

## **Scottish COVID-19 Inquiry**

### **Witness Statement**

Statement of **Adam STACHURA** - HSC0059

Statement taken at 1030 hours on Friday 15 September 2023 on Microsoft Teams.

#### **Introduction**

1. My name is Adam Stachura. My details are known to The Inquiry. I am head of Policy and Communications with Age Scotland based at 160 Causewayside, Edinburgh EH9 1PR and held the same role and title at the start of the start of the COVID pandemic.
2. I have met today with witness statement takers from the Scottish COVID-19 Inquiry, and I am happy to provide a statement about my experiences of the Pandemic. I am happy that documentation previously provided to the Inquiry by Age Scotland be included to assist in forming my statement. I am willing to provide a statement, to have my information within reports, and for my statement to be published. I have completed the consent form provided and I would be willing to provide oral evidence to the hearing. I consent to this statement being recorded.
3. I was appointed to my role in February 2018. One of my responsibilities is to act as a spokesperson for Age Scotland, including at parliamentary Inquiries and for the media.
4. Age Scotland is an independent Scottish charity and is registered in Scotland. It was formed in 2009 after the merger of Age Concern and Help the Aged. We are a brand partner of Age UK but are independent of them and operate in Scotland.

5. We have been in operation, in one way or another for the last 80 years. This is our 80<sup>th</sup> anniversary year.
6. Age Scotland is the largest national charity in Scotland for older people. We work to improve the lives of people over 50 and promote their rights and interests. We help older people to be as well as they can be, we promote positive views of ageing and later life and we tackle loneliness and isolation. We do this by providing information, advice and friendship via our free helpline, friendship line and information guides, supporting and enabling older people's community groups, promoting age friendly workplaces and communities, delivering health and wellbeing programmes and campaigning on the issues older people tell us are important to them.
7. We have a range of free community workshops available to older people and their families across Scotland, online and in person, on issues such as dementia awareness, social security, and, energy rights. Our Age Inclusive Workplaces workshops have supported more than 17,000 people and 270 organisations since it began. This includes helping tackle ageism in the workplace, support people to plan for their future with information about retirement, and improve intergenerational workplaces.

### **Accessing and understanding COVID briefings – overview**

8. In early March 2020, before the first national lockdown, officials from the Scottish Government, and I don't recall exactly who, got in touch with our former chief executive to explore how the charity might be able to help older people with information and advice about COVID-19 if the spread of the virus became more serious. This included how our national helpline might be able to scale up capacity to handle an increased number of calls, and how many calls we felt that it was possible to manage on a daily basis. We could see from the news from Europe and across the world that older people were at the most risk from COVID-19. Our view at the time

was that the Scottish Government recognised this, and their ask for us to really gear up our helpline to deal with the anticipated surge in demand for information and support would be an important means of helping people in the short to medium term.

9. The, then, First Minister, Nicola Sturgeon visited our HQ on 18 March 2020 to announce funding of £80,000 to assist with turning our helpline into a virtual call centre. This meant that staff could work from home, have the necessary equipment to do so, implement a VOIP phone service and database, and scale up capacity. She described the helpline service as “invaluable” and while speaking with staff said that she believed that for many it would be like a “fourth emergency service”.
10. With the assistance of this government grant, we redesigned our helpline operations and from having been receiving on average eighty call per day, we were able to deal with 1,500 per day pretty quickly. In the early weeks and months, we received around about 800 calls per day at its peak, though this would fluctuate depending on where exactly we were during the pandemic and when the government announced changes to lockdown rules and any additional support.
11. The reason for mentioning the change in our helpline operations and the role we were being asked to fulfil, is that there needed to be a non-digital means for people to find out more information, ask questions and seek advice. Hundreds of thousands of older people in Scotland weren’t online, living alone, and with few places to turn for support. The main route for this information, particularly at the start of the pandemic was through the broadcast briefings undertaken by the Scottish Government and UK Government.
12. These regular government briefings were found to be very valuable by the older people we spoke with, and clearly demonstrated by the high viewing figures. They were the primary source of the most up to date information regarding COVID-19 and the government’s announcements. Calls to our

helpline would spike in the moments after the televised briefings concluded.

13. Broadly speaking, at the start of the pandemic the public health messaging, and asks of the public, was simple, because it was the same from the Scottish Government and the UK Government. But as guidance began to vary, new initiatives or policies launched, or indeed the language used to describe the same thing – such as how to describe social distancing or “Hands, Face, Space” type slogans we would receive calls immediately afterwards from large numbers of people seeking clarification of what that meant or whose directive they should follow - UK Government or Scottish Government. It was occasionally quite confusing.
14. Often, we'd get phone calls saying, “Well, the First Minister said this, and the Prime Minister said that, what can I actually do?”. Sometimes, people would outline their situation and almost seek “approval”. Our response would always refer to what the guidance actually was, as opposed to what people hoped we would answer. We felt that our role was to try and rearticulate the guidance in as simple and as a human way as possible.
15. Often, we were trying to interpret and capture what the First Minister’s lunchtime briefing said, as calls would come to us immediately afterwards. It was also quite challenging as there was no written version of it available until hours afterwards and published on the Scottish Government’s website. The information could be confusing, sometimes contrary, and tough to capture quickly.
16. Often, we only had a very short time to prepare documents or briefings for colleagues who were on our helpline. They then had to read, understand and get a summary of what was said to be prepared enough to effectively answer the huge number of calls from older people.
17. Our policy team would produce these daily briefings as it wouldn’t be practical to have helpline colleagues stopping handling calls themselves as

there would be a steady flow of people contacting us throughout the morning and lunchtime until the briefings were happening.

18. We set ourselves a target of between around half an hour to 45 minutes after the end of the first minister's lunchtime briefings to have a document prepared and available for call handlers with the key messages and any associated detail. This would be a live document which was continually updated as existing elements changed and it also explained what those changes were too.
19. I know that these briefing documents were incredibly helpful to call handlers and the public who were getting in touch with us. I was really impressed with our team who undertook this work.
20. I still feel really frustrated about one aspect of the public briefings. While the support of the Scottish Government to us as charitable organisation was great, and that they identified Age Scotland as a key partner even before the pandemic struck, one of the things which I struggled to understand was why it took hours for the Scottish Government website to provide the detail of these broadcast briefings? You could be waiting until 3 or 4pm for the words contained in the lunchtime briefing to be available.
21. It's quite embarrassing that the only immediate or live "read out" of the First Minister's briefings, was from the SNP press office Twitter account. I can't quite understand why this couldn't also have been on the First Minister's official account or main Scottish Government account, too. The Scottish Government seemed completely unable to do that, despite presumably creating the thing in the first place.
22. So, simple, timeous communications were some of the most necessary things that we could have had but didn't and it was very frustrating.
23. I remember raising this issue with communication with some officials in the Scottish Government on our regular either weekly or biweekly calls

asking to get this information beforehand. You've asked us to be a partner to deliver the information to the public, can you tell us what the information is so we can prepare and support our communities? But it was never forthcoming. I recall being told that there was a very close circle of people with sight of the announcement script before the televised briefing, which I thought was understandable, but I'm not sure why it could be published immediately afterwards.

24. This is why we had to watch all of the briefings, take notes and create our own living documents. Annoyingly, the situation never improved from the government's side.
25. Overall, I think these broadcasts were incredibly effective at informing the public with regular, simple to articulate updates and done so in a very human way. Feedback from many older people we spoke with mentioned how they became an important part of the day, and a means to keep on top of what was happening.
26. I recall a moment in September 2020 when the BBC sought to stop regularly broadcasting the government briefings on the TV, instead making them available online. We felt that this was a poor decision and published a statement to this effect and asking that they stayed on the air. Primarily because hundreds of thousands of older people in Scotland didn't have access to the internet.

### **Access to and Adapting to the Use of Technology**

27. From probably May 2020 and for the following two years I took every opportunity, whether in parliamentary inquiries, responding to policy consultations, in meetings with politicians or government officials, or in the media to explain that, in Scotland, at that point, half a million over 60's didn't have access to the internet and around 600,000 didn't use a smart phone.

28. Lots of older people, people on low incomes and disabled people do not to have access to the internet and find it incredibly difficult to access services and realise their rights. And while we've had digital transformations in public services, which has broadly been a good thing and a natural progression, accelerated by COVID, it means that the huge numbers of those without internet access or indeed are uncomfortable with using websites and apps have been left behind and essentially discounted by many services and policy makers who push for online only services – or make offline options so hard to access that they become ineffective, and subsequently close due to low volume.
29. Without fail, this information about the scale of digitally excluded older people seemed to surprise whichever politicians or civil servants I spoke with. As time went on, more and more of them were becoming aware of this reality, but very little seemed to be done to address this enormous digital exclusion which affected some of the most vulnerable and disadvantaged people in our communities.
30. It just seemed to not click; how on earth are these people, excluded from that digital world which we all now operate in, going to scan a QR code, for example, to get to access services or order things? Or be able to contact a council service?
31. When public services such as local authorities, medical services and the like were not answering their phones anymore, how do people who need the help, but are without the internet, access it?
32. A welcome moment came following a large investment from the Scottish Government to set up a digital inclusion programme called Connecting Scotland. The aim was to offer a digital device and a data package to people without access. SCVO administered this. The first phase was aimed at older people, or those who were deemed clinically vulnerable or shielding, for the first few months of the pandemic. I think this was a pretty hard thing to operate and get to people considering the lockdown

restrictions. I understand that around 9,000 households were supported in this phase. The next phase moved to families and care leavers from August 2020 to April 2021. It reached 23,000 people.

33. Linking back to calls to our helpline, as soon as this was announced by the First Minister on a televised briefing, we received calls from older people asking how to get their free laptop. These asks caught our helpline team by surprise as they would have been entirely unaware of the initiative at the time, as we hadn't received advance notice. These requests from the public were, of course, not how the initiative was to work, but demonstrates how quickly the public sought action. It would take us a couple of hours to identify enough of the detail of this announcement to provide a proper briefing for our call handlers.
34. In terms of specifics, access to food retailers was particularly difficult in the first few weeks of the pandemic. For those who were shielding, clinically vulnerable and living alone – or with no one they could rely on nearby, shopping for food was a significant challenge. There were frequent calls to our helpline from people without food and no means of getting any as they were at home, unable to leave, and didn't have access to the internet. It was very distressing for callers, and our call handlers.
35. When online food shopping and delivery options proliferated, it could be a real challenge to secure a delivery slot. But without the internet it was almost impossible. However, I recall that you could phone Morrisons, they were a good example. If you were an older person and there was a local Morrisons you could phone them, complete a shopping order and pay for it all over the phone with a card as opposed to going online.
36. It wasn't just for buying essentials, food and the like, but having no digital access massively affected broader feelings of isolation and disconnected you from the huge amount of information and advice which was only available on the internet.



37. So, while organisations, like Age Scotland, can develop digital transformation projects and enhance our online offering, it is important to have a good means of access for the public who are not able, or comfortable using this means. For example, our public facing access point is primarily non digital. Older people can pick up the phone to us for free and we will help access the same information or service promoted online. But if you were trying to get in touch with local authority about a service, you just couldn't because everyone's working at home, and they hadn't worked out how to connect their people properly, reinstate phone lines, or have a face-to-face option. Sadly, most of these offline routes have never returned.
38. There were so many examples of people calling because they were and remain digitally excluded. They simply don't know where to go and search for information and if they were being forced to go to websites, they were generally difficult to navigate if you are not used to using them or search engines. A particular issue was navigating council and GP websites as feedback from older people had been that they were quite confusing, organised poorly and very text heavy.

### **Main Concerns Raised by Older People**

#### *Food/ Food security*

39. Our phone lines were very quickly inundated with calls from older people expressing real concerns about accessing food. When initial restrictions began and getting to food shops was difficult or a challenge for many older people who were asked to shield or socially distance due to vulnerability to the virus, there was a lot of food insecurity. There was a significant push for people to do grocery shopping online and use delivery or collection points, but hundreds of thousands of older people just didn't have access to the internet.

40. Our helpline received very distressing calls from people who had run out of food and had no means of getting more. They weren't online or weren't able to obtain a delivery slot from a supermarket. They would have no one else to turn to for help. Our team would try and match them up with local groups who had mobilised to either shop for people or arrange food parcels. This was particularly pressing before the local authority resilience teamwork had started or organising food deliveries and parcels.
41. I mentioned earlier that people without internet access had huge challenges, especially in the early weeks and months of the pandemic, of buying food from supermarkets and that solutions evolved such as one major supermarket allowing phone orders and payment by card. But for those without a pay over the phone option, or people reliant on using cash there was a growing issue as time went on. They had no means of accessing cash once what they had at home ran out and were told to shield. We did receive phone calls about this and people seeking advice as to what to do. They couldn't pay people who had bought things for them, and it would be very inadvisable to give someone else their bank card and pin number. Bank transfers out of the question if you were not online.
42. One issue which did come up regarding food parcels from the local authority route on many occasions was where dietary requirements weren't able to be catered for. Particularly for vegetarians who would receive meat products, or ethnic minority older people, such as Hindu or Muslim who would get beef or pork items and lacked access to staples such as lentils and rice – instead perhaps, pasta, which wasn't part of their regular diet. This was important to address.
43. Our own research in May 2020 found that 32% of respondents struggled to get food from a supermarket and 39% faced difficulties getting an online delivery.
44. With regard to access to food and supermarkets, we worked with a range of other charities including consumer rights organisation Which?, Carers

Scotland, RNIB Scotland, Action on Hearing Loss, Sight Scotland, and Guide Dogs Scotland in May and June 2020 to identify the access challenges facing our constituent groups and collectively seek solutions from government and retailers.

45. Together, we wrote to the First Minister, Nicola Sturgeon, and the major food retailers on 4th June 2020 outlining the challenges we had all identified for the people we supported and acknowledged the efforts that supermarkets had made since the beginning of the crisis, including an hour set aside for older customers, those with disabilities and their carers, and priority online delivery slots.
46. This letter sought urgent action to improve people's access to food, including that supermarkets work with the Scottish Government to ensure all vulnerable consumers, of any age, and their carers receive the support they need to access food; supermarkets to build on the steps they have already taken and adapt services to better meet the needs of older and disabled people; the Scottish Government to involve our organisations in work it is undertaking to identify those in need to prioritise them for home deliveries or support with getting food supplies, and therefore keep them healthy and protect the NHS from avoidable admissions; and improved coordination between the Scottish Government and local authorities, the food industry and local charities so that all options for providing food deliveries – from supermarkets to local shops and volunteers – are fully exploited.
47. The engagement we had with Scottish Government to address this at a national level proved to be more challenging. Partly because it was difficult to identify which specific minister might be responsible for this issue. As I recall from the time, the feeling among the group of organisations we were working with was that multiple Scottish ministers had some role but the informed view from Which? was that John

Swinney, Deputy First Minister, was in overall charge of resilience at Scottish Government level would be the go-to person.

48. Despite this representation from us and other charities, it felt as though at a government level, working with charities was not a priority or even something that was on their list of things to do. It was very hard to access decision makers at this time.
49. We were also aware that the Scottish Government was involved with Supermarkets, but so was DEFRA (Department for Environment Food and Rural Affairs – UK Government) and we were concerned as we did wonder to what degree the Scottish Government's engagement with the food sector was a duplication of effort, or whether, in fact, it was taken as seriously or co-ordinated with DEFRA's food sector engagement.
50. It felt that the biggest and ongoing impact on alleviating the pressures upon older people not being able to access food was not delivered by Government. It was achieved by community mobilisation, volunteer groups, neighbours, families who decided to take their own risk assessed action to support their older relatives. This had the most significant early impact on food security for a vulnerable isolated demographic across the entire country, and it continues as such to this day.

### *Isolation*

51. One of the unintended outcomes of charities and community groups being able to react really quickly, or in a nimbler way than government or local authorities, was that we were able to give people some degree of security and that there was someone else who wanted to hear from them, someone that is with them because people were experiencing desperate levels of isolation and loneliness.
52. For those with no one else in their life, or who didn't know who else to speak to, they could speak to us in a free phone call.

53. Even on the times and days where our helpline may have felt they weren't making an impact because the answers to the questions people were posing weren't available, they were actually making a really big impact, because we afforded callers a friendly and compassionate ear.
54. Somebody could listen to them and make them feel that they were valued as a member of the public, as an individual. These callers had maybe not spoken to anybody in weeks.
55. Because we had the capacity to take the calls, our friendship line was formed and became a stand-alone service accessible through our main helpline number. So, people who had gone from end of March through to the end of April and beyond, who were not seeing a single soul, knew that they could call us for a friendly chat. It wasn't a regular befriending thing, but it was a chat, and that would make their day.
56. And it's something that we still do as a service. We had the support of The Sunday Post newspaper in launching this at the end of April and start of May 2020.
57. In hindsight, as a by-product of actually trying to provide technical support through our helpline, the fact that people could just phone for a chat, when they had nobody else, seems obviously helpful. It was always something we did through our helpline as we knew isolated older people would want a chat but hadn't been a dedicated service until then.

**Delivering Care/ Accessing social care**

58. We received many calls regarding travelling to deliver support and care to older relatives especially at the start of the pandemic, when we were all told to stay at home and not to travel anywhere. Questions emerged like what, at that time, was deemed as a reasonable distance to travel to undertake this care? Could people leave their home to provide that care?
59. We advised that there were caveats with regard to lockdown and that you may go and deliver care to a loved family member or friend or older person.
60. Some mentioned that the police had stopped and questioned them about the validity of their travel and whether they were really travelling to deliver care. They felt that they were under a lot of pressure to prove it and to what degree that care was required.
61. Whilst the government advice was initially very simple, there would be reasonable examples where someone's situation didn't fit neatly into how it was expressed, and it was hard for people to always understand what was and was not possible or allowed.
62. People were so worried about COVID, worried about their family members who need support, worried about what actions would be taken against them if they were to go and do something which they thought they could, but actually couldn't. We had to reassure people frequently that their proposed actions did fit within the scope of the guidance. I think it was a real challenge for people to feel secure in the knowledge that they were allowed to do certain things, like travel to support someone with care needs, and much more so than we anticipated at the time.
63. There were also worrying calls about how people couldn't access their own social care packages any longer. Basically, in mid to late March 2020, social care provision dropped off a cliff. People began to be told that due to social distancing, lockdowns, ill health, shielding arrangements that

their social care package would be stopped or changed as carers could no longer support them. Families were asked to step in – and on many occasions that ask just wasn't possible, or they were just ill equipped to fill the void.

64. A particular example were from calls from people in Glasgow where the care provider for the council, Cordia, told them on that Friday, 20 March 2020, that their care would stop on the Monday. We immediately raised this with the Minister for Older People, Christina McKelvie, who assured us that government officials would take it up with the local Health and Social Care Partnership. We understand that en masse, care packages were stopped/paused with little to no notice.
65. It was incredibly difficult for older people and their families to make enquiries with social care providers or social work staff when packages and care was stopped or reduced as they couldn't reach people on the phone, or requests for review of decisions ended back at the same people who had made them in the first place. Our helpline team found themselves having to scabble around and find effective contact numbers on often less than user friendly websites to identify who callers would need to speak to.
66. The contact or engagement routes for these social work and social care services also all reverted to online only; compound that with the digital exclusion that many of the older people who relied on them faced and there was no way that pre-pandemic social care support could be asked about, let alone re-commenced.

### **Accessing Medical Care**

#### *Routine/Screening*

67. At the start of the lockdown, when you think about the initial Government messaging, "Stay Home, protects the NHS, save lives" and when that was

applied by many older people that we were in contact with, or communication through the groups we were networked in, it was taken very literally. They didn't want to be a burden on the NHS which was understood to be struggling to deal with the impacts of COVID, and also found it hard to access it in the first place as GP practices were to all intents and purposes closed.

68. With all this in mind, the people we were supporting and in contact with faced a double whammy of their immediate and longer-term impacts upon their health and accessing medical care.
69. In the immediate term, people could not access GPs, dentists, physios, chiropodists, or the routine care and screening services that they needed because it had essentially closed down.
70. A real issue we had picked up from our helpline relates to breast cancer screening and self-referral to breast cancer screening.
71. I think it was probably a year into COVID, when all the screening had been stopped for a while and was maybe only just resuming in some areas, self-referral was completed online, nobody was answering any telephones at clinics anywhere.
72. When you're 70 years old, you can self-refer for breast cancer screening; but people started calling us saying it has been closed, when can I start doing that again? Because they are digitally excluded, they are completely excluded from accessing that essential routine screening.
73. Our understanding was that the older you are, the more at risk you are of getting cancer in the first place. Also, if you are a survivor of breast cancer, that risk of getting cancer again increases even more.
74. Though these services have now reopened, fixing the big backlog was by sending out invitation for screening. But if you're over 70 you still could not self-refer until autumn last year. So how many people were missed?



How many developed cancers as a result of screening being closed? What is the impact of self-referral, at the time, being digitised?

*Accessing GP services*

75. GP Surgeries simply closed down for weeks, if not months at the start of the pandemic. To all intents and purposes, the delivery of GP services has changed irrevocably for older people. Where they cannot get online to arrange appointments, the challenges of getting through by phone to arrange appointments is a significant one. For many older people, telephone appointments are not appropriate because they often have complex needs. Compound this with the impacts of older people suffering early stages of dementia or other sensory impairments, telephone GP consultations are wholly inappropriate and exclude many older people from accessing medical care, which is often only for routine or minor screening, but if not delivered, will over time lead to greater and more profound negative health impacts. We know that the vast majority of older people prefer in person appointment and very few have a preference for video consultations.
76. In the first year of the pandemic we would receive many calls from people complaining that they couldn't get through to GP surgeries at all. When they did, they were referred to NHS Inform, online, or the surgery website, which would just say that we can't see people face to face and go to NHS Inform for support. Many GP websites were horribly designed and would have flashing sections saying not to call. Sometimes there would be conflicting information on the home page. That is a personal reflection at the time of looking at various GP websites following complaints from the public.
77. Of course, it wasn't possible with the restrictions in place to see people face to face unless it was a serious emergency, but the longer this was the case, people would report that they would be more unwell when they were able to access them.

*Emergency Medical Care*

78. Though we were not really receiving calls concerning emergency medical care issues, beyond access to GPs, at the start of the pandemic lockdown period, we were working with a small number of organisations with a focus on older people from across the whole of the UK to discuss pressing and emerging issues related to older people's experiences. It was chaired by the Older People's Commissioner for Wales and met online, on a weekly basis.
79. One issue, which was raised in April 2020, and particular to Scotland, was the Scottish Chief Medical Officer's COVID-19 Ethical Advice and Clinical Guidance. I can't recall exactly how it arrived with the group but there was a view from within this group that this guidance was vague when it came to how and who would be treated in a clinical setting if there was pressure on resources.
80. We felt at the time that some of the language with regard to decisions being made fairly and equitably was woolly, and could lead to decisions being made that an older person was less worthy of treatment than a younger person.
81. We and others including Scottish Care challenged the Scottish Government about this in early to mid April 2020, and there were two or three meetings with the Chief Medical Officer's (CMO) officials about rewriting and reframing this clinical and ethical guidance. These meetings included Scottish Care, Inclusion Scotland, the Scottish Commission for Learning Difficulty and others, but my notes from the time on participants are incomplete.
82. There was an EQIA process discussion following reviews from the Scottish Government and CMO in late May 2020.

**DNACPR**

83. From the end of March and through April was we were getting a significant number of calls from people saying they have been contacted, out of the blue by their GP, or sometimes it was the practise reception staff, asking if they would agree to having a DNACPR decision on their medical records.
84. People were calling us with concern as they didn't know what these things were and, in their own words, worried that it meant they wouldn't receive medical treatment if they contracted COVID-19. Calls were being received from all sorts of older people, with a variety of underlying conditions – as you might expect from this age group, many of whom were objectively healthy, just older than 50. This included people with dementia, who, despite GPs surely knowing that they had this illness and very well might not be well placed to answer such a question like this which was sprung upon them.
85. We were hearing from callers to our helpline, or people emailing us, that people who were objectively healthy, but were 50, 60, 70 years old whatever, were being asked to agree to this on the spot, at the time of that unsolicited call.
86. This was all completely counter to the established DNACPR policy and how we understood it should be introduced and discussed with patients. But it felt from the calls that there was a broad process of phone calls with no transparent purpose behind them.
87. Though we understand and appreciate that, clinicians don't have to consult with anyone about this; if they are presented with a particular medical situation, they can decide themselves what medical interventions, if any, might be counterproductive or not appropriate or increase risk to their patient. But what we felt was happening was that there was a conflation between what is a medical reality, alongside the negative impacts that these unsolicited calls were having on older people.

88. Over time, and after being involved in a range of meetings and discussions about this issue we have feel that the genesis of this lines up with when GPs were identifying shielding lists.
89. In March 2020 GPs were asked to identify people for the Scottish Government and NHS's shielding lists, identifying patients that they believed are most vulnerable to the virus, then some central process issued written letters to them asking to shield at home.
90. It was at the same time, or soon after this that people started getting phone calls from GP practices, whether from admin staff or a doctor or someone in between, about signing up to this (DNACPR). People were horrified and saying no way were they agreeing to this.
91. But the fact is people were getting these phone calls, out of the blue, to discuss it. They're just in the house and the phone rings, the GP practise asks them all this and they're terrified.
92. Our demographic's views as they routinely explained to us, were that they thought felt they had been written off; that this form would mean they won't get access to medical treatment.
93. This wasn't restricted to March and April. As an example, somebody got in touch with us later on in 2020 who was concerned about their grandfather who a veteran. He was over 100 years old and who still lived independently, on his own. We understand from this exchange that paramedics arrived at his door one day and they handed him a bit of paper and said, "you need to keep this by your bed". It was a DNACPR decision document or slip. A photo was taken and sent to us by email, and I remember seeing it.
94. The slip was signed by a clinician that said discussion had been had with patient and reason was just two words "communication difficulties". Presumably, linked to his hearing loss.

95. In this instance the DNACPR was not about them having any condition that would mean there is substantial or significant underlying health condition, which would be challenging if they contracted COVID; they were being written off because it was hard to communicate with them.
96. Even if it was the case that someone might face difficulties if they contracted COVID-19, why on earth is there a pre-emptive DNACPR? And particularly so with no discussion or any form of dignified process for the recipient.
97. From our discussions with other organisations such as Scottish Care as I recall, from media reports and calls to our helpline we had a sense that this was also be happening in care homes, where all residents were having DNACPR decisions issued in a blanket manner, not on an individual basis.
98. This was backed up at the time with conversations surrounding the issue we had with other charities and organisations in a plethora of informal settings, and from enquiries to our helpline. I heard of examples where there were cases of COVID in care homes, a medical response was not forthcoming. COVID was simply going to go through the care home and there was not the resources to help everyone. And it would be said that "we're not transferring you to hospital because you're in a sort of a safe place. We'll try and manage your condition as best we can in the care home environment".
99. We also found examples of people who upon leaving hospital found DNACPR decisions in their discharge papers without any discussion having been had with them. The box was ticked which said they had had a discussion, where in fact none was.
100. It was the end of May 2020, I think, when it was becoming apparent that there were so many of these instances.

101. I feel that it was a scandal; a scandal that people were being written off. And it wasn't just our view, people were telling us about what was going on and their experience of it.
102. We had discussions with the Scottish Government about all this and they stated that at no point did they ask GPs to start doing this and I have no reason to doubt this. So, on the one hand although this wasn't part of any official or transparent coordinated policy about issuing DNACPR decisions, all of a sudden this was happening on an unprecedented scale. We were getting phone calls to our helpline about this issue, where we have never had any contact about this subject before March 2020.
103. I still get quite angry about this because I recall a conversation I had in a broader meeting with the Scottish Government and some Age Scotland senior colleagues where we were discussing what we felt was a misuse of DNACPR. A policy officer for the Scottish Government's health department, whose name I cannot recall, was vigorously denying that this was the government policy, but she could not seem grasp what was actually happening in reality. She didn't quite understand or believe that people were phoning us up to say this was happening because as she put it, "no one's contacting the Scottish Government about this". The meeting was quite heated at this point and a senior colleague felt they had to leave it as they were hugely frustrated with the attitude from the government official.
104. I couldn't quite figure out what was going on. But in one of these many discussions we had with the government on the April and May 2020 period, a Scottish Government official made some comment at about this issue with DNACPR being linked to the timing of the shielding list being created. So, it has stuck with me this whole time.
105. It still makes me angry that generally healthy individuals had been asked to agree to DNACPR and the only linking factor was their older age.

106. And this is what I'm trying to disconnect in my mind; my anger from the cases we encountered as a reality, and that medical reality of how it can be used. We don't have a problem with DNACPR decisions as part of a broader part of anticipatory care planning. It is standard practise and it's sensible. But at times it felt like it had been misappropriated as a tool, used to define a group of people who might be more at risk of COVID, so they would be pre-identified and excluded from treatment.
107. I think it was the end of 2020 or early 2021 when trying to get to the bottom of the scale of this issue we actually sent every health board an FOI request about how many do not attempt resuscitation decisions had been issued in their areas, between March and June 2020 compared to March and June 2019.
108. Only one health board came back with any figures; all the others replied that they do not hold that information centrally because, these were just bits of paper, held on various medical records in various locations whether in hospital patient records, or GP patient records, or wherever.
109. Forth Valley NHS replied and gave us some figures that were pretty much the same over the two years and they were quite low for both periods. We didn't quite understand how they arrived at those figures especially if they don't keep information centrally.
110. There's a system, I think it's called SIPS, on the ambulance service records where there's some very basic information about all this. Sometimes DNACPRs are flagged there, if it's been recorded elsewhere, but we never got any figures from this system on the prevalence or otherwise of DNACPRs.
111. We had also written to the Scottish Parliament's Health and Sport Committee at the end of 2020, November as I recall, asking them to conduct an inquiry into the use and scale of DNACPR decisions in 2020 compared to previous years and to seek the origin of the March 2020

phone calls to patients. They replied to say that they would have no more time in the parliamentary calendar, pre-election, to do so.

112. We wrote to Healthcare Improvement Scotland on 18<sup>th</sup> March 2021, as we had identified that they might be the right agency who could investigate the use of DNACPR since the start of the pandemic. The Care Quality Commission (CQC) in England had that day published a report called "Protect, respect, connect – decisions about living and dying well during COVID-19" which found, as they put it, "worrying variation in people's experiences of do not attempt resuscitation decisions during the pandemic. I had thought that Healthcare Improvement Scotland were the agency in Scotland most like the CQC and that asking them to undertake a similar exercise and undertake an investigation into whether the practice around DNACPR decisions in Scotland had been acceptable or not.
113. There had been a useful response from Healthcare Improvement Scotland's (HIS) chief executive, Robbie Pearson, seeking to set up a meeting about this, which happened in late April 2021. HIS said that they didn't have the power to investigate this but could look at how the matter could be improved in the future. A roundtable discussion was suggested by them which would include HIS and clinicians, along with Age Scotland and some other charities who had similar concerns to us. This ended up happening in late January 2022.
114. In August 2021 we hosted a roundtable of charities to share our collective experiences of DNACPR decision enquiries from the public and our constituent groups. This meeting included the Health and Social Care Alliance, Sight Scotland, Inclusion Scotland, The Scottish Human Rights Consortium, Deaf Action, Glasgow Disability Alliance and the National Autistic Society. There were many common themes about poor use of DNACPR decisions and concerns about how they impacted the medical treatment of people who contracted COVID-19.



## Care Homes

115. There are 34,000 older adults in residential care homes in Scotland I don't think that there was enough effort taken to meet the needs and protect the rights of care home residents.
116. In early April 2020 we were getting phone calls from residents themselves and from their family members. There were three notable things that we were called about almost from the start of the pandemic: levels and quality of care in the homes, visiting access, and family members wanting to remove loved ones from care homes and move them into their own home. People were scared about their loved ones contracting COVID in a care home and as they weren't able to visit them, wanted to keep them close. Very understandable.
117. But, thinking especially about visits to care homes, managing that sense of isolation all residents and families felt; that needed to be addressed more quickly than it was. In the very early days, and first couple of weeks, you could understand to some extent that working out how to manage the complex care home estate so that the chance of COVID-19 entering was minimised would be difficult. The instruction was to lockdown and at the time some care staff were going to extraordinary length to isolate themselves from the outside world by staying in the home, in campervans in their car parks and such like. Quite remarkable dedication. I recall a sense at the time that any lockdown was going to be short lived and concerned family members calling our helpline seemed to hope this was going to be the case.
118. But as the first week of lockdown turned into two weeks, then into a month, and beyond, there was no real effort from government or health services and social care partnerships to implement an unlocking. It was hard to see what actions were being taken to address or alleviate the broader and significant negative impacts that this enforced isolation from families and loved ones was having on care home residents.

119. Family members calling us were concerned on two fronts. One was they were not able to get into the care home to see their family member and care for them while some were calling to say they were really concerned about other people getting into care homes who might bring COVID in.
120. There was a very tricky juxtaposition for us to understand here; one was a real desire to get into care homes to see loved ones, but the other was the fear around COVID being taken into the home and their loved ones getting COVID then dying very quickly and painfully as result of that. The balance of calls on this shifted to predominantly being about needing access two or so weeks into the first lockdown.
121. People desperately wanted to see their family members because up until then they had been doing so on a regular basis. Many family members were key carers, too.
122. Very quickly they had no means of contacting their loved ones at all. Then the first phase of visits, window visits were allowed but these were totally unsatisfactory. There was often no video communication possible. We were told by callers to our helpline that it was very hard for people to make telephone communication in the early weeks, and if that was possible it was quite unsatisfactory for the residents who had hearing loss and dementia.
123. So, we have this tough position early on in terms of understanding the issues surrounding the desperate need for visiting and recognising some people were anxious that people didn't come into the care home and inadvertently transmit COVID. This was not a short-term issue, it was not just two weeks or three weeks where some people could accept this time restricted separation if it meant that COVID -19 was not coming into the care home. But COVID was entering care homes at speed and scale. Visiting rights has become a major issue spanning the last few years and a lack of access still occurs. There comes a point when you just have to

make things happen and is incredibly frustrating that it was never a national priority.

124. There was a significant lack of PPE such as masks, testing for visitors and real focus on how to make visiting as safe as possible in care homes. It felt that care homes were not given what was needed to keep people safe.
125. For the first few weeks of the pandemic, through to early May 2020, we received frequent phone calls from people saying that they want to remove their family member from the care home to live with them at home and wanting to know how they go about doing that. But it was very hard to understand how they could achieve that properly if they have no access to any other means of social care support in the community or from the local authority.
126. The care homes were basically saying they were not allowing this. It was a significant But many families felt that the safest place for them was out of the care home. I understand that perspective and realise that this was probably only for the short-term until they had some sense of satisfaction that care homes were safe from COVID.
127. Organisationally, we understood the need to get the doors open again and resume visiting, but safely, and even if it was just for a small number of people. We were really not qualified to say how these doors should be opened, and how fast, because we're not clinicians, we had to take, to some degree, at face value the public health advice.
128. There does come a point where the negative impacts of being locked in for too long become obvious. People were calling us about the decline of their loved ones they were witnessing. Once they could get some kind of access, whether it was over video calls, photos, or through the windows, or even when they could have outside visits, there had clearly been a massive and swift decline of the condition of their loved ones.

129. Quality of life is so important and how or who was deciding on the balance of threat of virus and the impact of chronic loneliness in the precious time people had. We really felt we were regularly saying to the Government you need to get find a way of getting doors open and support safe visiting. This was a regular feature of our media comments: support safe visiting, give care homes everything they need to do this and make sure people's quality of life is good.
130. We were early advocates of having testing in care homes made available to staff and visitors. But at this early-stage testing and PPE just wasn't available in care homes. It felt that hospitals and medical provision was the sole priority so that made it even harder to get any movement. Care homes were spending fortunes on eBay or Amazon trying to find any suitable PPE. It's quite scandalous.
131. As an aside, at some point in the first few months of the pandemic we donated about £400 to the Kinross Men's Shed because they wanted to buy a second 3D printer to produce face screens for local social care staff. This demonstrates how desperate it was to get PPE into care homes and to social care settings.
132. Frustratingly, we would get reports that some care homes weren't necessarily following all of the guidance about how to best use available PPE. We saw Care Inspectorate reports about lack of hand washing, the same PPE gowns being used in multiple rooms, face masks not being worn properly. This will have increased the risk of infection.
133. It also has to be acknowledged that care staff or other contractors who have to go inside care homes, would be the origin of COVID -19 transmission. Would allowing families into care homes to provide some elements of care have increased that risk any further? Particularly if they were following effective infection control procedures, had good PPE and were tested before entry.

134. However, can you imagine as a member of staff at a care home, living in camper vans in the car parks, forsaking their own family and friends to make sure that the residents are safe? I sort of feel that these people have been forgotten about and they deserve some kind of national recognition for that level of duty.
135. The question is then; at what point is it crisis management and when does it move to having to adapt to new risks and pressures? How do we find a way of making this happen safely as opposed locking the doors and pulling up a drawbridge. Residents must have a good quality of life and that must reflect what they want, what we would expect for our loved ones and also for ourselves if we were there.
136. I still think about this a lot. It doesn't feel like social care was treated as seriously and as urgently as the NHS in terms of the government's response. Access to testing and to PPE wasn't freely available Care homes were kept slightly arm's length from all that decision making.
137. It seemed like decision makers were unaware of what was going on at ground level, just looking at a reports and bits of paper and statistics and deciding that care homes can't stay open.
138. They must have lost track of how long that care home has been closed. At what point in time does it become unacceptable for this to still happen, to become the norm? Does public health supersede quality of life as well? Do we politically care as much about this?
139. When people go into care they are towards the end of their life, broadly speaking, so this is an important time, it's a time that people need to be together as much as possible, because it is often so short. At this point in life, health deterioration is quicker. When I think of all that happened, the isolation, the loss of quality of life, to achieve a length of life; I wonder if that deterioration in general health and death happen more quickly because of the isolation? In many cases, I'm sure it did.

140. It just feels that there wasn't enough consideration or action to ensure that care homes were supported with everything they needed.
141. What is clear, is that the distress that all this has caused to family members, residents and care home staff has been extraordinary.
142. We should be ashamed that it remained like it did for so long.

### **Age Scotland Alleviating Some of the Difficulties Faced**

143. Age Scotland was very well integrated and engaged with other community third sector support, volunteer services and other charities with the purpose of being able to support the communities we all represented; whether these were national groups or geographical communities. There was such an array of us all operating in different parts of the country in different ways, and meant that we could signpost or refer people to services best suited to their needs.
144. Beyond being a phone service for people to get information and advice about COVID, people would phone us up asking how we could help them with their particular issue: access to food, friendship, picking up prescriptions and such like. We would be able to identify local organisations to support their particular needs because that work had been undertaken to map out the services and support that exists and use it as effectively as possible.
145. I think this was an excellent piece of work from colleagues, because, although we might not always be able to support someone directly, we could find out who could. There was such an incredible degree of community and charity mobilisation.

### **Longer Term Medical Impacts**

146. The impacts of essentially shutting down the NHS to manage the overwhelming impacts of COVID, being slow to re-establish essential routine and early, preventative medical interventions means that many health issues will have become more severe than they might otherwise have become.
147. From our point of view too many older people are now more unwell than they might have otherwise been as a result of the COVID -19 pandemic; not because they got COVID, but because of how the services have changed.
148. An example of this this is the longer-term impact of knee and hip replacement operations, people are waiting years for treatment; they are then more at risk of falls, increased frailty and arthritis. Your quality of life is severely limited, you're isolated in your own home because you've got lack of mobility and movement. You're terrified of falling in the street and the feelings of loss of dignity that comes with that. Then there is the fear of going to hospital and never leaving due to age related risks arising from what is quite invasive surgery.
149. For a whole range of medical interventions, many older people are now languishing on waiting lists. Are they being then treated as a priority? Or is it that now the intervention is so severe and so expensive that we are never going to get to you?
150. So, you're now going to need more at home medical and or social care, but can't get it, because we don't have enough availability.

### **Overall Impacts**

151. Very quickly and certainly by the summer of 2020, our very real impression was that for older people things were particularly fraught. People had no regular access to food, no access to medical services, no

access to social care, no easy access to friends and family to support them due to distance or fear of transmitting COVID.

152. Even when the world had opened for many people, older people were so worried about COVID that they did not go out. This compounded their overwhelming sense of desperation, sense of loneliness, isolation and abandonment. Our research at the time showed this.
153. Many older people who weren't online had great difficulty accessing their finances and pay for goods and services.
154. In a recent survey we undertook, it is clear that there has been a huge negative shift in attitudes about how older people feel about their lives.
155. Overwhelmingly, they do not feel valued by society; only 3% feel like it's easy to have their voice heard by decision makers; only 8% of people feel that politicians give due consideration to older people's needs. Access to healthcare is poorer; their overall health and wellbeing is poorer.
156. This is their perception of the societal take on older people, arising from their experiences of simply stopping altogether their access to social care, medical care, harder to access wider public services, the effects of DNACPR and feeling isolated from the services that maintain their quality of life and the ongoing threats to their health from COVID.
157. How older people feel about themselves and their place in society and how society values them has deteriorated terribly. Our sense is that life isn't good and it's getting worse for many older people. This is particularly to do with access to health, care and how they feel older people are regarded.

### **Lessons Learned**

158. Throughout the period under consideration by this Inquiry we had a really positive relationship and engagement with The Scottish Government,



particularly through Equalities Department. I feel that officials there were incredibly helpful and diligent in their work and would be proactive in seeking discussions with us on issues and emerging trends facing older people. There was, at the start of the pandemic, weekly meetings about what we identified through the helpline or other channels. These meetings would latterly move to fortnightly or monthly as helpline call volume dropped.

159. Despite these good relationships and high degree of contact we often felt that the questions we asked through them for the attention of wider Scottish Government officials or ministers, during the pandemic, didn't really result in any speedy resolutions or answers. When we would officially write to ministers, it would be many weeks until there was an acknowledgement, never mind a full response. It was hard to determine whether or how the information we were contributing on a regular basis about what the public were telling us was considered as part of a more informed decision-making process around COVID guidelines as they affected older people. The higher-level, or indeed more responsive feedback loop was lacking. I don't think that was too much to ask for.
160. It is vital to understand medium and longer-term impacts of decisions and how they affect some of the most vulnerable people in our society. Just because you're older doesn't mean that you're vulnerable but a lot of older people are vulnerable in lots of different ways, whether through exclusion, low-income, health conditions, no immediate support network and a whole array of other reasons.
161. The impacts of earlier messaging to protect the NHS had an unintended negative consequence on older people – perhaps everyone, but our insight is that from older people. Many went long periods of time without seeking medical care or GP assessments. This had an intense effect on their long-term health and well-being.

162. Particularly after having regular meetings with the Commissioner for Older People in Wales and in Northern Ireland, we came more to the view that there is a need for such a position in Scotland. This would be a statutory role, independent of government with powers of scrutiny and legal challenge where necessary, to uphold the rights of older people.

### **Hopes for the Inquiry**

163. We had campaigned with many others for this Scottish Inquiry to be established long before the Scottish Government accepted it was necessary. One of the key things that we'd asked the Scottish Government to include in the terms and scope was what and how DNACPR decisions impacted the lives of older people. We feel that a review of the circumstances and context surrounding, our perception of, the increase in DNACPR requests which our and other communities received, is necessary. Really understanding what happened, how it happened, why it happened and getting a proper picture of its impact is vital.
164. Why was social care let down so badly? Why wasn't it possible to provide such a crucial sector with the PPE, testing, support and financing it needed to keep some of our most vulnerable people well and alive. How were decisions about social care taken and could the outcomes we witnessed be avoided – this would include the interaction between health and social care such as transfers from hospital to care homes and how that contributed to the infection rates of COVID in these settings.
165. There is a broader fundamental question about whether and how the rights of older people in Scotland were considered as part of the decision-making processes regarding COVID guidelines and restrictions. As much as we all appreciate the enormity of the challenges, the impacts of services being closed immediately, kept closed for an indeterminate length of time, then only very slowly getting to grips with the enormous

backlogs, has all had a massive negative impact on the quality of life for older people. The question must be asked, does a right to life simply infer not dying, or does it mean something more valuable? Should it mean the right to having a life, a good quality of life? And how was that supported? There has to be a fundamental review of the real meaning of this right most especially as COVID related decisions affected many of the basic freedoms and rights which are vital to the overall wellbeing of older people as well as many other of the most vulnerable communities in our society.

Signed: Adam Stachura (*via email*)

Date: 09 April 2024