

Breaks for carers range from time out for themselves to providing replacement care while they are not providing care, for example, while a carer goes to their own medical appointments, or so they can have uninterrupted sleep to protect their long-term health. Caring can have a toll on carers' wellbeing. Often paid care such as domiciliary care or overnight nursing care would provide respite. They might need a longer break for an operation or to care for someone else. ASC would like carers to have a holiday as well as a break.

The challenges of the care market mean it is harder to secure replacement care. ASC can usually provide standard domiciliary care but this is sometimes not good



enough for people with more complex conditions such as dementia. Staffing and the range of provision is a problem not just with dementia. For example, a carer with a spouse with a complex mental health condition and children will need respite care that can look after both. There are Personal Assistants (someone to help who can be employed directly) but it depends on the right one being available.

In March 2021 the Carers' Centre opened up again after Covid but some services did not resume. While it was closed needs might have increased and at September 2022 there was a waiting list of about three weeks for a carer's assessment. There was a significant drop in demand for and provision of carer breaks during the pandemic but a significant increase in demand in 2022. Referrals into the Carers' Service increased by 77% from 260 referrals to 465 referrals when comparing April to August 2021 (260 referrals) and April to August 2022 (465 referrals); this has resulted in increased demand for replacement care services with spend increasing by around 40%.

The Carers' Centre meets with peer support group leaders, such as the Brunel group which are run by volunteers, every two months. The Solent Mind group is run by Remind and the Carers' Centre has other mechanisms for keeping the Remind service updated such as the Dementia Action Alliance.

Since the panel met in September 2022 Adult Social Care has commissioned a respite bed in Harry Sotnick House which can be booked. It became available from February 2023 and is already booked for the next three to four months.

### **Legal position**

Carers have legal parity of esteem under the 2014 Care Act and are entitled to a carer's assessment. This means that prior to the Care Act carers could request a carer's assessment but it had no legal status and it was often tagged on to a client's assessment. Since the Care Act carers are entitled to the same level of assessment and support as people who need support. Previously a social worker could have said that a carer was providing care and advised them to continue even if they were struggling. Now ASC has to ask if the carer is willing and able so, for example, if a carer is not willing to provide personal care ASC has to provide help. In addition, the 2022 Health & Care Act has a clause stipulating that when discharging patients hospitals should work with informal carers. Officers said there are now more "musts" than "shoulds" as recognition of informal carers has gradually increased.

### **Financial position**

There is much variation across the country with regard to paying for and financial help for respite care. Some local authorities give a bigger one-off payment but less non-chargeable help. Any financial provision for carers is agreed through a carer's assessment. In Portsmouth it is straightforward and there is no form to complete, just a conversation. ASC just need to understand what works well for the carer and what help is needed. However, ASC has to ask statutory questions, for example, if there are children in the home and what a carer can and cannot do.

The £150 one-off payment and sitting service are not financially assessed (they are not means tested). The one-off payment is provided via a pre-paid card. It is at least ten years since Portsmouth's one-off payment was reviewed and it has not kept up with inflation. Some carers just want some of the payment, not all of it.

The cost of the sitting service is not capped. Six hours is how ASC work out what is reasonable in terms of replacement care. Most clients have a package of care as well to meet their needs. The six hours is often part of a patchwork of other support. Many people who self-fund their care can still access the six hours' sitting service support. The idea is that it is preventative to avoid carers being unable to cope.

The two respite beds are charged at the local authority rate in line with the financial assessment used for the provision of a package of care and other ASC services. It is still cheaper than if paying as a private client so there is a charge but not the full charge. The financial assessment takes into account someone's capital and income but a certain amount of income can be disregarded so it very much depends on individual circumstances. Some may pay directly but not many in Portsmouth do as there is a high level of deprivation. Carer's Allowance is a continual issue and there have been public campaigns about it.

## **MEETINGS WITH CARERS**

### **Carers Count**

#### ***"I'm wife, mother, worker - when am I ever me?"***

Carers Count was held at the John Pounds Centre on 24 November 2022, which was Carers Rights Day. The one-day event, organised by the Portsmouth Carers Service, brought together carers, health and social care professionals and voluntary sector organisations to present the Portsmouth Plan for Carers. The launch of the Plan reflected how the council wants to support carers. Values are based on respect and the care given, recognition of carers' individuality and how challenging caring is.

There were guest speakers, discussion groups and information on support services in Portsmouth. One of the round table discussions was "Breaks - What does a good break look like to you?" Feedback from carers covered length of breaks and what makes a break meaningful.

#### **Length of breaks**

Comments showed that what carers want varies, demonstrating the importance of recognising carers' individuality and not taking a "one size fits all" approach. Some carers wanted five minutes for a cup of tea before the person they care for gets up whereas others wanted a week, or at least four days. Carers may just want to go out for dinner with a partner and not necessarily have an overnight break. Others said an overnight break was welcome. A break needs to be long enough to be worthwhile, for example, a carer was grateful the cared for went to a club but it was from 10.30 am to 3.30 pm which was not long enough for a day out so the carer ended up doing housework; another couple of hours would have made all the difference

#### **What does a break mean so it is meaningful to a carer?**

Breaks need to be individually tailored to carers by working with individual and what works for them. Breaks give carers time to process and think about their own wellbeing

Many comments showed that to be meaningful breaks should not create extra work or worry for carers, or at least remove it. For instance, a break means getting out of

the house and having a purpose other than tasks and the to-do list. Carers need practical support so when they return from a break their to-do list has not piled up, meaning that the break is not a break. It means being "off call" so the break is taken away from the caring environment and the carer is not called back. It means the carer can just go on the break and not do all the planning. The quality of the experience for the cared for person is paramount as carers feel guilty and do not enjoy a break if the cared for is not having a good time. They need to trust that the cared for person is being cared for.

Other carers noted that planned breaks are already in place but more spontaneity is needed knowing that the cared for can be looked after. Some wanted twin breaks for the carer and cared for. Others wanted normal sleeping arrangements so carer and cared for can be husband and wife. Breaks need to be taken before the situation reaches crisis point; early intervention is key. Some said the Carers' Centre was invaluable.

One suggestion was a Shared Lives or short-term fostering type arrangement for overnight respite where the cared for person would stay in someone's home. If the same person provided respite it would build a relationship but adults cannot be made to go if they have capacity. In addition, there are a lot of small houses in Portsmouth so potential hosts may not have a spare room.

Feedback from the other round table discussions on "Support - What does good support look like to you?" and "Being heard - How do you like to be listened to and included?" was relevant to breaks. For example, support needs to be reliable, accessible, consistent, good quality, affordable, trusted and not just the cheapest option available. Reflecting comments made at the meeting on 23 September, some carers said they sometimes felt overlooked by professionals but they are the "experts by experience" as they know the most about the cared for person

### **Solent Mind**

***"We laugh and cry together."***

On 5 January 2023 Democratic Services attended one of the regular meetings of a group run by Solent Mind in Cosham for carers for people with dementia.

Although the theme of the review is breaks it transpired that very few of the carers have had a break or a holiday. None seemed to have heard of the two respite beds in a local care home. As to the desired length of respite, one carer said one night of respite was no good. The biggest pull is "love and devotion" as carers do not want to upset the cared for person. One carer had stopped going out as it was easier to stay at home but that meant the carer was isolated and very lonely. Several said that as carers they would worry about the cared for person, which meant they would not enjoy the break. Some people with dementia are aware enough to realise they are away from home so respite in another location may be inappropriate. The type of respite that would be suitable depends on the nature of the dementia. Not all care homes or organisations will take people with dementia as some need specialist care.

The Intensive Engagement Co-ordinator suggested that someone staying in the carer's home for a couple of days four or five times per year to give them company,

help around house and take the cared for person out would be very beneficial for carers and also prevent situations reaching crisis point.

Many carers commented on the group's value, both for obtaining and exchanging information, and for its moral support. It is useful for making links and obtaining information on matters such as Attendance Allowance and disability allowances, as it can be difficult getting this information. The group is a means of accessing services and Solent Mind are sometimes involved when the situation reaches crisis point.

The group is "life support" as caring is 24/7. The group understands what each other is talking about and it is wonderful to support each other. They laugh and cry together.

### Emergency planning

Carers' biggest concern was emergency planning - the "what if?" question in what would happen to the person they care for if something happened to them and they could not look after the person. Many mentioned the difficulty of getting help outside of office hours, for example, when a relative had a fall on a Bank Holiday. Carers need specialist support if something happens to them, especially at night or out of office hours. It was noted that Hampshire County Council have a 24/48-hour emergency care service. Hampshire commission the Princess Royal Trust for Carers ([https://carercentre.com/emergency\\_planning.html](https://carercentre.com/emergency_planning.html)) who can provide up to 48 hours of care in an emergency.

When one carer was ill the group's Intensive Engagement Co-ordinator had sorted out many things, for example, she got the GP to call rather than the carer having to try to get through at 8 am. The carer now had good support from a social prescriber; the group can arrange social prescribers for people. (Social prescribing is a way of linking people via a referral from a GP practice with non-medical sources of support in the community.)

Some carers said what they need is a contact number in case of an emergency so once they call the number someone would know how to take over and perhaps send someone to the house. In one instance the ambulance crew stayed with someone who had no family until the police took them to a place of safety. The ambulance crew had seen the Lions pot in the fridge and recognised the person was a dementia patient. (A Lions pot is a 'Message In A Bottle' scheme where personal and / or medical details that may be needed in case of emergency are in a small pot that is kept in the fridge.) A sticker by the front door alerts any emergency services that enter the property to check the fridge for the pot.

Emergency planning was discussed at the Carers Count event. There are sources of information that can help with emergency planning such as the Jointly app (co-ordinates care by sharing information about cared for like appointments, tasks, save files and notes), This Is Me (for people with dementia), ICE (In Case of Emergency) bottle, Carer's Card, Hospital Passport (for people with learning disabilities).

Matters to be considered include a proper assessment and plan, who needs to be contacted, what happens if family live abroad and / or there are language issues, and carers' own disabilities. There is also the question of consent as the cared for

person cannot be made to go to a care home for respite if they do not want to go and have capacity.

### Finances and cost

The cost of care and how it was paid for was a matter of concern and uncertainty. Some carers did not know the cost or if it was means tested and, if so, what means testing involved. There was uncertainty around the cost of Telecare (Safe at Home), which provides services like pendant alarms and responders.

The cost of breaks might be an issue. There are specialist organisations which provide breaks for people with dementia but they are expensive, for example, a five-day holiday with full board on the Isle of Wight is approximately £1,300 per person. The restrictive cost of such breaks was mentioned at the Carers Count event. As with care homes, there is the question of who pays. Likewise, when discussing emergency planning there was a suggestion of having someone sit with the cared for person but the question of who would pay for this service was raised.

## **Brunel Carers' Group**

### ***"Ready for the onslaught again"***

On 20 February 2023 panel members and Democratic Services attended one of the regular meetings of the Brunel Carers' Group for carers for people with dementia.

Vicky Newman, the group leader, introduced the meeting by outlining the main issues carers face: The joint group leader, Liz, was also present.

- Respite used to be offered as regular breaks but now only seems to be offered in emergencies.
- Council owned facilities that offered respite have closed.
- The Council's procedures on respite, including availability of beds before Covid, are not always clear or well-known.
- If the cared for are deemed to have sufficient mental capacity they can refuse to go into respite despite carers being on their knees.
- Many cared for prefer to have respite at home but this may not be the best option for the carer who may be desperate for a break.
- Sometimes carers struggle to get respite for their own health needs, even leading to them refusing surgery, which impacts their longer-term physical and mental health.
- It is frustrating that respite cannot be organised well in advance of when it is needed as carers cannot plan in advance or confirm health appointments or operations.

Many carers spoke about the difficulties and stresses of arranging respite. One carer had to keep ringing round care homes to see if they could offer respite; a place became available when someone had died. He had to organise everything himself although the social worker phoned round a few places which was helpful. His wife has the sitting service on Mondays and Fridays so he has 5.5 hours off per week. His morning off is the group. As his wife needs care 24/7 if he goes out at any other time he either has to take his wife with him or risk leaving her alone. Other carers said attending the group was their respite.

With regard to how long carers would like for respite, responses ranged from a week off every few months to at least a fortnight with the spouse in a care home so as to be "ready for the onslaught again." Another was getting to the point where they would like a four-day break with one of their children or on their own. For others it was getting away or someone looking after their spouse. One carer needed respite for her husband after he was discharged from hospital to see how he was before returning home. A sitter is good for a day but the carer is looking at their watch. Some carers asked what would happen if anything happened to them. Care homes have to be able to cope with people with dementia. Some homes prefer to take people for weeks rather than one or two days. A buddy scheme was mentioned but the buddy needs to know what they are doing.

For most carers the first step in getting respite was to call the Carers' Centre though Centre cannot give a timeline. Many carers said they had to be in crisis to get help. One only got help when they themselves went into hospital. Some said the Carers' Centre was very good but after Covid their remit now is signposting.

As to whether respite was better at home or somewhere else, one cared for person needed care 24/7 so care at home would have needed shifts. Another said it depends on the stage of dementia. Another was more than happy to care for her husband but at a cost to her health. Carers are not all fit and able but they are still caring. They never mentally switch off and are never off duty. There is always anxiety and carers still feel guilty when the cared for person has died; they have survivor's guilt. People do not understand the plight of carers until they have been one. The needs of carers and the cared for need to be balanced as otherwise carers could not enjoy respite because of anxiety.

### Capacity and consent

Capacity and consent were mentioned several times. It was felt recent legislation had not helped the plight of carers and that the person with dementia had greater rights than the carer. [The Care Act 2014 is the main piece of [legislation](#) for the guidance around carers but the Health & Care Act 2022 contains a provision that carers should be consulted as early as possible by the hospital where a cared for person was to be discharged.] If the cared for are deemed to have capacity they are asked to confirm if they wish to go into respite and they are entitled to refuse. Carers' voices are dismissed and they are treated with suspicion. As the "meet and greet" function is the last to go the cared for present better than they are which complicates assessing capacity. They often say they can manage but the reality is very different, for example, saying they go shopping twice a week but have not done so for three years. Carers are often interviewed with the cared for present and it is difficult to contradict them. Interpreting what people say is important, for example, "home" for people with dementia is the most recent place they have lived in, which is what they mean when they say they want to go home, not their original home. People with dementia often pick up infections, often urinary tract infections which affect capacity, and carers cannot go in the toilet to test their urine if they are still able to use the toilet on their own as it is a breach of privacy.

The nature of dementia makes caring challenging. There are different types of dementia and then it depends on the stage it has reached. No two cases are the same. It affects the body clock so people get up at 4 am and roam around the house as they have no idea of the time or day; the carer tries to get them back to bed and then falls asleep exhausted on the settee during the day. People with dementia can

be violent, for example, spitting and hitting, leaving carers afraid they could be hit with a weapon when they are asleep. Carers have been arrested and falsely accused of abuse, particularly when a male looks after a female, when the cared for person has bruises but elderly people bruise easily, especially those with dementia.

### Communication

Not being able to book respite makes it very difficult for carers to cope with their own health needs as well as those of the cared for. This was linked to problems with communicating with health organisations and the way they operate. Not being able to book appointments in advance causes problems as carers cannot get someone in to look after the cared for person at short notice. Several mentioned problems trying to contact GPs. The group leader knew of a carer who was attacked by her husband as he thought she was having an affair as she was on the phone for so long trying to get an appointment. One carer could see a GP but that was because they lived in the same care home as their spouse. Medical records should have notes prioritising carers. One carer's housebound spouse was not on the system as housebound and was told they needed to go to the surgery for an assessment. The group leader said the Carers' Centre can provide cover for appointments above the six hours' sitting service. [The Carers' Centre has 'replacement care' which provides additional sitting service so that carers can attend their own medical appointments without having to take the cared for with or losing some of their existing sitting service provision.] However, one carer said she could not get help from the sitting service as she did not live with her mother. [When the carer does not live with the cared for the sitting service is assessed on a case-by-case basis. If the carer does not live with the cared for, they may be getting sufficient breaks or the cared for may be able to be left for longer periods of time which could deem them ineligible; however, this is not a definitive rule and Adult Social Care will still commission services when the criteria is met.]

Many carers said there are problems with communication and the left hand not knowing what the right hand is doing and asked if people communicated with each other. Lack of or poor communication between community and hospital social workers was mentioned. One carer had no notice of discharge and could not plan to book District Nurses to give medication; she had to be there as her mother would not let people in. It was difficult getting through to organisations when staff do not give surnames. Having different duty managers causes problems. However, the Portsmouth Rehabilitation & Reablement Team was very good.

Some carers mentioned problems with diagnosis. One said caring creeps up slowly as people do not realise they are becoming a carer and then they see something is really wrong. They have no idea what they need or what is available. One carer got a diagnosis for her mother when she had to see a GP for her own mental health. Some carers said they were "just left" after the cared for was diagnosed with dementia and had had no help since. One said it took 2 to 2.5 years to get a diagnosis. It is so tiring. One carer said it was much better when the Older Persons Mental Health Team wrote letters confirming diagnosis; now GPs do it and charge for writing the letter.

### Finances

Uncertainty around finance was mentioned, either being unable to get clear guidance or getting contradictory guidance, about how much people would have to pay. It was very confusing for carers who had never been involved with social care

before. Changing regulations can be confusing. One carer had had care organised by hospital social workers and paid for under special Covid funding but this time the carer has paid for everything. Some carers said they were not asked about respite when packages of care were arranged.

Getting Carer's Allowance and Attendance Allowance can be difficult. Carers need clear answers as to what can be done. They need a phone number they can use where there is someone who knows what they are talking about. They are aware of financial restrictions. Carers who work have additional problems; they sacrifice their careers.

There was some cynicism about the review. The group leader had raised these questions 20 years ago and asked what had been acted on. One said what the review is trying to do is laudable but was unlikely to be achieved because of finances. However, it could get the message across that if carers are not supported then the consequences will need to be resolved. The cost saved to the council by informal carers is huge; all carers want is a little back.

The councillors explained the scrutiny panel can make recommendations to the council's Cabinet. The Scrutiny Management Panel oversees the work of the individual themed panels, including seeing if recommendations from reviews have been implemented. Recommendations could also go to the Health & Wellbeing Board or the council's Directors. The pressures on budgets are huge but people working in healthcare can be innovative; there is also lobbying.

## **Conclusions**

Based on the evidence and views it received during the review process the panel has come to the following conclusions:

1. Noted the difficulties in recruitment and retention locally and nationally for social care.
2. Noted the invaluable contribution made by informal carers and their dedication.
3. Noted that a break has to be meaningful and not create extra stress for carers; carers' individual circumstances need to be taken into account, including contingencies for emergencies.
4. Noted that not being able to book respite in advance is a considerable cause of stress for carers.
5. Noted that carers may need financial help to pay for a break and that information on finances needs to be clear and accessible.
6. Noted the invaluable role played by the Carers' Centre, Solent Mind and Brunel groups in providing moral support and information for informal carers.
7. Noted the additional challenges of dementia: there are different types of dementia; the stage it has reached; the difficulties in assessing capacity and consent; changes to routine and surroundings can be disorientating and distressing for sufferers.



8. Noted that the challenges of dementia mean that it needs staff able to cope with them and that very few residential facilities accept people with it.
9. Noted that with adults their wishes have to be taken into account so capacity and consent have to be considered, which can be particularly difficult for people with dementia, but also that carers' wishes have to be taken into account.

### **Recommendations**

The panel made the following recommendations:

1. To request the Leader and the Chief Executive to thank Andy Biddle, Clare Rachwal, Ben Muller, the Carers' Centre, Solent Mind, the Brunel group and all other Adult Social Care officers involved in the review.
2. To acknowledge the care carried out by informal carers and the contribution they make.
3. For the council to support informal carers by identifying them, acknowledging them and offering practical support. For example, a support group for staff who are carers and flexible working to help them with their caring commitments.
4. For the council to acknowledge carers as individuals and "experts by experience" and treat them as equal partners in all its policies and strategies.
5. For all the council's strategies and policies to acknowledge the importance and requirements of informal carers and show how it will support them. For example, the Integrated Impact Assessment should take informal caring into account and consider being a carer a protected characteristic.
6. For the council to work with other large organisations to support informal carers in the city, perhaps through the Health & Wellbeing Board as it represents major employers. For example, to encourage partner organisations to treat carers as "experts by experience" and offer practical support, whether the carers are employees, customers or service users.
7. For the council to work with health organisations, perhaps through the Hampshire & Isle of Wight Integrated Care Board and the Health Overview & Scrutiny Panel, to support informal carers by making their policies and processes more accommodating to carers.
8. For Adult Social Care to investigate different types of respite, such as Shared Lives or fostering type arrangement or someone spending a couple of days in someone's home, as traditional types are not always suitable for people with dementia.
9. For Adult Social Care to enable advance booking of respite in council provision and to encourage other providers to enable it.

### **Integrated Impact Assessment**

An integrated impact assessment would be carried out when the Cabinet makes its decisions based on the recommendations set out in this report.



## Budget and policy implications of the recommendations

The following table highlights the budgetary and policy implications of the recommendations being presented by the panel:

	<b>Recommendation</b>	<b>Action By</b>	<b>Budget &amp; Policy Framework</b>	<b>Resource Implications</b>
1	To request the Leader and the Chief Executive to thank Andy Biddle, Clare Rachwal, Ben Muller, the Carers' Centre, Solent Mind, Brunel group and all other Adult Social Care officers involved in the review.	Councillor Kirsty Mellor	Within existing framework	None
2	To acknowledge the care carried out by informal carers and the contribution they make.	Director of Adult Care	Within existing framework	None
3	For the council to support informal carers by identifying them, acknowledging them and offering practical support. For example, a support group for staff who are carers and flexible working to help them with their caring commitments.	Director of Adult Care	Not currently within budgeted activity.	Staff capacity to facilitate the group, with the intention of it becoming self-sustaining.
4	For the council to acknowledge carers as individuals and "experts by experience" and treat them as equal partners in all its policies and strategies.	Director of Adult Care	Within existing framework	Share recommendations across Directors in the Council for cascade.
5	For all the council's strategies and policies to acknowledge the importance and requirements of informal carers and show how it will support them. For example, the Integrated Impact Assessment should take informal caring into account and consider being a carer a protected characteristic.	Director of Adult Care	This recommendation could be covered through the IIA process (currently being reviewed).	None
6	For the council to work with other large organisations to support informal carers in the city, perhaps through the Health & Wellbeing Board (HWB) as it represents major employers. For example, to encourage partner organisations to treat carers as "experts by experience"	Director of Adult Care	Within existing framework	Share recommendations of the report through HWB and use informal carers and how we support as

	<b>Recommendation</b>	<b>Action By</b>	<b>Budget &amp; Policy Framework</b>	<b>Resource Implications</b>
	and offer practical support, whether the carers are employees, customers or service users.			a subject for a HWB development session.
7	For the council to work with health organisations, perhaps through the Hampshire & Isle of Wight Integrated Care Board (ICB) and the Health Overview & Scrutiny Panel (HOSP), to support informal carers by making their policies and processes more accommodating to carers.	Director of Adult Care	Within existing framework	Recommendation that HWB write to the ICB with recommendations of the report. ASC to incorporate the recommendations into the next HOSP update.
8	For Adult Social Care to investigate different types of respite, such as Shared Lives or fostering type arrangement or someone spending a couple of days in someone's home, as traditional types are not always suitable for people with dementia.	Director of Adult Care	Project	Resource to plan and manage expansion of short stay capacity in the city. Can be incorporated into the current ASC short stay review process; likely to have a budget implication.
9	For Adult Social Care to enable advance booking of respite in council provision and to encourage other providers to enable it.	Director of Adult Care	Within existing framework	As of February 2023, respite is bookable through a limited resource in Council provision. This is in a pilot phase currently and may need to increase. This will have a budget implication.



## **Further information**

### **Portsmouth Carers' Centre**

117 Orchard Rd, Southsea, Portsmouth, Southsea PO4 0AD

Tel: 023 9285 1864

Home - Portsmouth Carers Service

[portsmouthcarersservice.co.uk](http://portsmouthcarersservice.co.uk)

### **Carers UK**

National organisation, started in 1960s, which seeks to make life better for carers by raising their voices together to call for change and seek recognition and support.

Carers UK has campaigned on the right to carer's leave for a long time.

[www.carersuk.org](http://www.carersuk.org)

### **Carer's Leave Bill**

The Carer's Leave Bill aims to make provision about unpaid leave for employees with caring responsibilities and to help support unpaid carers to remain in work alongside their unpaid caring responsibilities. At the time of writing it is at the report stage in the House of Commons with the third reading on 3 February 2023.

[Carer's Leave Bill - Parliamentary Bills - UK Parliament](#)

### **Carers Rights Day**

Carers Rights Day in late November is a national campaign that aims to raise awareness for the rights of unpaid carers in the UK, to highlight the challenges they face and help them get the support they need.

### **NHS Confederation**

Membership organisation that brings together, supports and speaks for the whole healthcare system in England, Wales and Northern Ireland.

[www.nhsconfed.org](http://www.nhsconfed.org)

### **Skills for Care**

Strategic workforce development and planning body for adult social care in England

[www.skillsforcare.org.uk](http://www.skillsforcare.org.uk)