

## Scottish Covid-19 Inquiry Witness Statement

Statement of **HENDERY/Ruth** – HSC0063 noted on 19 December 2023

### Introduction

1. My name is Ruth Hendery, I am 67 years old, and my date of birth is **Personal Data** My details are known to the Inquiry.
2. Before retiring, I worked in Edinburgh as a teacher and head teacher, with children with special needs. In 2018 I trained with Citizens' Advice and have worked with Edinburgh Direct Aid on projects to support children with complex needs in Bosnia and refugee children with special needs in Lebanon.
3. Both directly and through others, I was aware of Voices of Carers Across Lothian (VOCAL) and their work with unpaid carers. I used their services on a personal level to seek advice on guardianship and to find accommodation for a short break. I joined the VOCAL board in 2020, and now contribute to a number of committees. To this role I bring my personal experience of being an unpaid carer over a number of years.
4. My youngest son has complex needs including autism, learning disabilities and epilepsy. He now lives in a residential establishment and had a relatively good Covid experience. Since Covid we have resumed breaks and holidays together, with the wider family.
5. In recent years I have supported my elderly parents in their own home, until their deaths at 92 and 98 years old. My mother died during Covid and my father shortly afterwards. Latterly they also had paid carers, and my father died in hospital after a short illness.

**The Organisation to be spoken of: Voices of Carers Across Lothian (VOCAL). I would also like to talk about my own personal experiences during Covid.**

### Personal Experiences of the Covid Pandemic.

6. On 19 December 2023 I met with witness statement takers from the Scottish COVID-19 Inquiry team, and I am happy to provide a statement about my experiences of the pandemic.
7. I have signed the consent form provided. I am happy for my information to be contained within reports and published. I would

provide evidence at any hearing if required and have no dates to avoid, at this time, for February or March 2024. However, outside of these dates, I would appreciate as much notice as possible.

8. Throughout my statement I refer to the VOCAL Carer Survey carried out in 2021, and a similar survey carried out in 2023 on behalf of the Edinburgh and Midlothian Health and Social Care Partnership. The 2021 survey results have been published online. The 2023 survey results will be published online in January 2024. Both of these documents can be supplied to the Inquiry.
9. During the Covid pandemic my frail elderly parents found the whole lockdown experience very confusing and isolating. They were in their nineties and in receipt of four visits a day of social care services, largely funded by the local authority. My mother became fearful and unprepared to leave the house, as well as confused about why people were wearing masks. With family, she hated not being able to see our faces or to hug us. My father, who'd previously been able to get out and take buses e.g., to the library, was anxious and never recovered his confidence to travel independently.
10. Both my parents missed sharing significant birthdays with their family and were simply distressed when we stood out in the garden. It was painful for all of us to see their lives shrinking. My mother gave up and repeatedly asked us to help her to die. This was particularly tough on my dad.
11. Although medication continued to be delivered, my parents were confused that, initially, they could not see a doctor. They were neither good on the phone and had no IT skills. They could not always remember what they wanted to ask. Although my dad outlasted the periods of restrictions, he never recovered emotionally after my mum died. At least we had her at home and sidestepped contact restrictions to get my dad through. My dad never made it to the care home, dying in hospital, so I did not have personal experience of the visiting restrictions in care homes. Single rooms in hospital made it possible to visit him there daily for an hour booked in advance. If we helped with lunch, this could be a little longer.
12. My thirty-year-old autistic son lives in a Camphill community and lockdown was initially very confusing for him. He has severe learning difficulties and is largely non-verbal. He really did not understand what was going on. He hated change and the staff were already struggling with reduced staffing levels so the upsets to routines played havoc in what we'd seen as a tranquil rural environment that well met our son's needs.

13. The Community made a good adjustment by having each house locked down as a bubble, and they were able to negotiate with the Care Inspectorate that each house could stick to one workshop, so eventually some key routines were re-established. As time passed, we negotiated to meet at the estate boundary and, as weather allowed, walk in the hills - socially distanced of course. The worst time was when I got Covid and my son, whom I'd seen days earlier, was put into isolation. This was pure torment for everyone involved, only relieved by his love of his iPad and access to the Disney channel. It also helped that testing was frequent there, and results came back quickly. The Camphill community were good as things eased in offering all visitors tests and safe places outdoors to meet. It was very hard on those who simply could not understand why they couldn't have trips home and other breaks.

### **Voices of Carers Across Lothian (VOCAL).**

14. I was nominated and became a board member of VOCAL in February 2020, and I now contribute to a number of VOCAL committees.

#### **Pre-Covid.**

15. VOCAL is the Voice of Carers Across Lothian, an organisation run by carers for carers since 1994, it is true to its roots. Funding was (and still is) predominantly through statutory contracts commissioned by Edinburgh and Midlothian Health and Social Care Partnerships. Additional grant funding through the National Lottery and Scottish Government (via Shared Care Scotland and Inspiring Scotland) and fundraising contributed to about a quarter of funding.
16. We are very proficient at picking up funding from funding rounds. Public funding has shrunk, and many previously local authority services are now delivered by third sector organisations like VOCAL. We are both brokers for services provided by other organisations, as well as providing some direct services, such as guidance, counselling, and providing short breaks. Short breaks are vital to unpaid carers as they provide respite which is increasingly needed as being a carer can be extremely demanding.
17. VOCAL's carer support teams work with unpaid carers to help identify the issues affecting them and achieve the best possible outcome for carers. VOCAL delivers support primarily through two carer centres in Edinburgh and Midlothian, and through staff based in the community.
18. Individual carer support is mainly delivered through telephone and face to face appointments. VOCAL's counselling, group-work and training programmes were all delivered in-person. A Board of

Directors (Trustees) oversees the governance of the organisation, supported by a range of sub-committees with delegated powers and a senior management team consisting of Chief Executive, Deputy Chief Executive, and operation managers. Funding is primarily through statutory contracts (approximately three quarters of income).

19. VOCAL works individually with carers to identify a plan of support which can include work with other agencies; referral to benefits, legal or power of attorney surgeries; and access to a range of training and lifestyle management opportunities. We have five to seven different tasks which we undertake; signposting, guidance, advice, and counselling are the primary services that we offer.
20. VOCAL is highly effective at networking, particularly through GP medical practices. This is particularly fruitful as most people do not initially recognise that they are unpaid carers, being primarily concerned with the person for whom they care. VOCAL works to raise the profile of unpaid carers so that we can offer timely support and alleviate concerns for people who may not previously have navigated the health and social care landscape.
21. Before Covid we had lots of carer support staff available in public spaces such as local libraries, and our own offices. We were pushing to have our representatives inside other organisations with lots of face-to-face contact, to make our services widely accessible.

### **Impact.**

22. Many carers felt the burden that fell on their shoulders was an assault on their human rights i.e. to have a life of their own besides their caring roles. See evidence from the VOCAL survey and the current fear that resources intended to support unpaid carers may now be used to contribute to filling the budget deficit in coming years.
23. Neither is it appropriate that the needs of carers and the cared for should be conflated so that, for instance, any services for cared for people are seen automatically as respite for the carer, rather than the carer's needs being addressed separately.
24. The reason this is controversial is that the legislation around support for unpaid carers, chiefly The Carers Act of 2016, states that carers are entitled, in their own right, to support. There are statutory duties sitting around this legislation, including the right to have an adult carer support plan. Provision of support to carers is based on rights as well as legislation. The carer is a provider of a service and, as well

as the user of a service, has rights, much as a paid employee would have.

25. During Covid, self-directed funds should have given some families flexibility to recruit people to provide care as statutory services closed, but there was resistance to this in some instances. For instance, there should have been enough flexibility to allow family members to be paid to cover, when clearly there was a national staff shortage, making wider recruitment impossible. Unspent funds were and are simply taken back. Carers do not feel they are treated as equal partners, providing vital services. We have the legislation, policies, and strategies but not the delivery of support for carers. This is unsustainable going forward, even without any further pandemics.

### **Impact on VOCAL during the pandemic**

26. Although traditional fundraising (events, trusts, donations etc.) was significantly impacted, funding was provided by Scottish Government specifically for third sector and carer centres to build capacity and respond to the immediate demands of the pandemic.
27. Service delivery changed overnight. VOCAL was fortunate to have invested and prepared for more digital and agile delivery methods (e.g., telephones were cloud-based, staff used laptops), this enabled VOCAL to quickly move to home-working and digital delivery with little disruption to support for carers. Demand for carer support increased substantially, in part because carers were unable to access support through usual health and social care contacts, but also because the pandemic raised a number of immediate practical and emotional concerns for them (shielding, managing care at home services, PPE, employment, travel to care for someone, access to carer ID, vaccines).
28. Our records show that the total number of carer enquiries during Covid increased by 19% from 9958 (1/4/2019 - 31/3/2020) to 11816 (1/4/2020 - 31/03/2021). Carers had many Covid specific enquiries on a number of themes which we recorded, vaccinations and wellbeing being the most common, at 1373 and 627 respectively.
29. The types of enquiries changed significantly, and the types of support required by carers also changed significantly. It was much more about crisis support, crisis management. Documentation detailing information about the number and nature of enquiries during this time can be provided to the Inquiry.

30. The pandemic not only increased the intensity of caring roles for many, as local authority services closed, but it also led to a number of people taking on caring roles for the first time. In addition to an increased demand for carer support, the type of support and information required was very different – many carers presented in crisis, with a range of emotional and practical issues. For example, they were very keen to know about vaccinations, felt increased anxiety, stress, isolation, fear, loneliness, heightened emotional state, tiredness, and an increased physical load for carers.
31. On a practical level, carers wanted to know about carer ID letters, and how to gain access to their relatives. Carers had no way of proving they were carers so in terms of travelling to see the person they cared for, there were a number of local initiatives in partnership with Health and Social Care Partnerships where carers were provided with letters with the relevant logo on it. This increased the number of carers on our books as it led to many new carers coming forward, realising there was a value to doing this. In the early stages this was really important to carers as there was huge concern about going out and getting stopped. When the vaccinations came out, it could also be used to prove you were a carer to gain access to the portal.
32. The re-deployment of health and social care staff had an immediate impact on the number of carer referrals to VOCAL. New carer referrals and self-referrals dipped substantially in the early stages of the pandemic. In their absence, referrals from statutory services dropped from 40-50 per month to zero.
33. In the first six months there was a gap for people becoming new carers who would normally benefit from these referrals to access services. They did not have a direct link in to that support. As a result, VOCAL relied heavily on our external communications channels (social media, website, and email) to provide relevant and timely information and to ensure carers knew how to access support.
34. Eventually our service users increased in number, having found out about us largely through word of mouth, informal channels and through third sector contacts. As our reaction to Covid gathered pace, we were identifying information from government and passing it directly on. Our carer support practitioners were giving out large amounts of information to our users in response to the surge in enquiries associated with Covid.
35. Referral numbers increased during the summer of 2020 but remained below 2019 levels (approx.100-150 per month). From January to March 2021 there was a significant increase in the number of new carers (1,046 total, a 50% increase on previous years), which can in

part be attributed to publicity around the vaccination and access to it.

36. Since April 2021 new carer figures remained consistently at between 150-165 per month until March 2022, where we have seen a steady and sustained increase in new carer numbers (approx. 250-300 per month). There are likely to be a number of factors contributing to this but the wider recognition and awareness of carers through local and national media following the pandemic has had an impact. In addition, carers were incentivised to self-identify through the promotion of the vaccination programme, and latterly through the Short Breaks Fund which was increased and made available to carers nationally.
37. VOCAL offered an up-to-date e-bulletin linked to our website from about April 2020, indicating the speed with which we reacted to the ever-changing pandemic information which was being put out by Government. I do not know how many people subscribed to our website, but I do know that our paid and volunteer staff did their best to keep on top of all guidance on the Covid rules, to give accurate advice to carers.
38. VOCAL did not lose staff specifically as a result of the pandemic, and experienced similar staff turnover to previous years. However, the pandemic and lockdown had an immediate impact on our volunteers, who worked predominately from our two Carer Hubs in Edinburgh and Midlothian.
39. At the start of the pandemic VOCAL had over 50 volunteers, largely providing administrative support. Most were unable to sustain this during the pandemic, not least as their caring responsibilities multiplied as day and respite services closed. In other cases, their role was no longer required as support delivery shifted to staff working from home, and away from the carer hubs. A small number of volunteers continued to provide counselling and administrative support, but the number was significantly reduced.
40. Our volunteers provided a lot of in person services for example covering reception and training facilitation none of which was required during pandemic restrictions, so the impact was not as sharp as it could have been. Over the last year, as we return to more in-person and centre based activity, the volunteer numbers have steadily increased again, and we have had a focused and successful recruitment campaign over the last six months.
41. VOCAL has returned to more hybrid and in-person support, the need for volunteer support has increased again, to supplement our

workforce. Now carers can be supported through 1-2-1 delivery, if this is their choice, but also telephone or on-line support. The latter services proved surprisingly successful as, for many carers, cover was difficult to arrange, and time was precious so a call or zoom meeting was practically easier.

42. In July 2021 VOCAL applied to a trust fund for a volunteer coordinator to support the rebuilding of our volunteer infrastructure, retraining of staff line-managing volunteers, and a targeted recruitment campaign.
43. Besides losing volunteers due to lockdown restrictions and the need to support friends and family members impacted by service closures, there were a number who were elderly and/or had underlying health conditions and required to shield. As a result, sustaining their volunteering role during Covid would have been difficult if not impossible.
44. VOCAL successfully advocated for and administered one-off local funding in the form of micro grants to carers (the Carers Assistance Fund) which has not only benefited carers adversely affected by the pandemic and cost of living crisis but also encouraged VOCAL in additional partnership working. VOCAL worked with a wide range of third sector partners to reach a wider number of carers in greatest need beyond those directly engaged with our services.
45. The partnerships which were established to distribute Carer Assistance Funds and ensure they reached those in greatest need included local food projects and food banks, local community centres and groups working specifically with carers from ethnic minorities.
46. The big area of work was finding and funding short breaks for carers, and it was a step change because of Covid restrictions and the closure of respite care. Carers found themselves unable to get the breaks that had previously sustained them.
47. The Coalition of Carers in Scotland (CoCiS) was established 25 years ago in 1998. Our then CEO, Seb Fischer was instrumental in setting it up. VOCAL has been a member of the Executive Committee since inception, and has had a management role (finance, HR) for the Coalition for the last 10 years.
48. VOCAL worked closely with the CoCiS during the pandemic, who acted as a central hub for Scottish Government information, interpretation of guidance for carers and what that meant. We relied heavily on their e-bulletins for information provision.

49. In terms of carer ID letters, most of these had to be negotiated at a local level, organisations had to approach their local Health and Social Care Partnerships. It would have been very difficult to implement at a national level. VOCAL led proposals to develop carer ID letters for Edinburgh and Midlothian local authority areas to ensure carers could travel to provide care, and access similar benefits to NHS/paid carers (e.g., being given safe shopping times and later to be prioritised for vaccinations). CoCiS did highlight this as an area of best practice and could use their networks to encourage other partnerships to use this approach.
50. As previously mentioned, many of our carers found that counselling and contact online was a relief as they did not have to physically juggle caring and outside appointments; they could meet in the comfort of their own home without finding alternative care arrangements for those they cared for. Counselling support became highly effective, and we still have some digital services. We are now predominantly back to face-to-face delivery but not entirely.
51. My role as a carer representative on the Edinburgh Integrated Joint Board, has evolved over the last three years, and I recognised the value of timely briefings from the CEO, and online CoCiS meetings to be properly prepared. I feel I have been more in touch with the needs of carers, and better understand the issues directly impacting unpaid carers. A good example of this is the evidence of the most recent VOCAL, partnership sponsored, Carer Survey from 2023.
52. VOCAL contact with employers has developed in recent years. We are contracted by Health and Social Care Partnerships to work with employers. Since 2016 we have had a contract with the Edinburgh partnership to work and engage directly with Edinburgh based employers and that contract continues to date. We work with well over 150 Edinburgh based employers and for some of the biggest employers we facilitate a network meeting every quarter with their HR advisers. VOCAL provides training support to employers to encourage them to provide support to carer employees, such as encouraging flexible working arrangements. This has proved to be a very productive way of working.
53. We did a lot of work with them during the pandemic as they had quite a number of staff who were carers, many working from home, and they needed to consider how they could support them not only to carry out their day-to-day work but also to return to work. These meetings continued, digitally based, throughout the pandemic. Work was also conducted to develop awareness raising for employees who were carers at home.

54. From the beginning of lockdown, NHS and local councils were forced to close building-based services, such as day services, and many staff were redeployed to other services directly related to the response to Covid. This had a massive impact on unpaid carers. Some could not go to work as they had to take on all caring responsibilities for their relatives. The physical, emotional, and financial distress was huge, as we see from the results of the survey.
55. Many pre-pandemic services have not returned to similar levels, such as day and respite services, not least because funding has been reduced. Organisations such as VOCAL have grown, with partnership funding in some cases, and have been tasked with enhancing existing services. Pre-pandemic VOCAL distributed micro grants to allow carers to plan short breaks and, due to the Carers Act 2016, not Covid, the funding for these grants has increased year on year. But what we have seen since Covid is that day and respite services are just not there.
56. While we celebrate Scottish Government funding for unpaid carers, especially for those carers in financial hardship and those desperate for a break, funding for service delivery for those being cared for, has shrunk so there is much more work for unpaid carers to do to fill the gaps.
57. The 2016 Carers Act gave unpaid carers rights and the Scottish Government pledged to invest in carers. Sadly, as health and social care partnership budgets are stretched to breaking, these funds are now not ring-fenced. While Covid undoubtedly delayed the implementation of this legislation, for instance the right to have an adult carer support plan and carer's own support needs recognised, the post-Covid financial environment is increasingly challenging. Yet, if we do not support unpaid carers, we will endanger the most fundamental support for the most vulnerable people in our communities.
58. During the pandemic, partnership staff were being transferred to COVID critical services. Day services and respite services were closed, transport was disrupted, rehabilitation clinics were postponed, care packages were withdrawn. Carers were unable to use their Self-Directed Support (SDS) payments despite having the budget as there were no services to commission to bring in the support. Hospitals were being overwhelmed and we saw dire consequences with early discharge back to care homes. For many carers this was extremely distressing. VOCAL saw an increase in demand and as the survey suggests, many people were emotionally very stressed.

59. As the pandemic went on, VOCAL was, as described, working differently. Our staff numbers have grown by a third in the last three years as has our budget. This is not due to Covid but due to the Carers Act funding and a recommissioning of services. We were successful in being awarded new contracts with Edinburgh and Midlothian partnerships which contributed to increased growth. That would have happened regardless of Covid.
60. The number of unpaid carers seeking support has also grown. We have a lot more responsibility. The needs of our cared for people that were not met during Covid are now at a critical level and are more complex because they were not addressed soon enough. Although role descriptions themselves have not necessarily changed for our staff, there is recognition that the resilience to undertake that role has changed. Our teams have been stretched and report being themselves distressed by the growing complexity of the needs of the carers they work with.
61. To meet staff needs we have re-structured and have put in place a number of different training and coaching opportunities for staff to help build that resilience. We have commissioned the provision of a service similar to counselling/supervision for our front-line staff. These typically take place in group sessions which give them the opportunity to reflect on challenges and how to manage those. A high number of our staff are carers and practitioners, so we have counselling available for them too.
62. Short breaks are a prime example of the complexity of care needs. A family I have known for years has a son who had a full-time day service, and a 72-night respite package pre-Covid. Without any change in his needs, they had only a direct funding package during Covid, when they struggled to find suitable paid carers, and now only have a part-time day service and ongoing issues to use funds to buy any form of respite.
63. VOCAL's infrastructure - IT, phones - was primarily digital pre-COVID which enabled us to respond quickly without any business interruption to working from home arrangements, and moving our in-person supports and services online. Further investment (through carer capacity grants from Scottish Government via Scottish Council for Voluntary Organisations - SCVO) was required to update premises and equipment to continue with a hybrid model of service delivery during and now post-lockdowns. As a result, we now offer a mix of in-person and digital training, events and counselling whilst continuing to provide individual support through phone, in-person appointments and video links.

**Impact on accessibility to medical treatment by service users of VOCAL.**

64. Carers have typically been more involved in accessing medical services than the general population, often on behalf of the people they care for but also on their own behalf due to the pressure on their time to look after themselves. So, when lockdown first arrived and medical services were switched away from community to hospital-based services, carers were hit hard.
65. As operations were put on hold, many experienced a deterioration in their own conditions and those of those they cared for. Amongst the elderly living at home this undoubtedly contributed to premature deaths, particularly when family carers could not be part of a shared bubble. This affected carers with multiple caring responsibilities who could only be part of one bubble, and where elderly people had paid carers who asked the family to step back to reduce the spread of infection due to social distancing requirements. People who receive paid care still needed all the care they got from family members, but paid carers were being very cautious and did not want too many family members involved in the care because the more people coming to the house, the more risk of infection.
66. The authorities took time to appreciate that some people's homes had become mini-care homes but without the additional supports. There were delays in sorting out Personal Protective Equipment (PPE), test kits, food deliveries etc. CoCiS was more involved with this as it was a national issue. Carers are equal partners and yet PPE and equipment did not come immediately, it required a number of care organisations to lobby on their behalf to get access to PPE. Some carers were quite anxious about getting PPE. There was the initial delay and then the mechanics of accessing it was problematic. It wasn't just about giving care, it was when carers were out and about, they did not want to take anything back to their loved ones.
67. The psychological impact of lockdown and isolation and detachment from family support compounded the delayed recognition of emerging physical health needs. For many carers and those they cared for, this led to further deterioration in their physical health.
68. This bleak situation was offset for some by access to digital solutions to keep in contact e.g., in having phone conversations with clinicians, but these arrangements took time to set up, and of course many vulnerable people lacked the skills and equipment to stay in touch. Far more responsibility fell on the shoulders of paid carers whose fleeting visits did not equip them to cover the care routinely given by unpaid family carers.

69. The changing regulations were confusing and often seemed contradictory in managing the risk of catching Covid. One example is one family member was at home with his son who required 24-hour care. The carer was diagnosed with Covid but there were no paid carers. So, on the one hand the carer was being told to isolate and on the other hand he was having to care for his son who needed 24-hour support. There was really no choice there.

### **Impact on mental health**

70. Covid brought many frightening changes and uncertainties which undoubtedly contributed to people with fragile mental health struggling both with their own and their loved one's conditions and with accessing support as services were stopped, changed, and fragmented, leading to a marked deterioration.
71. One example of fragmented services was transport. If you had a day service, pre-covid, transport was included; it was an integrated service. During or post-covid they became two different things. You are assessed for a day service, and you then have to, separately, make an application for funding for transport and that department has its own criteria. The family I spoke of earlier who lost all their day service were told they could have two afternoons of day service but no transport. This is something that is very difficult to separate out whether this was because of covid or budget restrictions. During covid, all transport was taken away to focus on covid critical services, it was taken away from day services, so there was an opportunity to redesign at this time.
72. While some endured the loneliness and isolation but hoped the lockdown, with all its consequences for services, would have a short-term impact, what we now see is that services did not go back to the way they were, as a result of far more limited resources. The hard to reach are now even harder to reach - refugees, non-native speakers of English, people in extreme deprivation accessing food banks, disproportionate numbers of single parents (often female) caring for children at home. That sense of isolation is compounded and the idea of reaching out for support and actually getting support seems impossible, it becomes a distant hope for people. The reality is this has become the new normality, it is sometimes very hard to remember two or three years ago. There is quite a lot of talk about encouraging 'shift change' in expectations; for people to stop the pre and post Covid comparison.
73. The carers surveys that were carried out in 2021 and 2023 identified, from respondents' comments, an increased sense of desperation.

Those that were less likely to engage are even further from reach. That was one of the reasons we carried out the work with partnerships as previously mentioned; to reach out through key partnerships to engage with people in greatest need.

74. The surveys showed that both people with mental health issues, and the families who supported them, were hard hit by being locked down together. Even when restrictions were relaxed, many people remain fearful and anxious. VOCAL saw a 20% increase in carers reporting an impact on their own mental health over this period (2021-2023).
75. The situation for people in care homes, unable to see loved ones, was truly heartbreaking and should never be allowed to happen again. Proposals that at least one loved one/unpaid carer should be able to remain in physical contact are vital in preventing the marked decline in the mental health of both cared for and their carer's. The cruelest restrictions were seen at end of life. In hospices where only minimal contact was allowed, many carers and close family had far worse experiences and were scarred with the restrictions placed on contact which seemed to defy logic in terms of risk management.

#### **Impact on physical health.**

76. Again, VOCAL has seen a marked deterioration in carers' physical health tied to the restrictions of lockdown. We have long worked with GP practices to identify carers, so when they stopped in-person appointments and then moved to telephone consultations, it became harder to update carer lists and identify new carers and put support in place to promote access to services. Since the vulnerable and their carers are already more likely to be less physically robust, they suffered disproportionately during this period.
77. Issues accessing medication and lengthening waiting lists added to carer concerns. Unable to access hospital services undoubtedly meant some were far sicker when they did get help and were far less likely to make a good recovery.
78. End of life care was particularly difficult during periods when medical services were under greatest pressure and health and social care became fragmented. Especially when services were stretched. Restrictions on being with loved ones in their last days were particularly cruel, and this experience has clearly scarred many carers. That others disregarded the contact restrictions makes many even more bitter and angry. Carers were left physically and emotionally exhausted.

### **Impact on families.**

79. I'd like to highlight the greater burden that fell on women in families that provided care. At times when services stopped more women had to cut their work hours or give up altogether to fill the gaps left. This was evidenced in our Carers Surveys. In 2021 the VOCAL Carer Survey was carried out by Scot Inform on behalf of VOCAL, with a total of 1,286 carers responding (4 in 5 were female). In this report 33% of respondents said they had stopped working because of caring responsibilities and 29% had reduced or given up hours at work in order to be a carer.
80. In 2023, Scot Inform carried out a similar survey on behalf of the Edinburgh and Midlothian Health and Social Care Partnerships which had 1,694 carer respondents (75% were female). 30% have reduced or given up hours at work to care, and 35% have stopped working because of caring responsibilities. 18% said they were finding it harder to sustain employment.
81. Often juggling caring for other family members, their own households and caring responsibilities, women's mental and physical health has deteriorated. We are not seeing things go back to pre-pandemic normal since services are not all up and running, and they are still covering where day and respite services were once in place. Many have multiple caring responsibilities, juggling children, and elderly parents. Again, their sacrifice has simply gone largely unnoticed and local authorities demand more as resources shrink further.
82. Young carers had a particularly difficult time during this period as schools shut and they were left isolated with the family they supported, often invisible to the authorities. It took time for services to reach out e.g., with deliveries of food. Working from home and trying to care is exhausting and undoubtedly many young carers lost education they will never be able to make up. Of course, we also know that many children simply won't be going back to school after such a prolonged period of dislocation and disruption.
83. For those carers who still have family who are shielding, issues like going back to work are much harder, and have contributed to many, mostly women, losing hours or jobs altogether. Working from home may have had some advantages, like no travel time and being better able to juggle caring responsibilities, but now employers are keen to see a return to pre-Covid working arrangements, which is challenging.

84. Through the Employer Network we can see that there are employers who are trying hard, but their model of business often requires people to be in the office. They would love to say 'work from home' but it is not effective for them. On the one hand there is a push to have supportive practice and policies in place, but if you don't have the infrastructure around it to allow someone to go to work, such as transport and day services for the cared-for, then carers simply can't work. The infrastructure of services we have seen eroded have really impacted on this.
85. Not getting breaks from caring, often the only respite from demanding carer roles, has reduced carer resilience and we know from survey returns, how many families are broken, i.e., where relationships have broken down and statutory services have had to take over. Restricted access to family for those in care homes, was deeply painful, especially when the situation wasn't understood, given they saw staff going in and out. Not being allowed to share loved ones' dying days fractured families and added to their grief.
86. I am aware of one woman whose husband had a brain tumour and the family watched him die during Covid. They were only allowed to be with him one hour per day for the last five weeks of his life. At some point, a consultant said they would allow them an extra hour, one at a time. These restrictions had a huge impact in that three years on, the woman and her children still feel intense rage at losing such precious time.

### **Financial impacts.**

87. Financially, carers suffered disproportionately during furlough as they were less likely to have full time or permanent work. As services stopped, carers found it harder to juggle caring and paid work, even when offered home working. There were many low paid carers who were in public facing jobs that meant they ran greater risks to their own health.
88. When lockdown arrived, shielding vulnerable family members became a barrier to accessing food and there was a six-to-eight-week lag before food deliveries to known carers began. Lists of carers were incomplete, and partnerships relied on carer organisations locally and the Coalition of Carers nationally, to identify those in need. The same was true for the provision of PPE. It was also harder for carers who did not have good digital access to manage from home.

89. Many carers are on benefits, trapped by their caring responsibilities in poverty. They often have higher costs in terms of heating so being forced to stay home was expensive. Washing bedding and clothes are often more frequent and needing healthy or special foods is more expensive. Many were already juggling food versus fuel. Financial and other inequalities were simply embedded by Covid restrictions.

### **Lessons Learned.**

90. The services have not been replaced within statutory organisations, and organisations such as VOCAL cannot do what statutory services did with consistency.
91. Overall, carers had an especially difficult time as a result of the pandemic and services were slow to respond to their needs. Given that unpaid carers outnumber paid carers and are the front line in the drive by Health and Social Care Partnerships to keep and support people in their own homes, we absolutely need to “Think Carer” as we plan for the future. Carers have to be seen as equal partners, and not as an afterthought. The legislation to support carers is there, and we need to resource social care so that carers and the cared-for never need to go through such devastating and detrimental times again.
92. During Covid, self-directed funds should have given some families flexibility to recruit people to provide care, but there was resistance to this for instance to allow family members to be paid to cover, when clearly there was a national staff shortage. Unspent funds were and are simply taken back. Carers do not feel they are treated as equal partners, providing vital services. We have the legislation, policies, and strategies but not the delivery of support for carers. This is unsustainable going forward, even without any further pandemics.
93. Access to vulnerable loved ones seems a human right and something would have to be in place to ensure some contact is maintained in the event of future pandemics.
94. In terms of human rights, the rights of carers, particularly the multiply disadvantaged carers have to be directly taken into account. We have to have those carer support plans and proper emergency plans.
95. We need to do more working with employers and education providers. It goes right back to identifying carers, having the conversation with carers about what their needs are. Then to reach

some accommodation to meet their needs, particularly in challenging times.

- 96. One of the key things has to be the adult carers support plan, they were never supposed to be just for emergencies, they were supposed to be good practice. Everyone who is supporting someone in primary care should have a plan in place so that next time they will have a point of contact.
- 97. Through Covid we have seen that an already fragile infrastructure has been eroded and that lack of infrastructure requires radical change. You can tinker around the edges of it – train people up and get people working - but if that basic infrastructure is not there, people cannot return to work. People cannot make choices, real choices about whether they can continue caring or not.
- 98. There are key things they must respect, adult carer support plans and, for young people, a young person’s plan. If there is no process to identify risk, which is what these plans are, then these people are invisible, they are not even on the radar. These are basic fundamentals that have to be right.

**Hopes for The Inquiry**

- 99. There needs to be a draft plan, which would include a communication plan, and a financial plan. It needs to be stress tested and impact assessed. Everyone needs to be onboard; carers need to be involved in planning; people cannot be at cross purposes. The right people have to be involved. We need structure and function and having a plan.
- 100. There needs to be a robust infrastructure of support for carers. The legislation is there.

Signed..... **Personal Data** .....

Date.....29th December, 2023.....