

OPUS2

Scottish Covid-19 Inquiry

Day 4

October 31, 2023

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(10.00 am)

THE CHAIR: Good morning, everybody. Mr Gale, when you are ready.

MR GALE: Thank you very much, my Lord. Good morning.

My Lord, there are two witnesses today, albeit that they are going to be giving evidence in different forms.

The first witness we have is Mr Henry Simmons, who will be introduced in a few moments. The second witness is Dr Jennifer Burns. Dr Burns has provided the Inquiry with a lengthy and detailed statement. She is the head of the British Geriatric Society. She is not, however, keen to give evidence orally to the Inquiry. So, given that her statement contains a considerable amount of interesting and relevant, in our view, material, it is my intention to read large sections of the statement out. The timing of that is that that read of her statement will commence at 2 o'clock, after lunch. So Mr Simmons will be the only witness this morning.

So, Mr Simmons, please.

THE CHAIR: Thank you very much indeed for that explanation, Mr Gale.

MR HENRY SIMMONS (called)

Questions from MR GALE

THE CHAIR: Good morning, Mr Simmons. Thank you very much

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for coming. Please take a seat and make yourself comfortable.

Good. Now, I see you have some papers. I don't know if you want anything in front of you at the moment, just your statement and stuff. That's fine.

Very good. When you are ready, Mr Gale.

MR GALE: Thank you, my Lord.

Just for everybody's reference, Mr Simmons' statement, the reference is SCI-WT0566-000001, and it will be displayed on the screen as we are going through it.

Mr Simmons, good morning.

A. Good morning, Mr Gale.

Q. Could you tell the Inquiry, please, your full name.

A. It's Henry Simmons.

Q. Your date of birth is known to the Inquiry, but I think it suffices for present purposes to say you are 56.

A. Yes.

Q. You are the chief executive of the charity Alzheimer Scotland Action, which is more easily known, I suppose, as Alzheimer Scotland.

A. Yes.

Q. At paragraph 4 of your statement you tell us that you have held that position since 2008, so for the last 15 years.

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A. Yes.

Q. And you were in that post during the whole of the pandemic and remain in that post.

A. Yes.

Q. Can you tell us a little bit about your background, Mr Simmons.

Before you became chief executive, what did you do?

A. So I am a registered social worker. I started my career off in the mental health world. I trained as a registered mental nurse in Lanarkshire, and then I worked in London for a period of time and Leeds for a short period, and then I returned to Scotland to work for a local mental health charity for several years. I then worked for Enable Scotland for ten years, and I have only really had three big jobs in Scotland since becoming the chief executive of Alzheimer Scotland.

Q. Really just in general terms, can you tell us what your role as chief exec of Alzheimer Scotland involves?

A. Yes, sure. So Alzheimer Scotland is a traditional charity insofar as we have a large membership base across Scotland. We really set out to do three main things, which is to prevent and cure dementia, and our goal is to make sure no one goes through the experience of living with dementia on their own.

My role is the day-to-day running of the charity.

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We have, at the present time, around 400 staff. We provide a number of initiatives that we self-fund through our fund-raised income. So we run dementia resource centres, brain health centres. We also, you know, provide a network of dementia advisers, a 24-hour helpline. We fund research projects. We fund various initiatives within NHS, including Alzheimer Scotland consultants, both nurse and AHPs. And alongside that, we are commissioned by health and social care partnerships to deliver two main forms of commission support: one that is post-diagnostic support services, and the other is registered day services or community connection projects.

Alongside that, my role is to oversee our campaigns, our public policy engagement, all of our communications, and, indeed, represent the 90,000 people living with dementia in Scotland as well as possible.

Q. Some of that material that you have just given us is incorporated in your statement in paragraphs 5 and following.

Just to be clear, when you say you have 8,000 members across the country -- that is at paragraph 5 -- what constitutes a member for you?

A. So a member is someone who signs up to support -- be a member of Alzheimer Scotland. It is not someone that

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1 we would be supporting; it is someone that actually is
 2 a bona fide member with rights to vote, obviously, at
 3 our annual general meeting and other events.
 4 Q. You also say that you have over 90,000 "Dementia
 5 Friends". What are they?
 6 A. So that is different from obviously a membership. The
 7 Dementia Friends programme is a real engagement of
 8 people who wish to do something positive to support
 9 people with dementia, and we train them in a very
 10 small-scale way to become a supporter and, in some ways,
 11 just a general sort of like friend towards the dementia
 12 movement.
 13 Q. Also you say that you are supported by over 1,000
 14 volunteers.
 15 A. Yes.
 16 Q. What areas do volunteers volunteer in?
 17 A. So, I mean, like, if you -- I mean, from the very top
 18 level of the organisation, our trustees, for example,
 19 are volunteers and regarded as such and giving their
 20 time for free. Our helpline has been in existence now
 21 for over, I think, 30 years, and that is run by a team
 22 of volunteers. And then we have many volunteers who
 23 support our local services, and just give extra support
 24 on a day-to-day basis for people. You know, it's quite
 25 a broad church of volunteers.

1 Q. Thank you.
 2 If we just go on in your statement -- I will take
 3 some of this read short -- at paragraph 9 you say that:
 4 "We are commissioned for post diagnostic support
 5 services for people with dementia and now employ
 6 approximately 120 Post Diagnostic Support Link Workers."
 7 Can we go perhaps to pre-diagnostic, because I think
 8 it is something you mention subsequently in your
 9 statement.
 10 So far as pre-diagnostic work is concerned, does
 11 your charity have any involvement in that or any
 12 particular interest in that?
 13 A. Yes. I mean, at the present time, we have been
 14 developing a new significant initiative to engage people
 15 significantly before they start to develop any form of
 16 symptoms of dementia even through our prevention work
 17 and our project called Brain Health Scotland. Over the
 18 past probably ten years, we have learned much more as
 19 a dementia community about the potential of prevention,
 20 and there are 12 lifestyle circumstances which we now
 21 have a very strong universal agreement that if we
 22 actually tackle sooner and earlier with some form of
 23 personalised risk reduction, we can make a substantial
 24 difference towards people developing dementia. So that
 25 is one area that we are obviously working in.

1 There is also the area where people who -- and the
 2 journey towards receiving a diagnosis of dementia, it's
 3 a rocky road, Mr Gale, it's not a smooth process, and
 4 people can be, you know, for some time in a position
 5 where they might be experiencing some form of mild
 6 cognitive impairment or other forms of symptoms. So all
 7 of our dementia advisers and helpline and our services
 8 will provide people with support at that point.
 9 Q. I think one of the points that you make later in your
 10 statement -- and we will come to it in due course -- is
 11 that, during the pandemic, there were considerable
 12 difficulties in the pre-diagnosis stage of dementia.
 13 A. Without a shadow of a doubt, and I can say more about
 14 that just now, Mr Gale, if you would like me to.
 15 Q. Well, leave it until we come to it in your statement,
 16 but I think it is worth flagging up at this stage.
 17 Also in paragraph 9, you refer to that you have
 18 around 17 registered small-scale day services. What are
 19 they?
 20 A. So day services are geared more towards people who are
 21 progressing towards the more sort of moderate mid-stages
 22 of their time living with dementia, and our approach to
 23 that is that you need to develop very specific forms of
 24 support for people during the day services that are
 25 really required to be small, focused, quite intensive.

1 It's about perhaps someone being with us for a day
 2 participating in cognitive stimulation work,
 3 reminiscence work, one-to-one support, general peer
 4 support groups. So our services might have somewhere in
 5 the region of between 8 to 12 people each day, and the
 6 individuals might attend for two or three days per week.
 7 They tend to be commissioned by health and social
 8 care partnerships, and they are registered with the
 9 Care Inspectorate as such, so they are registered
 10 services. It is different from our community projects
 11 that we run in groups, activities that we run on our
 12 own, which aren't registered, but these are registered
 13 and regulated in that fashion, Mr Gale.
 14 Q. Are these geographically spread throughout Scotland?
 15 A. Yes. I mean, we operate mainly in areas, obviously,
 16 where the health and social care partnership are looking
 17 to provide this type of support. Not everyone does.
 18 Not everyone is able to commit to small-scale services
 19 and have to use, perhaps, larger environments that we
 20 don't do. But, yes, I mean, we operate from Shetland
 21 all the way down to the Borders and Dumfries.
 22 Q. Thank you.
 23 I think you also -- and you have hinted at this
 24 already -- have a 24-hour freephone helpline, and did
 25 that continue throughout the pandemic?

1 A. Yes, very much so. I mean, we accentuated our helpline
 2 support to really make that our front line during the
 3 pandemic.
 4 Q. You then say that your link workers -- this is
 5 paragraph 12 -- are working with at least 5,000 to 6,000
 6 people after diagnosis each year.
 7 A. Yes.
 8 Q. That cohort of people, is that within the community or
 9 within both the community and the care home locations?
 10 A. The model of post-diagnostic support is primarily based
 11 on our five-pillar model, which is a model we developed
 12 probably about 12 years ago, prior to the first national
 13 dementia strategy, and the essence of it is that we will
 14 work with people as early as possible in their journey
 15 with dementia, and the earlier and more timely that we
 16 can work with people, the more we can do to build their
 17 network of resilience, support, across their community;
 18 the more we can do to actually help people maintain
 19 their community connections, social connections, in some
 20 cases employment.
 21 You know, it's a very, very sort of early form of
 22 intervention that we have really been very proud of,
 23 because Scotland was the first country in the world to
 24 make this a commitment and a guarantee and to really
 25 give that type of consistent support, albeit we have

1 never managed to achieve it 100% across the country,
 2 maybe 50%. But what it does is it really helps people
 3 who are going through that rocky journey towards
 4 diagnosis to get some choice, power and control back
 5 into their lives, to start to come to terms with the
 6 illness, to understand it, to build up person-centred
 7 plans about how they are going to live well with it, to
 8 build connections and peer support, and it's a very
 9 important part of our system that is all dependent on
 10 that link worker role.
 11 We have another model which is for people who are
 12 a little bit more progressed, and that is called
 13 an eight-pillar model, and often people who are getting
 14 a diagnosis at that early stage, they need a bit more
 15 support and a bit more of work.
 16 In terms of the care homes, our view is absolutely
 17 that if someone gets diagnosed in a care home, they
 18 should still receive that same level of support. But
 19 what you will find is that, in terms of sort of
 20 prioritisation and resource, we have never had enough
 21 link workers to deliver across the whole of the country,
 22 and I think a lot of areas who commission that, which
 23 would be the health and social care partnerships, gear
 24 things more towards the community as opposed to the
 25 care home environment, and it is an area that is often

1 discussed, Mr Gale.
 2 Q. Thank you.
 3 I am just interested -- you mentioned I think
 4 earlier, and also again in the most recent answer,
 5 a person-centred approach. Would that also include the
 6 family and the carers of somebody in early stage and
 7 then perhaps a more progressive stage of dementia?
 8 A. Yes. When we say person-centred, it encapsulates all of
 9 that, and our view is that, in order to help someone
 10 live well with dementia, you have to look at their whole
 11 social system of support, and you have to understand the
 12 strengths within that that you can build on, and the
 13 areas where you might need to put additional supports
 14 in. So the family, the extended family, the person's
 15 community, the person's sort of, you know, broader
 16 networks, are the foundations of how you build that
 17 person-centred approach. And everyone will need
 18 a different form of support at that point, and it will
 19 be very sort of individualised, but that is, in essence,
 20 the basis of that approach.
 21 Q. I think one of the things that I have picked up from
 22 your statement -- and please correct me if I have got
 23 this wrong -- one of the important aspects of the work
 24 that you do in relation to supporting those with
 25 dementia is to try to establish for them some sort of

1 regular and organised daily routine.
 2 A. For some people the -- as I mentioned earlier, you could
 3 have a two- or three-year period which is very traumatic
 4 before you receive a diagnosis. So people will start
 5 perhaps having difficulty remembering issues. They
 6 might have difficulty, you know, with just basic sort of
 7 day-to-day, you know, issues about the community,
 8 forgetting things, and actually really struggling, and
 9 they will then find their way to a GP, and it might take
 10 a year or two before they start to get -- they get
 11 a diagnosis. And during that time, people can often
 12 stop doing things; you know, it might be they don't go
 13 to church anymore or they stop going to their golf club.
 14 They withdraw. They get pretty anxious at times. So
 15 what we are trying to do is to bring all that back out
 16 with individuals, and to then use that community, that,
 17 you know, strength of community alongside what the
 18 person's choices are and what their hopes are, and
 19 really, Mr Gale, to inject a bit of belief that you can
 20 live well with dementia at that point.
 21 And that is quite a transformation, because 15 years
 22 ago the view was: there is no point giving someone
 23 an early diagnosis of dementia because there is nothing
 24 you can do about it. The general perception -- which
 25 sometimes still permeates -- is that this is a condition

1 that is only about, you know, much older people and it's
 2 part of growing older. It has never been properly
 3 understood that this is actually a brain disease process
 4 which is progressive, and the earlier that you intervene
 5 with, you know, personalised supports and plans, the
 6 better someone can live well.
 7 Now, our view is very much that if you give
 8 high-quality post-diagnostic support to an individual --
 9 and I mean high quality; I don't mean two sessions or
 10 one session, I am talking about a year's worth of really
 11 high-quality, skilled intervention, building all of the
 12 aspects up of that five-pillar model -- you will
 13 probably help someone avoid unnecessary admission to
 14 hospital, and most definitely an early admission to
 15 care homes, if you build that resilience .
 16 Q. I think one of the things that we have heard about and
 17 will continue to hear about -- and I think you have
 18 alluded to it already -- is that dementia isn't
 19 necessarily a disease that is associated with the
 20 elderly or very elderly, because we have heard lot of
 21 pre-onset dementia.
 22 A. Yes.
 23 Q. Is that something that your charity is particularly
 24 engaged in?
 25 A. Yes. So, as I say, there is an image around dementia

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1 which is quite, you know, significantly founded on
 2 a stereotypical image which is actually wrong. I mean,
 3 there are something like 4,000, perhaps 5,000 people
 4 living with dementia under the age of 65. There are
 5 forms of dementia that exist in children. There's
 6 childhood dementia. So if you think about dementia less
 7 as that being the condition and think about the brain
 8 diseases that lead up to dementia, you will soon realise
 9 that the reason it perhaps, you know, manifests itself
 10 in older age is because of the duration of time that the
 11 disease has had to progress through someone's brain. It
 12 changes the perception.
 13 So, I mean, one of our key aims is to help people
 14 understand that, that actually, you know, whilst indeed
 15 many, many older people experience dementia, that has
 16 actually been building up for numerous years, and
 17 support needs to be put in place much, much sooner, to
 18 help do all the things I described in terms of that
 19 building resilience and helping people live well with
 20 dementia. And we thankfully are doing some good work on
 21 that in Scotland. I think we actually are a little bit
 22 ahead of the curve with this, which is something to be
 23 proud of, I think.
 24 Q. Thank you.
 25 Can we go to paragraph 13 of your statement, please,

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1 because I think you transition from giving some of the
 2 background and the services that your organisation
 3 provides to talking about the campaigning aspect of your
 4 organisation.
 5 I am going to ask you to read some of this, if
 6 I may, Mr Simmons. Before I do, can I just ask you at
 7 this stage, and perhaps preparatory to some of the other
 8 information that I am going to seek to obtain from you,
 9 obviously you say in paragraph 13 that, as a campaigning
 10 organisation, you seek to influence policy and change;
 11 in the period before the pandemic, were you involved at
 12 any stage in preparing for a pandemic -- not necessarily
 13 the pandemic we experienced, but preparing for
 14 a pandemic?
 15 A. We only became involved in early March, February. We
 16 weren't part of a pandemic planning group of any nature
 17 prior to the pandemic, no.
 18 Q. Do you feel -- I will deal with this in a little more
 19 detail -- it would have been of advantage to Scotland,
 20 society in general and obviously those suffering
 21 dementia in particular, if you had been involved in that
 22 pre-pandemic planning?
 23 A. I think if there had been any work done to prepare for
 24 a pandemic that did not include a very significant focus
 25 on people with dementia and us as an organisation, that

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1 would be a huge mistake.
 2 Q. Right.
 3 Just taking that probably a little bit further, and
 4 I think probably fairly obviously, that is because
 5 I think you and a lot of others that we have heard from
 6 within the Inquiry, and will continue to hear from, did
 7 envisage that one of the groups that would be most
 8 impacted by a pandemic which involved, in particular,
 9 isolation were those in care homes and the elderly,
 10 particularly those suffering from dementia.
 11 A. Yes. I mean, Mr Gale, look, our perspective is if you
 12 sort of break things down into really vulnerable groups,
 13 you have close to 30,000 people living within
 14 care homes, probably 18,000 to 20,000 of them have got
 15 dementia diagnosis and some not; and then you have got
 16 60,000 people potentially living in the community at
 17 home, and they are spread across the spectrum of the
 18 condition. So many, many people living at home will be
 19 in the advanced stage of dementia and maybe receiving
 20 a level of support that allows them to stay at home;
 21 many others will be in that middle/moderate stage,
 22 receiving support from organisations such as ourselves
 23 and many others; and then there will be people who are
 24 in that very early stage who are just coming to terms
 25 with the diagnosis; and then you have the group who are

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1 just on the way to getting a diagnosis.
 2 So that is a huge population that rely mainly on
 3 human intervention. There are only four drugs to
 4 support people with dementia, and they don't support
 5 every type of dementia. So the essence of how we care
 6 for people with dementia is all about individual
 7 support, and about really detailed understanding of how
 8 to best support that person and their family. If you
 9 don't have that, you -- well, we will probably, I am
 10 sure, discuss it, but you will find very quickly the
 11 crisis that people find themselves in without that level
 12 of support.
 13 THE CHAIR: Just a second, Mr Gale. May I ask a question of
 14 Mr Simmons.
 15 You said a couple of answers ago that you weren't
 16 involved in any planning prior to March. You didn't
 17 give the date, but I am assuming it is 2020.
 18 A. Yes.
 19 THE CHAIR: Yes.
 20 It's also apparent from the parts of your statement
 21 that Mr Gale has already been asking questions in
 22 relation to that your organisation has a fair bit of
 23 connection with the Scottish Government. I see they
 24 fund you for certain things, and it's also fairly
 25 obvious that you have a degree of dialogue --

1 A. Yes.
 2 THE CHAIR: -- no doubt varies from time to time with
 3 Scottish Government, is that fair?
 4 A. Yes, my Lord.
 5 THE CHAIR: Do I infer -- and I think it is a fair
 6 inference -- that the Scottish Government never
 7 approached you prior to March 2020 to ask for your views
 8 or any input you may have in relation to pandemic
 9 planning?
 10 A. No, they did not, and we never approached them either.
 11 It wasn't something that was on our radar that we were
 12 trying to get access to. I mean, our focus and policy
 13 work was very much on developing the dementia
 14 strategies.
 15 THE CHAIR: No, I understand that, but you will understand
 16 I'm -- no offence to you -- more concerned with what the
 17 Scottish Government may or may not have done.
 18 A. Yes.
 19 THE CHAIR: Mr Gale.
 20 MR GALE: Thank you, my Lord.
 21 Just going back to paragraph 13 of your statement,
 22 I wonder if I could ask you to read from paragraph 13
 23 through to the end of paragraph 15, because I think this
 24 encapsulates a lot of your campaigning and some of your
 25 ongoing work.

1 A. Yes.
 2 As well as raising awareness of dementia, we
 3 campaign for the rights of people with dementia. We are
 4 a campaign organisation seeking to influence policy and
 5 change, and we do that through developing strong
 6 research evidence--based policy reports or by running
 7 significant campaigns. At the present time, the two
 8 best examples of that are:
 9 Our Fair Dementia Care campaign, which seeks to
 10 bring an end to what we regard as unfair charging
 11 policies in residential care for people living with
 12 advanced dementia. We are presenting to the government
 13 at the present time a strong legal case to what we think
 14 is the basis of that, and this has been a two- or
 15 three-year campaign.
 16 Our Long Term Care Commission, which is chaired by
 17 Henry McLeish, former First Minister for Scotland, and
 18 Henry also chaired the Fair Dementia Care commission for
 19 us. This is looking at what long-term care looks like,
 20 particularly as a consequences of the pandemic.
 21 We also have a large piece of work ongoing about
 22 research and prevention, and we are running a project
 23 that is mainly funded by the Scottish Government, which
 24 is about brain health and dementia prevention. This is
 25 called Brain Health Scotland and is trying to help the

1 public understand much earlier what they can do to
 2 protect their brain health, and this is an example of
 3 how the charity tries to innovate and develop new ways
 4 of thinking.
 5 Alzheimer Scotland funds research projects. Some of
 6 these include supporting a brain tissue bank at
 7 Edinburgh University, funding an Alzheimer Scotland
 8 centre for policy and practice at the University of the
 9 West of Scotland, and, until recently, funding a centre
 10 in Edinburgh that has been ongoing for over ten years.
 11 We also run an important research recruitment
 12 programme in Scotland called Join Dementia Research,
 13 which is a UK-wide initiative. Our aim is to prevent,
 14 care and cure, and our mission is to make sure no one
 15 faces dementia alone.
 16 Q. Okay, thank you.
 17 Now, the next section of your statement, you go on
 18 to consider the impact of the pandemic on front-line
 19 services. This is obviously quite a significant section
 20 of your statement and a significant area of your
 21 concern.
 22 So, again, I would like you to read through that
 23 section and, at the end, I will ask you one or two
 24 questions about it. But if you read, if you would, from
 25 paragraph 16 through to 33, please.

1 A. So prior to the pandemic, we were trying to prepare for
 2 the potential impact the pandemic would have arriving
 3 here in Scotland. We saw what was going on in Europe,
 4 and we were incrementally carrying out initiatives and
 5 engaging with government. I have to say that the
 6 engagement at the start of the pandemic with the
 7 government was particularly good. We were working very
 8 closely with senior government officials, the
 9 Deputy Chief Medical Officer and highlighting the
 10 concerns and issues.

11 We were concerned that there is a huge population of
 12 vulnerable people who at that point in time were having
 13 to absorb very frightening information that the pandemic
 14 was coming. We were trying to keep things stable, keep
 15 people well—informed, to make sure each time a new phase
 16 was coming, we were communicating that to people. We
 17 were also highlighting back to government about the
 18 concerns — what the concerns were from the front line
 19 and how we could work together to alleviate some of
 20 that. An example of this was a leaflet that went out to
 21 everybody in Scotland about emergency contact details,
 22 including our helpline number.

23 We were trying to balance the risks of what we were
 24 facing. We had 500/600 staff many of them were going to
 25 be engaging directly face—to—face with service users

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1 through services or home visits.
 2 A challenge for us was when track and trace stopped,
 3 as we were still running services for people, and to
 4 minimise the risk to our day services, we set in place
 5 several protocols, including buying 600 thermometers.
 6 We gave a thermometer to every member of staff and
 7 monitored each person’s temperature before coming to
 8 work.

9 When test and trace at that time stopped, there was
 10 a period when people had to isolate if they had
 11 a symptom, and there was not the availability for
 12 testing. During that process, we were communicating to
 13 government the challenges to day services and indeed
 14 home visits.

15 When lockdown occurred, we went from a fully
 16 functioning organisation providing all face—to—face
 17 support to having some 600 staff working at home.

18 The impact of that on us as an organisation was that
 19 a good number of people who previously had been
 20 receiving care from us were now at home and not able to
 21 go out, and needing quite a lot of support. What we
 22 then tried to do was increase our helpline capacity, and
 23 we encouraged people to contact us if they needed things
 24 like food, medication or just connections.

25 We also worked out a way all the staff that

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1 previously ran our day services went onto the phones and
 2 started making sure people were okay. At that time, we
 3 got everyone settled down and worked out who were the
 4 most vulnerable people. We couldn’t go into someone’s
 5 house, but we could go and do an essential door visit to
 6 make sure someone was okay or drop something off to
 7 them.

8 The team leaders we had in place were all working
 9 through detailed assessments of individuals to
 10 understand who was most at risk. If there were people
 11 with high levels of vulnerability, we would be
 12 highlighting that. The most important thing was to
 13 maintain contact with people to make sure that they were
 14 constantly engaged with us, and over time our colleagues
 15 got very skilled and articulate at developing support
 16 through telephone contact.

17 We then started running online support groups and
 18 activities. We started using Teams and Zoom. All of
 19 our football groups, artwork and therapeutic activities
 20 moved online, which I think was a remarkable
 21 achievement.

22 We were painfully aware that, behind all of that,
 23 there was a population of people that the digital and
 24 online activity would be difficult to reach, and our
 25 localities were doing well and seeking to continue the

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1 support for people.

2 Our concern wasn’t just for the people who we were
 3 supporting. There are 90,000 people living with
 4 dementia in Scotland. We were 100% certain that, as
 5 soon as the measures of lockdown started, the pressure
 6 on that community, especially on carers, would be
 7 inordinate, and we were extremely concerned about what
 8 their experiences would be like.

9 That group included people who recently had
 10 a diagnosis but who weren’t able to access
 11 post—diagnosis support. There were also people waiting
 12 for a diagnosis, and that is a horrific place to be.
 13 They couldn’t get it. All other services around about
 14 that dementia diagnosis were closed.

15 There are lots of people with dementia with complex
 16 needs. It was also a challenge to navigate
 17 non—face—to—face contact with GPs, and we were concerned
 18 there would be a physical impact on some people because
 19 they couldn’t access the general healthcare services in
 20 the same way. There were complex hurdles to access
 21 these services.

22 In addition, there were people living at home and
 23 people living in care homes, and our responsibility as
 24 a representative organisation was to try and highlight
 25 the issues these individuals were experiencing directly

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1 into government, and use that information to reshape our
 2 services .
 3 The impact on our staff was huge. To begin with, we
 4 had to get staff in a place where they made the
 5 transition to working at home, and we helped them do
 6 that. We then started to embrace technology, and an
 7 example of this is I did a weekly update video call for
 8 all staff. We tried extremely hard to keep staff
 9 on board. I think they found the initial days traumatic
 10 as our staff are all about relationships with people.
 11 They did their best to maintain relationships .
 12 My main concern at that time was for the people
 13 living with dementia in the community. There were three
 14 big areas that we felt would be problematic for them.
 15 People would run out of money quickly, food or
 16 medication, and a lot of people we supported would have
 17 their regular routines of popping out to the Post Office
 18 to pick up their pension, get some shopping then go to
 19 the pharmacy. All that stopped. We were trying to make
 20 sure no one was left completely on their own with that.
 21 During this time, we had a strong connection with
 22 the Scottish Government's Dementia Policy team. I was
 23 talking almost daily with senior civil servants trying
 24 to influence policy, but at the same time get advice
 25 back. I felt at that time we did some positive work to

1 help the communication and let the government understand
 2 the experiences people were going through, and we were
 3 receiving information back relating to how COVID
 4 spreads, etc.
 5 Q. I will just stop you there, Mr Simmons.
 6 Just going back over some of the things you have
 7 said in that section, right back at the beginning, in
 8 paragraph 16, you say that at the start of the pandemic,
 9 the engagement with government was particularly good,
 10 and you say that you were working very closely with
 11 senior government officials, the Deputy Chief Medical
 12 Officer, and highlighting the concerns and issues.
 13 Can you give us a little more detail of that,
 14 please.
 15 A. Yes, sure. So what we engaged around were primarily the
 16 issue of how, first of all, we communicate. So we
 17 designed leaflets explaining, you know, the virus and
 18 how to use the sort of measures in place at that time.
 19 So we designed joint leaflets and shared that
 20 communication. We were also getting advice about how
 21 the virus spread, and there was quite a bit of dubiety
 22 at that point in time. So there were issues about:
 23 could it be spread just through people having symptoms,
 24 or if someone was asymptomatic, would it spread?
 25 Mr Gale, like I described to you, at this point we

1 have hundreds of people, indeed thousands of people,
 2 receiving support within our services, and we are trying
 3 to make sure that we don't become a risk factor within
 4 that, and we are trying to make sure that all of our
 5 staff and the people that are coming are following, you
 6 know, good hand and respiratory hygiene.
 7 Q. Just to stop you there, you say you wished to avoid
 8 being a risk factor; how would you have been a risk
 9 factor?
 10 A. I think if our staff hadn't been really, really diligent
 11 and all the mitigating measures, and if we hadn't been
 12 so focused around making sure that if people had any
 13 symptom at all -- which is where the thermometer was
 14 important, because in the first couple of weeks we maybe
 15 had one or two people around one of our services that
 16 might have been going through the test and protect
 17 system, which meant they had been connected to someone
 18 who had been tested, and so we were able to monitor that
 19 very carefully. That stopped, so we were then faced
 20 with: what is the best way of ensuring that any of our
 21 staff coming to work actually are as safe as possible?
 22 So the idea that we came up with was: well, one of
 23 the key symptoms is a temperature and a cough, so that
 24 led to us having a very consistent process of every
 25 single member of staff, before they came to work, went

1 through a protocol of taking their own temperature,
 2 making sure they had no symptoms, making sure they
 3 hadn't been around anyone with symptoms, and then coming
 4 to work safely. I think that was essential to keep it
 5 going.
 6 And that is where we were engaging. We were talking
 7 to senior officials. We were getting advice back about
 8 the symptoms. We were part of a group that was trying
 9 to keep things going for probably quite an intense two-
 10 or three-week period.
 11 Q. In that very early period, your dialogue with government
 12 officials, I understand that you were receiving from
 13 officials information about transmission of the virus,
 14 etc; what were you giving back to officials at that
 15 time? What information at that very early stage were
 16 you conveying back to officials?
 17 A. So the types of thing -- we were probably at that point
 18 just highlighting the scale of services and the number
 19 of people that we would be thinking about. Sadly, we
 20 don't have very good data on dementia in Scotland, and
 21 we would be, at that point in time, getting an
 22 assessment of: how many people had phoned our helpline
 23 up, what were the issues coming through the helpline,
 24 what types of things do we have to think about, and we
 25 would feed that directly in.

1 We would also be feeding in our experiences of what
 2 was the interpretation of our community in terms of the
 3 measures that we have been asked to take and is that
 4 working, what do we need to do about that, and we would
 5 feed that in.
 6 Q. Now, I don't want you to disclose the names of any
 7 particular officials that you were dealing with, but was
 8 there a particular department that you were liaising
 9 with, with this information?
 10 A. Yes, I was working extremely closely with the dementia
 11 policy team at that point in time, a named individual,
 12 and the type of relationship that we had was actually
 13 quite longstanding; we had worked together on a number
 14 of strategies, so that was fine. But we would be able
 15 to call each other within a half hour if we needed to
 16 speak, there wasn't any delay. If there were issues
 17 that we had to discuss or engage with, both parties
 18 would react to that. We were taking it incredibly
 19 seriously, trying to get as much safety into our system
 20 as possible.
 21 Q. At that very early stage -- and I think we are all
 22 mindful of the fact that in many respects we were
 23 dealing with the unknown --
 24 A. Yes.
 25 Q. -- what was of particular concern to you at that very

1 early stage?
 2 A. I think we obviously were looking across to Europe, we
 3 were seeing the types of things that were happening. We
 4 were getting information about the fact that, actually,
 5 this virus could be airborne, and there was, you know,
 6 in the early days, I think a fear level that was
 7 permeating through our community in such a way that, you
 8 know, it was just terrifying for people, and my biggest
 9 concern was to try and make sure that those individuals
 10 that we were connected with and supported felt confident
 11 in the advice that we were giving them, and that the
 12 advice we were giving them was accurate and as detailed
 13 and as well balanced as possible, and trying to reassure
 14 people that we would be there for them and we would help
 15 get people through this.
 16 Q. An aspect of that is obviously communication.
 17 A. Yes.
 18 Q. We will come to this in further detail as we go through
 19 your statement.
 20 What are the particular difficulties of
 21 communicating with the dementia community, if I can put
 22 it that way?
 23 A. I think what -- we obviously have a very sort of
 24 dedicated communications team, and there are various
 25 ways that we would reach out to people. So at that

1 point in time, there are a number of people that you
 2 know through their families and connections that you
 3 could probably reach through a social media
 4 communication, for example. But for many more people,
 5 it's a matter of writing and a matter of engaging and
 6 directly communicating.
 7 We also have a large group of people who receive
 8 updates -- a monthly update from myself as just members
 9 and supporters. So we can get general communications
 10 out. But what we were never able to do -- and we simply
 11 wouldn't have had the resources for that -- would be
 12 identify who the 90,000 people living with dementia are
 13 in Scotland and send a communication out directly to
 14 everyone. We had to rely on public messaging coming
 15 from government across the broader areas of
 16 communications to reach that community.
 17 Q. I take it also -- if I can put it this way -- the tone
 18 and content of what you would be communicating would be
 19 important, given the recipients of the information.
 20 A. Yes, and that is where I think the partnership working
 21 was pretty much important, because we were agreeing what
 22 the main message would be and then putting that out into
 23 as -- well, for want of a better term, as
 24 dementia-friendly language as possible, trying to make
 25 it something that people could understand, and I think

1 that was -- that worked pretty well, Mr Gale.
 2 Q. Thank you.
 3 I am just taking a number of points from that
 4 passage, a number of paragraphs that you have read,
 5 Mr Simmons.
 6 Can we go to paragraph 30, where you talk about
 7 people living at home, people living in care homes, and
 8 you say:
 9 "Our responsibility as a representative organisation
 10 was to try and highlight the issues that these
 11 individuals were experiencing directly into Government
 12 and use that information to reshape our services."
 13 I think you have explained what you were trying to
 14 convey to officials. Can you just explain how you were
 15 utilising the information that you were receiving to, as
 16 you put it, "reshape our services"?
 17 A. So if you imagine that we start to receive a really
 18 significant increase in number of helpline calls and
 19 issues and concerns about, shall I say, for example,
 20 people worried about getting money, worried about
 21 getting medication, food, so we would then feed that in
 22 and follow that up with perhaps some proposals about
 23 what could be done about it. And indeed, from my
 24 perspective, what we did -- and this is a little bit
 25 further on, Mr Gale, from the very early stages, but

1 what we did was we realised that we had to bolster that
 2 front—line support, so as well as having the helpline,
 3 we then brought in some of our dementia advisers
 4 and skilled practitioners to help people at that point
 5 in time. We also then sought to use our localities to
 6 provide that front line.
 7 But what was also happening was that other
 8 organisations — there were other really good community
 9 initiatives starting to take place, so you would want to
 10 try and make sure that that was all strategically coming
 11 together and that there was a connection between that,
 12 and at one point the general idea was that there may be
 13 one national helpline that would then feed people out
 14 into sort of like, you know, more specific areas. So if
 15 someone contacted the national line, they would then —
 16 if it was someone with dementia, they would then come to
 17 us and we would support that person or support that
 18 locality.
 19 So this work was — I mean, I don't think it ever
 20 really got, like, a fully embedded strategic sort of,
 21 you know, strong position going forward, but in the
 22 early days, that was the type of work that was being
 23 discussed and the types of things that were being looked
 24 at and considered.
 25 Q. Thank you.

1 You mentioned that the impact on your staff was
 2 huge, and I think we can readily understand that; not
 3 only at the beginning of the pandemic, but as the
 4 pandemic progressed.
 5 Did you lose many staff — I mean, did many staff
 6 just leave the organisation during the pandemic?
 7 A. That was never a big feature. I couldn't give you
 8 an absolute figure just now. But, no, I mean, I have to
 9 say, the — what — if you imagine, our staff are
 10 ranging from a support worker who works within day
 11 service, to a dementia adviser operating across
 12 a community to a link worker. Their level of commitment
 13 was remarkable, and I think — I mean, it is further on
 14 in the statement, Mr Gale, but our staff were wanting to
 15 be out in the front line, they were wanting to visit
 16 people, they were wanting to open up services. They
 17 weren't stepping back from it; they were desperately
 18 keen to step towards it. And, as a chief executive,
 19 that was probably one of the most challenging things for
 20 me, was to see all of these staff who were dedicated and
 21 committed to helping people, but having to hold them
 22 back.
 23 Q. And I imagine something about which you would be very
 24 proud.
 25 A. Without a shadow of a doubt. I think the way that our

1 staff, when we got back out, were very brave, and what
 2 they did to innovate and develop, and to go the extra
 3 mile for people, I probably don't even know the extent
 4 of that, but the sort of ethos amongst them was just
 5 remarkable.
 6 Q. Can we go on to the impact on individuals and families
 7 at paragraph 34. Again, can I hand back you to read
 8 some of this, please. If you read from paragraph 34 to
 9 the end of paragraph 40, please.
 10 A. The people we supported were extremely impacted by all
 11 the measures, and I think disproportionately by the
 12 measures overall. If you were to start at the far end
 13 of the dementia spectrum, the people with advanced
 14 dementia who require 24—hour care, who live in
 15 a care home environment, maybe not having the capacity
 16 to consent or the ability to agree to some of the
 17 measures that were being implemented. What we were
 18 concerned about was the day—to—day experience of people
 19 being isolated in their room.
 20 Then there were people with more advanced dementia
 21 who were looked after in terms of day services or looked
 22 after at home by their families. This was a significant
 23 level of need, and all of those individuals were now
 24 getting passed onto families. There was little in the
 25 way of other support to get into that person's home, no

1 respite, and a lot of our work previously had been
 2 giving family carers the opportunity to have a day or an
 3 afternoon respite.
 4 Due to the pressure on the families, we got a sharp
 5 increase of helpline calls and people looking for
 6 increased levels of support on the telephone. We then
 7 increased our helpline capacity to give people more
 8 support and so we could take more calls, and we found
 9 there were lots of stress and distress.
 10 Q. Can I just pause there. Stress and distress on whom?
 11 A. The majority of calls we were receiving were directly
 12 from carers, and at this point in time, Mr Gale, what
 13 happened was that everything stopped around about that
 14 carer and that family, unless there was a real sort of
 15 significant, substantial need and a big level of support
 16 going in, and the family were then faced with — and
 17 this is at the point of lockdown — being entirely on
 18 their own, 24/7, with very little access to support.
 19 If you can imagine that someone who is trying to
 20 understand that, who is living with a complex form of
 21 dementia, and a carer on their own trying to help that
 22 person understand that, but not just that, trying to get
 23 through their day, not knowing if they are going to be
 24 able to get their shopping or have a meal for the next
 25 day, not knowing if they can get to their GP, not

1 knowing if they can get access to any form of support —
 2 this was the types of calls we were receiving, and the
 3 type of stress and distress that our community was
 4 under.
 5 Q. Thank you.
 6 Carry on at 37, please.
 7 A. Then there is the group who were recently diagnosed. We
 8 would have normally been working with many of these
 9 people to help them build resilience to continue to live
 10 well with dementia so that they could keep going to
 11 everyday community activities. That all stopped. At
 12 the point of diagnosis, we tried to use every single
 13 part of the person's community and their own personal
 14 strengths to build a platform that gives them resilience
 15 to live well with dementia. That platform was not
 16 there, with only their family for support.
 17 Finally, you had a group of people who were waiting
 18 on a diagnosis, and there are potentially 15,000 to
 19 20,000 people each year developing dementia in Scotland,
 20 and all of them sitting not getting a diagnosis.
 21 What we saw very quickly was that the impact of
 22 lockdown and the measures were falling on carers, family
 23 members and the stress they were under was huge. People
 24 were desperate. In addition to these issues, some of
 25 these people developed COVID symptoms or COVID and were

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1 admitted to hospital. Carers were not allowed to go
 2 with them. Our staff were dealing with carers saying,
 3 "My husband has been taken to hospital in an ambulance,
 4 but I can't go with them". There were many people who
 5 never saw their loved ones again. We quickly saw trauma
 6 and pain and levels of despair that I have never
 7 witnessed in my whole working life before. We tried our
 8 best to help them but, very quickly, it became a crisis.
 9 In the initial stages, we were preparing for the
 10 pandemic, and this included producing information
 11 leaflets, communications and risk management approaches
 12 to try and keep services going. We were in a situation
 13 where we tried to remodel our services to give people
 14 support. At that point, we saw very quickly through our
 15 front-line services a level of crisis and stress.
 16 Q. Now, can I ask you a few questions particularly about
 17 paragraph 39 and 40.
 18 Obviously one is progressing into the pandemic, as
 19 you are reflecting here. I am not particularly
 20 concerned about precise dates, Mr Simmons, but I think
 21 we can infer various things from what you say, and if
 22 you can give some indication of time frames, that would
 23 be helpful, but I am not looking for precise dates.
 24 You say at the beginning of paragraph 39:
 25 "What we saw very quickly was that the impact of

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1 lockdown and the measures were falling on carers ..."
 2 A. Yes.
 3 Q. First of all, can you give some context to what was
 4 "very quickly"?
 5 A. So, I mean, for us, even the message about lockdown
 6 caused significant stress to people, and the calls to
 7 our helpline, probably as soon as lockdown was
 8 announced, was: what am I going to do? How can I get
 9 help? What is going to happen?
 10 Soon after that, the issue about whether or not
 11 people could go and visit someone, in terms of their
 12 family members coming to that person's house, in terms
 13 of social care provision, what we very quickly saw was
 14 that most things stopped and people were, as we know,
 15 locked down. That is when I think the normal levels of
 16 community support, the normal levels of family support,
 17 the normal levels of state facilities and support just
 18 were gone, and people were trying their best to get
 19 through that.
 20 So we did have — I couldn't give you a precise
 21 number, but within a two- or three-week period, you
 22 know, we certainly had people who were really struggling
 23 to get access to their medication, who were really
 24 struggling to — online shopping wasn't a great big
 25 thing in that period of time. There was — I mean,

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1 these were — the primary initial concerns we had was,
 2 like, goodness, people won't have cash, they can't get
 3 out to go to the bank. They maybe went to the
 4 Post Offices; they are all shut. They won't be able to
 5 go and get shopping because you couldn't get it in
 6 supermarkets. It was really practical, you know, like,
 7 essentials that we were deeply, deeply concerned about
 8 getting to people.
 9 Q. You give the example, which I think is probably
 10 obviously anecdotal, of a carer phoning up and
 11 indicating that her husband had been taken to hospital,
 12 query whether that person was ever going to see her
 13 husband again. Was that something that happened on
 14 a number of occasions?
 15 A. Yes. Yes. Again, I'm afraid I don't have any sort of
 16 like hard Quantative data on that.
 17 Q. No, I am not looking for that.
 18 A. But, Mr Gale, I mean, very often, I would have staff
 19 members needing to be supported by our senior leaders to
 20 deal with that, because they were receiving calls of
 21 that nature quite frequently. And just — I mean,
 22 family members just in absolute, you know, bewilderment
 23 as to: how on earth can my loved one go to hospital and
 24 for me not to be able to go with them or see them?
 25 And then we also had people trying to get contact

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1 numbers in the hospital, trying to find out where their
 2 loved one was, and, you know, I completely understand
 3 the difficulties hospitals were experiencing at that
 4 point in time, but there was just that basic, you know,
 5 information about how a person was doing and how they
 6 were fairing and what the treatment plan was, just
 7 stopped, and in a sense -- not in every circumstance,
 8 obviously, but for some people, that was the last time
 9 they saw their loved one, and they then had to deal with
 10 the -- well, the grief and the trauma of that.

11 But we were picking up -- and not just us; I'm sure
 12 other organisations very much were in the same
 13 position -- we were picking up people in that position
 14 and trying our best to help them deal with that. But
 15 very, very traumatic for that individual, and for the
 16 staff that were dealing with that.

17 Q. You mentioned twice in 39 and 40 -- you say, "Very
 18 quickly it became a crisis", and then you refer to
 19 "a level of crisis and stress".

20 Can you indicate what you mean by "crisis", and for
 21 whom it was a crisis?

22 A. Yes. So my meaning of "crisis" in that circumstance is
 23 that it is not just for one individual, it's not
 24 a one-off event; it is pretty broad, it's happening
 25 pretty regularly, and it really -- it needs urgent

1 attention. And I think there is no doubt it is a crisis
 2 for the individuals involved, but for us, we were
 3 looking at this and thinking: we've moved from
 4 a reasonable system -- not a perfect system of, like,
 5 dementia care at all in Scotland, not perfect at all,
 6 but we've moved from a reasonable system, reasonably
 7 well-positioned in terms of diagnosis and
 8 post-diagnostic support and day services and advanced
 9 care, to having none of that, and we are expecting
 10 somehow, through, you know, their own resilience and
 11 determination, families to pick up on all of that on
 12 their own.

13 That is where the crisis came from, and that is, in
 14 my opinion, an unreasonable expectation, to think that
 15 you can take away a whole care system and hand that over
 16 to families to deal with.

17 THE CHAIR: Putting it objectively, would it be fair to say
 18 that the services which you had, as you explained, over
 19 a relatively long period of time developed and were
 20 developing could no longer be delivered by you?

21 A. My Lord, that is exactly correct. Everything had to
 22 stop. And the difficult part, my Lord, about that is
 23 that it's all that human intervention which is the
 24 service. So it's all based on your ability to interact
 25 and support individuals and give them that strength of

1 connectivity and connection, and that is the thing that
 2 probably we were very proud of about -- in Scotland, and
 3 not just Alzheimer Scotland, but a lot of dementia
 4 practitioners, having transformed our system over the
 5 past 15/20 years towards that, and I think had
 6 a reasonable system. It did stop.

7 THE CHAIR: Mr Gale.

8 MR GALE: Thank you, my Lord.

9 Just taking that slightly forward, Mr Simmons, you
 10 had a difficulty -- or your staff had a difficulty -- of
 11 providing the level of service that you had been doing,
 12 and, of course, those who were in a position in the
 13 community to care for people with dementia were
 14 similarly having a difficulty in providing the sort of
 15 level of care that they could provide.

16 A. Yes.

17 Q. So it was just -- make it sound facetious, but it was
 18 a double-whammy.

19 A. Yes, without a shadow of a doubt, and I think that
 20 the -- I mean, at that point in time, as I referred
 21 earlier -- later on, Mr Gale, in my statement,
 22 we weren't pandemic experts, we weren't -- we didn't
 23 understand how to handle a pandemic. We were trying to
 24 help people understand why these measures were there.
 25 We were taking the advice and the lead from the

1 government and scientists on that. But at the same
 2 time, every aspect of what you would regard as
 3 a community infrastructure was just having to stop. And
 4 that is where I think the -- a human service of the
 5 nature of dementia care, you can't do that. You just
 6 can't stop everything, you know. That is where the
 7 biggest problem starts to arise.

8 Q. Can we go to paragraph 41 and following, because there
 9 you say "What we did about this".

10 Again, can I ask you to read through to the end of
 11 paragraph 45, please.

12 A. So in May 2020, we wrote a proposal to the government
 13 requesting that we open our resource centres to provide
 14 people with short respite breaks. This was two months
 15 into the pandemic.

16 We were so deeply concerned that people needed
 17 respite, social connection and opportunity, and we
 18 designed a system to use all our resource centres, with
 19 proper social distancing, with very small numbers, for
 20 a couple of hours. We felt that people were missing out
 21 on this.

22 We started highlighting these issues directly into
 23 the dementia policy team at the Scottish Government,
 24 and I wrote a couple of proposals at that time. The
 25 biggest areas of concern in the early days was the need

1 to give people help and support.
 2 What seemed to happen was that the Scottish
 3 Government created the structures through which they
 4 were going to make bigger generic decisions. An example
 5 of this was the CPAG group that was set up, and other
 6 groups were established. CPAG is Clinical Professional
 7 Advisory Group. Our proposals, which in the past would
 8 have been decided upon by the dementia policy team, had
 9 to go through the bigger groups and boards, and we never
 10 got permission to open up our resource centres in May
 11 2020. It was at that point I felt that dementia started
 12 to get lost and our client group started to fall down
 13 the priority order.
 14 We didn't get our centres opened up until a year
 15 later, even though we had a comprehensive risk
 16 assessment and plans. We were constantly writing,
 17 campaigning and highlighting that need. We published
 18 the first version of our COVID-19: The Hidden Impact
 19 report in November 2020, and we updated this in July
 20 2021. The report highlighted all the concerns that we
 21 had. The impact of the measures on people's physical,
 22 psychological and emotional health were huge, but add
 23 into that people living with dementia and their family
 24 going through this -- it's phenomenal. We pushed hard
 25 for our resources to get opened back up. The impact of

1 these centres not being open was detrimental to their
 2 health and well-being.
 3 Q. Can I stop you there. A few things from that section of
 4 your statement, Mr Simmons.
 5 Going back to paragraph 41, you say in May 2020, so
 6 two and a half months into the pandemic, you wrote
 7 a proposal to government requesting that you open up
 8 resource centres. Why did you do that?
 9 A. Sorry?
 10 Q. Why did you do that?
 11 A. Mainly because of what I have described, Mr Gale, the
 12 crisis that people were going through and what they were
 13 experiencing. And also, whilst we were -- and I should
 14 say I think we were supporting a lot of people in a very
 15 positive way through our online and digital activities
 16 and connections. We delivered about 6,000 online groups
 17 and were helping many people in that way, and for many
 18 people that was quite a strong level of support. We
 19 just knew so many other people who couldn't utilise the
 20 online supports needed that time, needed some support,
 21 needed some respite.
 22 We also wanted to use our skills because, I mean,
 23 within our services, we know there's things that we do
 24 help alleviate the symptoms of dementia. We know that
 25 by providing cognitive stimulation, engagement in proper

1 activities and reminiscence work, we help people
 2 maintain their sense of self, we help people just live
 3 better with dementia, and we weren't reaching everyone.
 4 So our concern was that.
 5 And actually, I think I was very, very fortunate
 6 insofar as I had a really great safety and well-being
 7 team who got on top of all the sort of measures and
 8 guidance, and we wrote really detailed, very intricate
 9 proposals about how we could do this safely and in a way
 10 that would meet all the guidance that was available at
 11 that time.
 12 Q. Obviously a point I was actually going to ask you about:
 13 how to do this safely; this was a part of what you were
 14 proposing to government.
 15 A. Yes. We actually, like, you know, submitted it as part
 16 of our Rule 8 evidence.
 17 Q. Yes.
 18 A. We wrote very detailed -- from the point of someone
 19 leaving the house to coming to the centre and what would
 20 happen in terms of cleaning everything and all the sort
 21 of forms of cross-infection measures. We -- I think my
 22 team did a fantastic job with that, and it could have
 23 been done, in all regards, as safely as anything else
 24 was being done. You know, there are no guarantees that
 25 it was non -- risk-free, it was obviously going to have

1 some risk attached to it, but the balance that we were
 2 arguing was the risk of not doing it was starting to
 3 outweigh the risk of doing it, and we were quite
 4 confident that if the measures that were in place to
 5 minimise risk were competent, then we could have
 6 competently delivered that.
 7 Q. We will come to the balance that you have alluded to
 8 there in due course, Mr Simmons, but so far as you were
 9 concerned in May 2020, this balance was coming into
 10 play?
 11 A. Yes.
 12 Q. You say in paragraph 44 that the government structures
 13 that were in place, particularly through the CPAG group,
 14 were ones, as you put it, "to make bigger generic
 15 decisions".
 16 A. Yes.
 17 Q. Do I take it as a consequence of that the more --
 18 I won't say "micro", but the more detailed proposals
 19 that you were making in relation to dementia, you put
 20 it, were lost?
 21 A. Yes, Mr Gale. What we found started to happen was that
 22 that very strong connection and engagement with the
 23 dementia policy team continued. The dementia policy
 24 team -- and we are on the outside of this, Mr Gale, so
 25 I can't say for a fact what happened there, but the

1 impression that I had was that the dementia policy team,
 2 rather than being able to make a decision, had to refer
 3 that up the way, and that that decision or that request
 4 then had to be put in balance with numerous other
 5 decisions that were being made, and what seemed to us to
 6 happen was that — this is where the formation of
 7 blanket decisions started to come into play. So it
 8 would be things like: no day care can open up at the
 9 present time, no visiting in hospital, no — very big
 10 sort of like generic approaches to decision-making.

11 Now, we followed on our arguments, not right at this
 12 point in time but later in the day. We were arguing to
 13 say that dementia policy team actually should have been
 14 a directorate and it should have had its own dedicated
 15 directorate, and that directorate should have had the
 16 power to look after the issues of people with dementia
 17 throughout this pandemic, and we really — we got to
 18 that later on in the day and wrote proposals to say this
 19 is what really needs to happen. Because the size and
 20 scale of dementia and the number of people living with
 21 dementia, and indeed the issues that were evolving
 22 within care homes, it was merited to have a dedicated
 23 dementia lens and focus and to make decisions
 24 specifically around that.

25 And in a sense, Mr Gale, the — you know, these

1 would be — these were big decisions that could have
 2 been taken. They weren't small minutiae. You know,
 3 arguing to restore a form of, you know, human
 4 intervention and care for people with dementia across
 5 Scotland is a big decision, and it really should have
 6 had its own focus. And I think what happened was that,
 7 you know, we were trying to do what we have always done,
 8 which was produce evidence and be responsible and, you
 9 know, diligent in our efforts to get that in front of
 10 key officials and ministers where required. But we
 11 just — we struggled, and we got — I have to sort of
 12 say that, you know, we were getting support from the
 13 dementia policy team to try and push these things on.
 14 We got good support from areas — like we wanted to
 15 convert our day services to home-based support and we
 16 got help to get the Care Inspectorate registration and
 17 stuff, so there was stuff that was still happening that
 18 was good. But what really, in my view, stopped
 19 happening was this engagement of: let's look at
 20 dementia, let's look at 90,000 people, let's think from
 21 the point of pre-diagnosis to diagnosis to, you know,
 22 late-stage care, what are we going to do about that?
 23 And I feel we should have had a specific strategy around
 24 that. We got a recovery plan a little bit later on, but
 25 that missed a lot of what could have been done earlier.

1 Q. Two things that I can perhaps, again, ask you about just
 2 for your comment.

3 I am anxious not to put words in your mouth, but
 4 I will: did you get the impression that once your
 5 representations went from the specific dementia policy
 6 team beyond that, there was a lack of priority being
 7 attributed to it?

8 A. It's very difficult. As I say, we weren't inside to see
 9 what the reaction was. But what I suspect would happen
 10 would be that we might be making a case for people with
 11 dementia, and then, from my own experience, I am pretty
 12 certain the learning disability community would be
 13 making a case from their perspective, and I am sure
 14 others would be making a case. So the various policy
 15 teams would be sort of like trying to deal with these
 16 issues and representing that into a body such as CPAG to
 17 make decisions.

18 Now, obviously, from my perspective, I am going to
 19 argue the case and say: for people with dementia, like,
 20 we would have expected to see someone look at our
 21 proposals and say: so here's an organisation here that
 22 is willing to get their staff back out into the front
 23 line, that is prepared to sort of try and mitigate these
 24 risks and want to work with us to do that; let's at
 25 least try and give it a go. Yes? And then build on the

1 priorities behind that. Particularly when we produced
 2 our hidden impact report in November. By that point, we
 3 had one day service that we managed to get open just for
 4 a short period of time in Dundee, and then it had to
 5 close again because we went into a further period of
 6 lockdown. But we feel that we produced a very
 7 well-informed comprehensive report that highlighted all
 8 of that we have been discussing today, Mr Gale, and put
 9 that in front of government. We felt that that would
 10 have and should have been treated with a significant
 11 degree of reaction.

12 Q. The other point that I would just like to ask you
 13 directly, Mr Simmons: you didn't get permission to open
 14 your resource centres in May 2020; what was your
 15 reaction to that?

16 A. I think, again, look, we had to have some sense of
 17 understanding that we weren't pandemic experts, so we —
 18 yes, we sort of mooted it on the 20th and we wrote
 19 a proposal on the 29th, and then what we did was we kept
 20 giving people the support we were giving. We then
 21 decided to produce a really well-researched report that
 22 I mentioned, the hidden impact report. So we went from
 23 just writing proposals and making Recommendations
 24 through proposals to writing really detailed reports
 25 with an evidence base behind it alongside that that

1 became our argument. So we just kept going, and, you
2 know, we -- it's not the first time that we would be
3 dealing with government issues, trying to make our case
4 and having to consistently make it for prolonged periods
5 of time, and what we did keep doing, though, was we kept
6 our community informed that we were trying, and we kept
7 people aware of the fact that we were trying.

8 And there were parts that we could understand that
9 it might be difficult, amidst everything that was going
10 on, for people to be so focused around about our one
11 proposal, but the truth is that the proposal was just
12 a reaction to the stress and crisis, and it was just
13 a starting point of what we wanted to see change.

14 THE CHAIR: Mr Gale, it's past 11.15 now, so I think we
15 should take a break.

16 But before we do, I would like to ask Mr Simmons one
17 question arising out of what you have just been
18 discussing. It starts with the penultimate sentence in
19 paragraph 44, "We never got permission to open our
20 Resources Centres", and you explained how you submitted
21 a plan to them, it was a detailed plan, it had been
22 thought through, there was a fair amount of work, and
23 I think I infer from what you have said that it went on
24 when that wasn't accepted and you prepared a further
25 plan, an impact study, which was submitted in November.

1 I understand that, and that is very clear.
2 You also have, in fairness, said that you accept you
3 weren't pandemic experts, and that no doubt Scottish
4 Government had other interested parties that they had to
5 consider as well, but was there any time, in May or
6 after May, in between May and November, that the
7 Scottish Government entered into dialogue with you about
8 these plans that you had submitted?

9 A. My Lord, we were regularly discussing this with our
10 contacts in the dementia policy team, and I think it
11 would only be fair of me to say that I suspect they were
12 regularly discussing it with their other bodies and
13 groups, and I think that the -- as I mentioned, not
14 being in the room, but I think it would have been a very
15 busy room with many, many agendas and issues being
16 brought to bear, and what we wanted to do was give the
17 dementia policy team enough evidence and strength of
18 argument to take that into these environments, and try
19 and ensure that they could make the case for us, which
20 is what really was the only way we were going to get
21 decisions made, my Lord.

22 THE CHAIR: Yes, I understand, but you are making
23 an inference that the dementia policy team were taking
24 the issues you were raising to some other body, let's
25 assume at a higher strategic level; was that ever

1 explained to you?
2 A. Yes, and I had access to emails and exchanges and saw
3 what was going on, my Lord, and it wasn't that nothing
4 was happening, and I suppose from my perspective it was
5 a matter of, like, just keeping pressing on all
6 different quarters and different areas and trying. And
7 I have to be very honest and say that there was some
8 risk and trepidation about, you know, are we doing the
9 right thing here by trying to get to this point? At
10 that point in time, I couldn't have said I was 100%
11 confident that there was no risk to this at all. But
12 I knew what I think people needed and what had to happen
13 and was prepared to take that risk.

14 So we were trying to work through the system as it
15 was to get the best outcome, and, to be fair, the fact
16 that we got one opened in November before we went back
17 into lockdown I felt was quite an achievement, quite
18 a success, because no one else had at that time, and we
19 were probably, I think, in some ways getting used as
20 a potential sort of pilot case to see if it were
21 possible.

22 So I think that, you know, all things considered,
23 getting to the point where we got one open and we
24 started to see that it would work gave us great
25 confidence, and at that point we started to get stronger

1 and stronger about what we felt could happen through the
2 reports and the engagements.

3 THE CHAIR: Okay. That is clear. That is helpful. Thank
4 you.

5 Shall we come back about 11.35?

6 MR GALE: Thank you, my Lord, yes.

7 THE CHAIR: We will take a break now, Mr Simmons.

8 THE WITNESS: Thank you.

9 THE CHAIR: Good.

10 (11.20 am)

(A short break)

11 (11.35 am)

12 THE CHAIR: Right. Thank you again, Mr Simmons.

13 Mr Gale, when you are ready.

14 MR GALE: Thank you, my Lord.

15 Mr Simmons, can we go back to your statement at
16 paragraph 46, and I think you begin with a caveat there
17 that you are aware and were aware that you were not
18 pandemic experts, and had to be guided by Public Health.
19 You then carry on to make a fairly significant
20 statement.
21 statement.

22 Could you just read paragraph 46, please, and then
23 we will look at the individual points that you have set
24 out.

25 A. I was aware we were not pandemic experts and had to be

1 guided by Public Health. Once we realised how the
 2 infection travelled, we could understand some of the
 3 reasons why it could be difficult for us to do what we
 4 wanted to do, but we got stronger in saying the impact
 5 on people was so significant that we were seeing people
 6 in the early stages of dementia jump to a mid-stage,
 7 more advanced stage rapidly, and all of this is
 8 contained within the COVID impact report, and we
 9 highlighted --

10 Q. Can I stop you before you go into the particular points.
 11 This seems to reflect an increasing confidence in
 12 the view that, against the -- if I can put it this
 13 way -- matter of infection control, there was
 14 a balancing concern that you had in relation to the
 15 impact on the dementia cohort within Scotland; is that
 16 right?

17 A. Yes, Mr Gale.

18 Q. You go on to highlight the following key points. And
 19 I have read this several times and I think, overall, it
 20 is a very, if I may say, comprehensive and a very
 21 insightful set of points.

22 I wonder if you would just read through them,
 23 please.

24 A. So we highlighted the following key points:

25 The impact of social isolation and loneliness.

1 Impact on well-being and mental health of the loss
 2 of usual support networks, both formal and informal, and
 3 resulting loss of meaningful social interaction.

4 Negative impact on relationships; frustration of
 5 people with dementia not understanding the reasons for
 6 restrictions leading to friction within the family and
 7 carers.

8 Impact of increased burden of care on family carers
 9 and resulting carer stress.

10 The trauma of increased stress and distress among
 11 people with dementia and the family carers who were
 12 trying to cope with it alone.

13 Carers reported a decrease in their physical
 14 and mental health from the additional burden of caring
 15 as a consequence of the lack of previous formal/informal
 16 supports.

17 The impact of not being able to spend time with
 18 family members in care homes caused substantial levels
 19 of anxiety and emotional trauma for both families and
 20 people with dementia.

21 People with dementia and their families reported
 22 that the symptoms of dementia increased, and those
 23 cognitive skills declined as a consequence of the
 24 isolation they experienced.

25 The emotional stress and loss felt by carers of

1 people with dementia being admitted to care homes
 2 because of accelerated symptoms of dementia and carers
 3 struggling to cope.

4 Emotional trauma care home admissions which were
 5 often abrupt, unexpected and often pressured because of
 6 lack of alternative supports.

7 The emotional trauma of bereavement during the
 8 pandemic, not being there at the death of a loved one,
 9 restrictions in funeral services, lack of ritual and
 10 family support in grieving together.

11 Carers delaying treatment for health conditions and
 12 ignoring their own health due to their increased caring
 13 responsibilities and lack of respite or breaks from
 14 caring.

15 Carer exhaustion, overwhelming stress, and feeling
 16 inadequate.

17 Q. Just two points I would like to pick up from -- well,
 18 actually, three point, if I may.

19 The third bullet point that you make there, the
 20 negative impact on relationships; what relationships do
 21 you have in mind there?

22 A. So the way that we conducted this research, Mr Gale, was
 23 that we got all of our link workers to talk to people
 24 and go through an assessment of what was happening. So
 25 people were finding it difficult to be in the lockdown

1 environment, perhaps on their own, and just sort of
 2 having to deal with some of the challenges and
 3 difficulties of that intensity of living with dementia
 4 and not having anyone else to help you with it and being
 5 there all the time. So we were getting some reports
 6 that there were frictions and difficulties there amongst
 7 relationships that people were experiencing, that they
 8 needed a bit of support with and a bit of time out from
 9 that they couldn't get.

10 Q. And obviously respite was not really an option.

11 A. No.

12 Q. Also you mention that people with dementia and their
 13 families reported that symptoms of dementia increased.
 14 Is it possible to measure that? Can one actually see
 15 that happening?

16 A. I certainly think that you -- if you were living with
 17 someone who had a recent diagnosis of dementia, you
 18 would be looking at perhaps key things that -- what were
 19 the main issues. So someone might, for example, be
 20 forgetting routines, forgetting, you know, like names,
 21 forgetting places, stuff of that nature, or indeed just
 22 having some difficulty with basic function. There's
 23 a big difference between that early form of symptoms to
 24 someone reaching a point where they don't recognise
 25 themselves in a mirror, where they perhaps have no real

1 understanding of just, you know, where they are and what
2 is happening, and the progressive nature of that. You
3 would see that very quickly.

4 And I think perhaps that is two different sort of
5 like, you know, extreme positions I have described
6 there, but what we concluded was, on balance of
7 everything that we were hearing, that it looked like
8 people who were in the earlier stages were moving very
9 rapidly to the mid-stages.

10 Q. Was it possible, from the work that you had done and the
11 research that you had then gathered, to at least make
12 an assessment of a causal link between anything that was
13 going on and that increase in the rapidity of the
14 disease?

15 A. Yes, we couldn't have -- that would have required
16 a really proper, detailed research approach, but we were
17 confident enough to take what we were hearing from our
18 link workers and what we were getting directly reported
19 from people, carers and people with dementia themselves,
20 to make an informed statement that it was quite clear to
21 us that, because of the lack of any other forms
22 of intervention to support someone's living well with
23 dementia and reduce their symptoms, their symptoms were
24 getting far worse.

25 And then on top of that, I think the

1 interrelationship between physical health and frailty
2 and dementia is also quite important and quite complex.
3 So what we were seeing were people who -- not even being
4 able to go out and get a walk because perhaps that could
5 have led to some difficulties because of social
6 distancing and things of that nature. Physical health
7 was significantly declining. We reported on that.

8 And we also were seeing some changes in medication
9 prescriptions. So people were getting, you know -- we
10 heard more frequently people were getting prescribed
11 anxiolytics and more sedative medication to help
12 alleviate some of the pressures and tensions. Now, what
13 that then does is it makes people far more sedate and
14 they sit longer and that causes more sort of like
15 physical problems.

16 So I think we couldn't say for definite, but I think
17 we could make a very well-informed statement around it,
18 Mr Gale.

19 Q. I think it is important that you mention a physical
20 impact, because one of things that I think we picked up,
21 certainly in reading some of the statements -- and
22 perhaps one that wouldn't necessarily be immediately
23 apparent -- is a lot of people seem to have reported,
24 either in their loved ones or individuals reporting
25 themselves, difficulties and adverse effects on posture.

1 A. Yes.

2 Q. Is that something that you came across?

3 A. I think we certainly -- we probably would describe it
4 more generically around about frailty, and one of
5 the things obviously we are doing very often within our
6 services and everyone is encouraging people is to keep
7 active, to keep engaged, to keep walking, to keep your
8 heart functioning and your musculoskeletal system
9 getting utilised. That is very difficult when you're
10 in that sort of lockdown period, and the frailty
11 issues -- I mean, I am not a frailty expert, but, again,
12 I think what you will hear from experts is that it's
13 quite rapid. You don't have to not be doing something
14 for very long to lose muscle mass and lose posture, and
15 you really need all of that rehabilitation and
16 physiotherapy support to rebuild that and engage it.

17 So it doesn't take long for there to be quite
18 significant decline physically in people who are not
19 mobile and being supported with that.

20 Q. Just the final point, if I may -- and it perhaps may
21 seem a slightly insignificant point, but I am not sure
22 it is -- the final bullet point, you mention that, so
23 far as carers were concerned, there was a feeling of
24 inadequacy. Can you just give some context to that,
25 please?

1 A. Again, Mr Gale, that would be coming through our -- our
2 link workers are dealing with people in that early or
3 mid stage, and they are getting -- constantly, you know,
4 talking to people and getting the sense back from -- you
5 know, "What more can I do? I am not doing enough.
6 I feel my loved one is declining. I can't get access to
7 help for them."

8 So you would have, you know, that group of people,
9 and then you would have people who were a little bit
10 more progressed who were talking to our dementia
11 advisers and phoning our helpline, and just feeling that
12 probably when they had a need to get access to some form
13 of help or support, that they couldn't do it, they
14 couldn't deliver it themselves, and that sense of, you
15 know, just feeling inadequate, rather unfairly, I think,
16 was very common. I think people felt, "I should be able
17 to fix this", and you had broader family members coming
18 in hoping that they can fix matters to support their
19 mother or father, and they just couldn't. So that level
20 of overwhelming stress and then exhaustion and then just
21 feeling inadequate, it was very common in people.

22 Q. Okay.

23 Could you go back to paragraph 47, and from there on
24 to paragraph 59, you talk about further things that you
25 did and interactions that you had with government.

1 Would you read on from 47, please.
2 A. As an organisation, we make sure we work with evidence.
3 We put all of that into the Hidden Impact report and
4 made several recommendations. Things like the balance
5 of risk between the measures and the social engagement
6 requirements of people living with dementia, use of
7 anti-psychotic medication. There is evidence presented
8 in the report of other people's work that demonstrates
9 the increase in anti-psychotic medicine, and we were
10 campaigning about the impact of the excess death
11 reports. In that first year, we moved quickly into
12 saying as clearly as we could how this was having
13 a massive effect on our community. We demonstrated
14 aspects like how difficult it would be for someone
15 living with a significant level of dementia to try and
16 deal with understanding social distancing and all the
17 measures.
18 We wrote letters and reports to relevant ministers.
19 We had meetings with ministers, such as Claire Haughey
20 and Jeane Freeman. All of this is listed in our
21 documents that we submitted. From mid-March 2020
22 onwards, we had regular contact with senior Scottish
23 Government officials from the dementia policy team,
24 mainly via email contact and a regular one-to-one call.
25 We were also part of a weekly stakeholder engagement

1 meeting and, throughout this time, we were explaining
2 our concerns and offering proposed solutions. We have
3 been advised that we cannot share the email exchanges,
4 but to give you a sense of what we did, here are
5 a couple of early emails that will allow you to see how
6 these concerns were built into a proposal to open our
7 day services back up for the specific purpose of
8 alleviating the pressure on so many carers and avoiding
9 the ongoing trauma.
10 So on 20/4/20, I put this to the officials :
11 "It might be helpful to share some of our further
12 thinking on this. As you know we are starting to see
13 a high volume of calls from our helpline with people
14 struggling to cope with the pressures of lockdown. We
15 think that when people start returning to work, the
16 current family based supports will be lessened and the
17 potential of some people in significant difficulties
18 will increase. We don't think people remaining at home
19 and receiving one-to-one support is enough for some
20 people or for their carers. We are considering if we
21 could use our current day services to provide some form
22 of one-to-one support and much needed respite for those
23 in greatest need.
24 "The scenario might be, for example, a previous
25 eight-place day care service three staff could provide

1 three places each day, providing almost one-to-one day
2 care support with lots of room to do so safely, adhering
3 to social distancing and stringent cross infection
4 measures. We think this could be done, but would need
5 full support in terms of testing and PPE.
6 "We can obviously expand on this, but to me it is
7 definitely possible. One that would allow us to do some
8 meaningful work with individuals and provide much needed
9 meaningful respite for carers.
10 "We probably will also want to think through small
11 scale forms of therapeutic groupwork, peer support and
12 community connections for those less advanced in the
13 earlier and mid-stages too. We can't expect people to
14 remain completely isolated for several months to a year
15 and I think we could argue that these are essential
16 clinical needs as much as social. We could be talking
17 to this group of people, asking their views on this, and
18 coming up with some safe, small opportunities for people
19 and their families that will complement the online
20 support and connections. Again, similar to the above
21 scenario, this might need to be done with those in
22 greatest need."
23 We continued to highlight these issues and, on
24 29/4/2020, I wrote:
25 "Thank you for agreeing to consider this proposal.

1 We are desperately keen to develop this and safely offer
2 some form of therapeutic activity for people with
3 dementia and provide some critically important respite
4 for their carers. I have been talking directly with all
5 our staff, Link Workers, Dementia Advisors, locality
6 teams and volunteers and listening to the issues they
7 are dealing with and I am quite clear it is not an
8 exaggeration to say we are sitting on top of a pressure
9 bubble that is ready to burst. Reports from our teams
10 tell me their support calls are getting longer, families
11 are deeply concerned that they can't keep this going and
12 the level of pressure and need for a break is as high as
13 it can be. This is the main driver behind the proposal.
14 "I also attach an update message for all the people
15 we support and our members, I feel duty bound to reflect
16 to them our understanding of their needs and the current
17 circumstances I want them to know that we are engaged in
18 this discussion. We would like to send this out as part
19 of an automated scheduled member update on Thursday PM,
20 therefore an early indication that this is something
21 that could be considered would be very helpful.
22 I realise it would be too much to ask for any agreement
23 in principle by this point, so any initial reactions,
24 processes or information required and indeed if it were
25 seen not to be possible that would be very helpful. As

1 always happy to chat with you and relevant colleagues as
 2 required.”
 3 The update referred to in this email can be found on
 4 page 1 of Alzheimer Scotland’s inventory document 5.
 5 Despite this early indication and preparedness for
 6 us to attempt to alleviate some of these issues in order
 7 to avoid further trauma, we were only able to open up
 8 one centre by August 2020. This was a very small-scale
 9 initiative and had to be closed back down again when the
 10 measures were changed towards the end of the year. It
 11 was not until July 2021 that we managed to open these
 12 services on a small scale across the country.
 13 It is normal that the highest proportion of most of
 14 the people who contact Alzheimer Scotland are family
 15 members and carers, and this was the case during the
 16 pandemic. This information comes to Alzheimer Scotland
 17 through many routes: our 24-hour freephone dementia
 18 helpline, our national network of dementia advisers, our
 19 post-diagnostic support link workers, and others, all of
 20 whom continued to support people with dementia and their
 21 families throughout the pandemic, using mainly telephone
 22 and online support.
 23 A cause for concern for us was the decision-making
 24 processes becoming a blanket approach. An example would
 25 be: no one can do any day care, no one can go into

1 a hospital to someone, no one can access a care home.
 2 We were inundated by people with distress saying,
 3 "I can't go to hospital to see my mum or dad and they
 4 are dying".
 5 Initially we understood that people might not be
 6 able to enter a care home, but we were also aware that
 7 there should be a better way of looking after those
 8 individuals with dementia and their families.
 9 For example, I wrote position statements saying any
 10 families denied access to a care home should be offered
 11 a named person. The named person would help them
 12 understand the logic and rationale and help them
 13 understand the changes to the guidance. We never
 14 thought it was fair to leave the care home manager to
 15 deal with all the families on their own.
 16 Q. In that section you quote from two emails where you put
 17 proposals to officials, both in April 2020. So the
 18 context of that is, again, very early in the pandemic,
 19 and you were making these proposals.
 20 In paragraph 54, you say that, in terms of the
 21 email, you were asking that if something could be
 22 considered, it would be very helpful. Was it
 23 considered, do you know?
 24 A. We didn't get a kind of clear agreement in principle
 25 that it was going to be considered or that we could feed

1 that back to our members. What I know happened was it
 2 was put into these other groups and bodies that we
 3 described earlier, and it certainly was given some
 4 consideration, but we didn't get what we wanted.
 5 Q. You also mention, and you have previously mentioned, the
 6 issue of a blanket approach in paragraph 58.
 7 A. Yes.
 8 Q. As you were progressing and your thinking was
 9 progressing, and the input that you were getting from
 10 your members and from the dementia cohort in Scotland,
 11 did you have doubts as to the wisdom of a blanket
 12 approach?
 13 A. Yes. I think, Mr Gale, to begin with, we, like many
 14 other people, didn't know exactly how to handle the
 15 situation, and were guided by the information and advice
 16 that was coming through from the science, as was often
 17 said, and indeed Public Health. By the summer, we were
 18 starting to say: this does not make sense, and the whole
 19 issue of a blanket ban, for example, on people going
 20 into hospital or not doing day care and perhaps —
 21 I mean, very significantly, without a shadow of
 22 a doubt — the care home situation, with families not
 23 being able to visit, was a very blunt instrument to deal
 24 with very detailed human concerns, and I think it
 25 remained for far too long the standard approach to

1 determine how we looked after people.
 2 Q. In that evolving approach that you were having, were
 3 you, either individually or as a group, an outlier in
 4 that, or do you know if others were sharing the same
 5 views?
 6 A. Well, I think there were others who were ahead of us on
 7 this and stronger, perhaps, much quicker about this, and
 8 we certainly were very supportive of their right to be
 9 expressing these issues. I don't think we were
 10 necessarily an outlier. I think within our community,
 11 the dementia community was probably alongside us, and
 12 the dementia community is much more than just
 13 Alzheimer Scotland.
 14 Q. Yes.
 15 A. So there are many, many, many elements to that where
 16 we've got deep connections, and that included our nurse
 17 and allied health professional consultants, and a lot of
 18 people with very considerable experience.
 19 What we were starting to hear more of was, actually,
 20 you know, infection control systems, forms of barrier
 21 nursing, there are methodologies that could be utilised
 22 in a more specific and precise way that actually could
 23 probably have dealt with things as well as a blanket
 24 approach did.
 25 Q. I think we heard last week from four core members of the

1 Care Home Relatives group, and they in particular made
 2 reference to an open letter that had been sent to
 3 Nursing Times -- I think you are probably aware of
 4 this -- signed by a number of infection control experts.
 5 A. Mm--hmm.
 6 Q. Did you at that time share that approach, that in some
 7 way infection control could be used properly and as
 8 an aid to allowing people into care homes to see their
 9 loved ones, instead of a barrier to them going into
 10 care homes?
 11 A. Our position on that was, again, that we were starting
 12 to see an emerging understanding of a different view,
 13 and what we then asked of the decision-making process
 14 and Public Health was: why? Why are you saying that
 15 a care home has to close again or people can't access
 16 it? What is your evidence for that? And why does this
 17 other body of evidence not have any weight within this
 18 process?
 19 So we weren't taking a side, we weren't saying we
 20 are 100% on this side or 100% on that side; what we were
 21 trying to do was to understand: what is the logic and
 22 rationale for your decisions, and why are these other
 23 matters not, you know, being given any weight? I think
 24 that was perhaps at that time trying to be balanced, but
 25 really desperately keen to see issues like visiting be

1 reinstated safely.
 2 Q. Did you receive, really from anybody, a rationale in
 3 support of a blanket approach as opposed to the more
 4 nuanced approach that you had obtained, informed from
 5 your membership and, indeed, had experienced from other
 6 sources?
 7 A. We wrote to Public Health when some of the decisions
 8 were getting made and we did on a few occasions get
 9 responses back just explaining what the guidance was,
 10 and I don't think that -- I don't think we actually
 11 pushed much further on that, to be honest with you,
 12 Mr Gale. We never got a complete, detailed explanation
 13 as to why the blanket approaches, the way that things
 14 were, and we started not to accept it and we started to
 15 argue against it.
 16 Q. Yes.
 17 Can you remember, just very generally -- and
 18 I am not asking for a date -- when you started to argue
 19 against it? When did you see the force and perhaps the
 20 overwhelming force in the contrary view that you were
 21 propounding?
 22 A. So we started arguing against blanket decisions in April
 23 2020, when we wanted to open up our day services and we
 24 wanted a clearer opportunity to provide that respite
 25 support, and we continued with that.

1 Where we probably, I think, started to get confident
 2 around about things like allowing people into care homes
 3 was towards the sort of like later end of sort of
 4 November and December, where we had been really trying
 5 to make an argument that people don't understand the
 6 guidance and are not applying the guidance, people are
 7 not being supported, and you might wish to come on to it
 8 later, but we did write significant proposals about how
 9 we could support families better during that period of
 10 time. We called for a named person. And to be
 11 perfectly honest with you, I do not think it is
 12 unreasonable when you consider that all of these
 13 families were going through the most traumatic and
 14 stressful and difficult experience of their life, with
 15 one care home trying to look after 30 or 60 families on
 16 their own, that should have been an area where there was
 17 significant investment and support given to people, and
 18 at the very least a named contact to help them
 19 understand what was possible, what wasn't possible, what
 20 might be possible, and to push that forward, and to help
 21 the care home interpret the guidance and understand what
 22 is required.
 23 So at that point in time we still weren't 100%
 24 certain saying, you know: yes, absolutely, let's stop
 25 this and let's move towards a more nuanced approach, but

1 we were beginning to get more confident.
 2 I think when the vaccinations came through, we were
 3 in probably no doubt that there was no need, at that
 4 point in time, for blanket approaches, and it should all
 5 have been about individual agreements around about sort
 6 of like the care home, the environment, and that is
 7 probably around the time when, you know, Anne's Law was,
 8 certainly from my perspective, something that should
 9 have been implemented.
 10 Q. I don't want to take you out of sequence, but
 11 paragraph 92 in your statement, you indicate that you
 12 support Anne's Law. However, you say it is also getting
 13 watered down a little by the government. We will come
 14 to that in a moment. But at present, and going back to
 15 the late part of 2020, you were in support of
 16 Anne's Law?
 17 A. I have been -- to be honest with you, we were in support
 18 at that time of the need -- well, our campaigning point
 19 at that point in time, which was a public statement that
 20 we made both in the media and to government, was that
 21 every person should have a named person. That was our
 22 most concerned point. We absolutely wanted to see
 23 people getting access in terms of visiting. We weren't
 24 expert enough to say that it could happen at that point
 25 in time safely, so we were balanced in our approach

1 there, but towards the latter end of that year, we got
 2 absolutely definite that people needed to get access.
 3 Q. Okay, thank you.
 4 If we go back to what you proposed at paragraph 60,
 5 and could you read on there, please.
 6 A. As well as proposing to re-mobilise our day services, we
 7 also argued that there was more that needed to be done
 8 and could be done to support families. There were
 9 thousands of workers in the health and social care
 10 system, many on furlough, and we advocated that every
 11 family should have a named person. We got some hearing
 12 on that, but it did not go as far as I would have liked.
 13 We then wrote a proposal on that based on giving
 14 families greater support. This led to short-term
 15 funding of what we termed an Action and Rights team, and
 16 that team became an important part of helping families
 17 advocate and understand the guidance.
 18 We also put in proposals to Scottish Government
 19 based on our front-line knowledge and received funding
 20 for a small counselling service to help people facing
 21 loss and trauma. This was funded for two years and
 22 started in June 2021. We also proposed in 2021 a fuller
 23 carers support programme, which was funded by the
 24 Scottish Government and commenced in early 2022. There
 25 were three elements to this. Given by this time our

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1 centres had started to re-open, we ran a series of
 2 on-the-ground support and respite for carers. We set up
 3 a dedicated carer space within our virtual resource
 4 centre and we developed an innovative fund called Time
 5 for You, which provided carers with grants up to
 6 £350 for personal and innovative respite.
 7 A good example of the Action and Rights team's work
 8 was with essential visit guidance, which was poorly
 9 understood. Our Action and Rights team were able to
 10 help people understand the guidance and we would
 11 advocate on their behalf. We then started to work
 12 closely with other groups that had emerged, such as the
 13 Care Home Relatives groups and others that wished to
 14 have visits to care homes. What we campaigned for was
 15 the support people needed to understand the guidance.
 16 We would tell people how to go about getting
 17 an essential visit and we would advocate with the
 18 care home and say: this person meet the criteria and you
 19 need to allow that to happen.
 20 So we received funding for six months for the Action
 21 and Rights team, and we now fund that from our own
 22 service funds. There were lots of people who were not
 23 receiving care from us, like many family carers. They
 24 couldn't get a visit to a hospital or care home, so
 25 these people contacted the Action and Rights team. We

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1 also provided an advocacy service so that people could
 2 understand their rights and essential visits.
 3 The documents we provided to the Inquiry reflect
 4 what people with dementia and carers were telling us
 5 through the tens of thousands of interactions we had
 6 with them through our front-line staff and volunteers
 7 during the pandemic.
 8 As we started to understand the guidance, we got
 9 more confident. We started to engage with people who
 10 knew about barrier nursing and proper techniques. We
 11 found that there were ways that things could have been
 12 done and we started to get more challenging, asking why
 13 access was denied. We approached that in a far less
 14 public manner than the Care Home Relatives group. We
 15 did that through the channels we had with the Scottish
 16 Government. I think that was the right position to take
 17 at that point in time.
 18 As things progressed, there was new evidence of the
 19 value of face masks, isolating people in their rooms in
 20 care homes, and things started to become less certain
 21 about the Public Health guidance. What we saw was that,
 22 as things opened up again, if there were any outbreaks,
 23 then care homes closed again. We would say: why? This
 24 cannot be the response.
 25 I personally felt that the Public Health concerns

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1 and focus remained for too long the driving force for
 2 decision-making, and that impacted people in the most
 3 profound way. We had no influence at that point in the
 4 decisions that were being made.
 5 At the time we published Hidden Impact report, our
 6 level of influence was nothing like it should have been.
 7 Our community was not a high priority, and I think the
 8 issue in care homes was being viewed through the lens of
 9 the care home sector, with PPE, staffing and visits
 10 being the main concern. What we were concerned about
 11 was that people were dying in these environments and did
 12 not have access to their loved ones, with no quality of
 13 life. As part of our Fair Dementia Care campaign, we
 14 knew that many of these individuals were also paying for
 15 it. There were people dying of COVID in care homes, and
 16 some of them were paying £1,200 to £1,600 a week for
 17 that.
 18 I circulated communications saying that, when these
 19 people die, you need to ask yourself if it is right for
 20 the family to receive a bill. This highlighted to me
 21 the inequality of people with advanced dementia in
 22 care homes being charged for their care. We were deeply
 23 concerned about that.
 24 We also campaigned and argued for studies to look at
 25 anti-psychotic medication. Anti-psychotic medication

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1 started to get used in a way that we were concerned
 2 about. We were advocating that this should be studied.
 3 There was some evidence in the Scottish Government
 4 report that there were increases in the use of this
 5 medication.
 6 Q. Now, I would like you to carry on reading from your
 7 statement, but after you have finished the section on
 8 care homes, I would like to revisit one or two points.
 9 So if you would continue on to the end of
 10 paragraph 79, please.
 11 A. The figures quoted in our Rule 8 response is that there
 12 are approximately 29,465 long-stay residents in
 13 care homes in Scotland, and of that, 18,500 having
 14 dementia. Evidence from research highlights the risk of
 15 COVID infection associated with the size of care home
 16 facilities, larger facilities posing a greater risk of
 17 outbreak among residence, including death. I think
 18 within the community, dementia was the most common
 19 pre-existing condition that people had when they died of
 20 COVID. What that told me was that people with dementia
 21 were really impacted. There would need to be a lot of
 22 research conducted to figure out why that was the case.
 23 When it came to care homes, what we were hearing was
 24 that people had to be isolated in their room. They had
 25 no social contact. The image of someone living with

1 dementia is that of someone who is frail and elderly.
 2 A lot of people were active and wished to be involved in
 3 the social activities. The therapeutic nature of a care
 4 home is important. Potentially what was happening was
 5 30 or 60 residents would have to live in their rooms.
 6 The consequences of that were their mental health would
 7 be significantly affected by that, unable to see
 8 relatives or having to see relatives through a window.
 9 If people living with dementia in care homes are
 10 faced with staff wearing a mask, that, in our opinion,
 11 would have an impact on their well-being. Someone
 12 living with dementia in the advanced stages struggles to
 13 have a sense of time, place and person. When looking
 14 after someone with dementia, you need to help them with
 15 a sense of self and well-being using reminiscence
 16 techniques, social stimulation, cognitive simulation.
 17 That is all mainly done in a care home on a group basis.
 18 The impact of COVID was that this was all taken
 19 away. You could assume that the impact of that on
 20 people was hugely significant in terms of their ability
 21 at that point in time. I would suspect that levels of
 22 stress and distress would be higher. How do you calm
 23 someone down in that situation if you don't have the
 24 non-pharmacological interventions to do that,
 25 for example music therapy?

1 The excess death reports that were eventually
 2 published demonstrated to us that being in a care home
 3 was a high-risk environment, not just because it was
 4 a shared environment, but how they had to react to the
 5 risks.
 6 There is no doubt that there was a lack of
 7 preparedness in care homes for having equipment such as
 8 PPE. Lots of things could have helped. One of the reasons
 9 for our long-term care commission is that what seems
 10 obvious is that people in small environments fared
 11 better during the pandemic. These smaller environments
 12 might have allowed for a more person-centred support to
 13 continue, but that was difficult within a larger
 14 environment. These smaller environments included
 15 care homes and alternatives such as supported housing
 16 units.
 17 Care homes needed more staff who were properly
 18 equipped to provide that non-pharmacological
 19 intervention on a person-centred, one-to-one basis.
 20 Care homes did not have that, and the consequences were
 21 that it had a direct impact on staff and individual
 22 residents. I believe in retrospect we should have found
 23 a way of making sure those families that wanted to visit
 24 were able to. They could have been managed into that
 25 environment and help people confined within their rooms.

1 Families were desperate to get in.
 2 The situation was that families were outside
 3 windows, desperate to get in, staff who were in
 4 care homes already taking the risk and moving around and
 5 being in public, and finally people in that environment
 6 were in bubbles, not getting that much needed
 7 non-pharmacological family support. It would have been
 8 logical to find a way of getting that family member to
 9 enter and provide that. If that situation was to happen
 10 again, we would be advocating for families to enter in
 11 the safest way, just like anyone else entering that
 12 care home.
 13 Q. Can I revisit a number of points that you have made in
 14 paragraph 60 onwards.
 15 Just one point I have been asked to raise with you.
 16 At paragraph 64, Mr Simmons, you refer to the funding
 17 for the Action and Rights team. What period, can you
 18 remember, did the Action and Rights team operate in?
 19 A. So we submitted two proposals around about the autumn
 20 period of 2020. It wasn't submitted at that point in
 21 time under the name of the Action and Rights team; it
 22 was later, towards perhaps, like, you know, early winter
 23 that we determined that term. We received confirmation
 24 of that and put that team together around about
 25 February/March 2021.

1 Q. 2021, okay. And that lasted for six months?
 2 A. It was funded by government for six months.
 3 Q. I'm sorry, yes.
 4 A. But we determined it was so important that we continued
 5 it. And during that six-month period, it received about
 6 113 referrals, and then since it has had about over 500
 7 people that we have been advocating help and support to
 8 access visits.
 9 Q. Why was funding stopped?
 10 A. To be fair, the agreement was basically a short-term
 11 response to the situation, and it was -- the proposal
 12 had a three month and a six-month option, and we were
 13 content that it should continue with our own resources
 14 going forward.
 15 Q. Now, taking what you have said and what we proposed and
 16 the sequence in which you have set this out in your
 17 statement, there appears to be, at least as I read it,
 18 a growing confidence in the view that you were taking
 19 that there should be a counterproposal and a counterview
 20 in relation to visiting, particularly in care homes, and
 21 access to loved ones.
 22 You say that you became more confident -- that is in
 23 paragraph 66 -- and then in paragraph 78 you say that:
 24 "I believe in retrospect we should have found a way
 25 of making sure those families that wanted to visit were

1 able to [do so]."
 2 Do you feel, in retrospect, that you could have
 3 campaigned harder for this at an earlier stage?
 4 A. I think not, given what knowledge we had at the time.
 5 What we wanted to do -- and, Mr Gale, bear in mind that
 6 there was the option of an essential visit in the
 7 guidance. So what we wanted to do was to ensure that
 8 that was delivered, hence the Action and Rights team.
 9 So our perspective was that we actually are denying
 10 people access here when they had a right to it, and that
 11 wasn't well understood, and I am sure many colleagues in
 12 the care home sector will tell you the guidance changed
 13 so often that it was very difficult to keep up with the
 14 guidance.
 15 So our first point and port of call was to get
 16 people the opportunities that were already there, and we
 17 were, I think, quite successful with that through the
 18 Action and Rights team. We helped a lot of people move
 19 from not being able to visit to having an essential
 20 visit. And I think probably if I had known then what
 21 I know now, yes, absolutely, we would be saying: look,
 22 this is not tolerable, we have to let people in. But at
 23 that point in time, we were working on the basis of the
 24 essential visits being there, and still there being
 25 quite a substantial level of guidance and pressure

1 determining that this blanket approach was the right way
 2 to go.
 3 And it has to be said that there was competing
 4 perspectives on this. So as a broad church
 5 organisation, there were other voices that were not as
 6 well organised or well developed that we had access to,
 7 who were as equally concerned about visiting taking
 8 place against the guidance of that time.
 9 So we are not a single-focus campaign organisation.
 10 We have a rather broad church, and we had to balance up
 11 all of that. And I am not saying it was huge numbers,
 12 but there were significant numbers of people as equally
 13 concerned about getting this right from a different
 14 perspective.
 15 So our position was to drive forward on what people
 16 actually were able to access and ensure that they got
 17 that, and at the same time, seek to influence the
 18 decision-making processes as best we could.
 19 THE CHAIR: You are not a proselytizer, you are
 20 a pragmatist.
 21 A. Yes, my Lord.
 22 MR GALE: My Lord.
 23 Put another way, you are a broad church, but within
 24 that broad church, you, and obviously a significant
 25 cohort of your colleagues, had a particular view as to

1 what was the correct approach.
 2 A. I think where our expertise lies, Mr Gale, is in the
 3 community environment. So we are not a care home
 4 provider. We do have one small supported unit,
 5 supported housing unit, but we were not experts, and we
 6 do have a lot of views on the care home sector, as you
 7 will see from the rest of my statement, but we weren't
 8 confident and expert enough, in my view, to be doing
 9 anything other than that which we did, which was to use
 10 our expertise in understanding people, understanding
 11 what their experiences might be, and trying to give them
 12 the right help to work their way through this.
 13 Q. You phrase it in paragraph 79 that:
 14 "It would have been logical to find a way of getting
 15 that family member to enter and provide that."
 16 Now, obviously you are referring to care homes in
 17 that context.
 18 A. Yes.
 19 Q. What was the logic? You may have already told us this,
 20 and you may be repeating what you have already said, but
 21 could I just understand what the logic was for you?
 22 A. I think by the time we reached that point and the
 23 conclusions, it would have been -- the logic would have
 24 been that the family members could without a doubt have
 25 helped with the non-pharmacological support and

1 intervention of people. They could have been part of
 2 the care team, Mr Gale.
 3 Q. Yes.
 4 At paragraph 80 you deal with the impact on
 5 hospitals and care homes. Perhaps you could just read
 6 that through for us.
 7 A. In respect of the impact on transferring patients from
 8 hospital to care home settings, I have mentioned this
 9 within the Rule 8 response to the Inquiry. I believe
 10 the Mental Welfare Commission for Scotland looked
 11 carefully at this also. There were several measures and
 12 emergency legislation that were put in place to enable
 13 that transition. The facts were that those individuals
 14 were not tested prior to going into care homes or other
 15 environments more than likely had an impact. I can make
 16 a well-informed assumption that someone who had not been
 17 tested coming out of hospital, where they could have
 18 developed COVID, was undoubtedly a mistake.
 19 We were concerned and remain concerned that people
 20 who are in hospital in the normal course of events
 21 should return home when they are being discharged. The
 22 issue was that patients were being moved from a hospital
 23 to care home instead of returning home, most likely as
 24 community services had been closed. These individuals
 25 and their families have had a double detriment; they

1 were denied the right to return home, and denied the
 2 right of community care services.
 3 The points I was making in June 2020 was to provide
 4 support for carers of those people who were in care
 5 homes. We were advocating that people should have
 6 access to a named person. Each care home could have
 7 been given a team of four or five staff to look after
 8 families and be there to support them. That was our
 9 argument on how this could be done. Instead of that, it
 10 was left to the care home manager to do that work or
 11 staff member trying to make sense of complex guidance.
 12 If more had been done, it would have been easier for
 13 people to understand why they couldn't visit a care home
 14 and, when they could visit, how to do that safely.
 15 Our proposal for the creation of our Action and
 16 Rights team and our counselling service should have been
 17 considered much earlier and been much bigger.
 18 We were pushing for the rights, care needs
 19 and emotional support of family carers to be much higher
 20 up the priority order. We were also looking for
 21 essential visits to be delivered where and when
 22 possible.
 23 The Care Home Relatives group were running a big
 24 campaign and doing a fantastic job. As the vaccination
 25 was introduced, we were much clearer that people should

1 have essential visiting rights. I think how the
 2 government starting working directly with the Care Home
 3 Relatives group and involved them in policies was
 4 a positive move.
 5 We were doing everything we could to make sure the
 6 needs of carers were being respected. Once we had our
 7 Action and Rights team in place, the Care Home Relatives
 8 groups started to utilise that and we built a stronger
 9 relationship.
 10 Q. Can I pause there, and it's really just on one point
 11 that I would like your view, because it is something you
 12 have mentioned on a number of occasions, and that is
 13 guidance. I think you have said on a number of
 14 occasions, you prefaced that with "confused". Can you
 15 just give a little context to that, how you felt that
 16 was an obvious problem?
 17 A. I think, Mr Gale, to contextualise that, what seemed to
 18 happen in terms of the care home environment was that
 19 what you had was you had a number of perhaps very
 20 skilled care home operators running their services and
 21 then faced with the pandemic, and they then were brought
 22 into this arena where every step of their actions was
 23 being determined by guidance, which was changing on
 24 a frequent basis. They were also then subjected to
 25 different forms of scrutiny beyond just the regular care

1 inspection to health boards taking some responsibility
 2 over care homes, and quite a sort of wrap-around sort of
 3 focus into the care home, which was then about
 4 implementing the guidance as quickly and, like -- well,
 5 immediately in some cases.
 6 But what we were aware was that the group that was
 7 developing the guidance was being -- we had members of
 8 our staff that would have been part of that CPAG group,
 9 offering some advice. But as the guidance changed, it
 10 often would be put out late in the day, with
 11 an expectation of it being implemented the next day, and
 12 a general level of -- I think an unnecessary level of
 13 stress around about that care home having to respond to
 14 that almost immediately. And the care home staff are
 15 trying their best to deal with many, many people with
 16 not very much support, and many, many families want to
 17 come in and visit without much support, and I feel that,
 18 as a community, we should have provided much more
 19 support around about the care homes, not just left it to
 20 the care home staff, but brought in teams to help
 21 the care homes understand the guidance, not just ensure
 22 they enforced the guidance but understood it, and help
 23 families understand it, and that is where our named
 24 person argument really sat and was formed around,
 25 Mr Gale.

1 Q. Thank you.
 2 Right, you conclude your statement with a section on
 3 lessons learned. Again, I would like you to read
 4 through that, and then I would like to pick up one or
 5 two points from it with you.
 6 A. So we have a care home estate built not by a commission
 7 or design process. It was built in the early 1990s by
 8 entrepreneurial investors who built up this network of
 9 some 1,000 care homes in Scotland. In the early days,
 10 these people were trying to make substantial wealth
 11 and investments, and it was funded through the
 12 Department for Work and Pensions. So care homes at that
 13 time were viewed in a different way, and many people
 14 were making choices about going to live in that type of
 15 environment.
 16 Over the decades, the nature of care homes has
 17 dramatically changed to such an extent that they became
 18 not a care home, but an extension of hospitals, to look
 19 after people with complex needs. There are also issues
 20 about how these are funded and supported.
 21 The flaw we will make if we do not look at that
 22 estate after COVID will be that we will just have to
 23 live and accept what happened in care homes. What we
 24 need to do, in my view, is build a new approach; design
 25 an approach to long-term care that will have the ability

1 to manage pandemics in a way that we never find
 2 ourselves in that position again.
 3 We need to rebuild and redesign care homes. They
 4 should be able to cope with a pandemic, and if there is
 5 a future pandemic, they should be built in such a way
 6 that you can isolate individual parts of the home to
 7 make sure people are not denied access to visits.
 8 Recommission the whole approach.
 9 As a society, we must look at the number of people
 10 who died in care homes with dementia. The excess deaths
 11 within these settings was huge, a person and a family
 12 behind every number. Another pandemic is going to come,
 13 and if we rely on large-scale environments to look after
 14 people with dementia and just make sure there is PPE,
 15 that is not good enough.
 16 There should be a taskforce redesigning care homes,
 17 making them COVID safe and to make sure all these rights
 18 are protected.
 19 We also support Anne's Law; however, that is also
 20 getting watered down a little by government.
 21 Everyone has been affected by the impact of the
 22 pandemic. However, when you look at the experience of
 23 someone who had significant dementia and cognitive
 24 impairment, trying to understand a pandemic and the
 25 pressure that their family is under, then that is so

1 much more difficult, and dementia just got lost.
 2 What we now know through facts and figures was that
 3 dementia was one of the most significantly impacted
 4 communities, and the most significant co-morbid
 5 condition in terms of all deaths.
 6 There are only four drugs available for people with
 7 dementia. What they do is alleviate some of the
 8 symptoms; they do not treat the disease. Everything
 9 about supporting someone with dementia is personal. It
 10 is face-to-face, community-based support, and
 11 using non-pharmacological therapies. To take that away
 12 again would be horrific.
 13 We have noticed a huge lag in our community coming
 14 back out. Some of our resource centres are not being
 15 utilised to the same extent as they were prior to the
 16 pandemic. I think there is still an enormous pressure
 17 on carers.
 18 We kept the Action and Rights teams going, but we
 19 are actually going to quadruple the size of this as
 20 people need a lot of support and help. Our dementia
 21 advisor structure was localised so moving forward we
 22 will bring some of this service into the centre. This
 23 will allow us to give people an immediate response where
 24 we can. There are people out there who can't access an
 25 assessment and are in distress. It is like the tsunami

1 that was created in terms of the pandemic then led to
 2 a dam, and that dam is sitting there with all these
 3 people backed up behind it. Our helpline calls are
 4 still phenomenal.
 5 We have a very direct experience of who we support
 6 but we also have a duty to represent those who we don't
 7 support and the quieter voices. That transfers into our
 8 campaign works. We also need better data as at present
 9 there are people waiting for 12 months for a diagnosis.
 10 There is a broader debate ongoing with government
 11 about our Fair Dementia Care and Charging Policy and we
 12 have a legal argument ongoing that people were being
 13 denied access to a re-assessment of their need when
 14 their needs change. That is with the Scottish
 15 Government just now.
 16 Q. In conclusion, you indicate that your belief is that
 17 the facts stated in the statement are true and that you
 18 are aware that this will, together with the evidence you
 19 have given today, form part of the record of the
 20 Inquiry.
 21 A. Yes, Mr Gale.
 22 Q. Just a few points from that final section, Mr Simmons.
 23 One of the final points in paragraph 98 you say:
 24 "We also need better data."
 25 Data about what?

1 A. It would be helpful if we knew exactly how many people
 2 were diagnosed and had dementia at the present time. We
 3 lack that type of data. I think we don't know that just
 4 now, so everything we are doing in terms of the number
 5 of people with dementia is based on estimates, as
 6 opposed to factual data. I think we could also be doing
 7 with data in terms of the transfer and exchange, so data
 8 between NHS to care homes and social care. There is
 9 much work to be done in terms of data.

10 Q. Is that something that you feel your organisation could
 11 usefully input into?

12 A. Oh, yes. We have always done quite a bit of work
 13 applying the various methodologies to work out figures,
 14 so there are things like Eurocode and different
 15 approaches and, to be honest with you, you could apply
 16 two or three different models and end up with numbers
 17 that vary between 10,000 and 20,000, and we just -- we
 18 are just a wee bit in the dark on this and we have
 19 recommended that we must look at that, alongside that
 20 broader argument about the fact that -- we can estimate
 21 how many people are developing dementia. You would then
 22 think you would consider how you commission a long term
 23 care environment, particularly how many care homes you
 24 would require, how many places you would need and that
 25 you would commission subsequent services based on that

1 information. One of our big failings is we don't have
 2 that and we don't statistically commission the estate of
 3 long-term care, that emerges mainly through private
 4 sector investment based on market forces and philosophy,
 5 and that is where I suspect that, if you've got the
 6 right type of data and you flow that into strategy, then
 7 you would sort of probably commission things in
 8 a different way.

9 Q. Thank you. What you say at paragraphs 88 and 89 is also
 10 very interesting. You conclude at 89 by saying:
 11 "We need to rebuild and redesign care homes."
 12 Do you mean that physically?

13 A. Yes, I think -- Mr Gale, the view we have coming
 14 through this is that there is some evidence that
 15 suggests that it's the large-scale environment that is
 16 perhaps the most risky one to be in. Now, as
 17 I mentioned a moment or two ago, that environment hasn't
 18 been specifically designed or commissioned based on what
 19 we know to be the needs of our population, it has been
 20 determined by investors and -- in the main investors,
 21 some local authorities do commission and develop their
 22 own services, but it has been designed in a way that
 23 it's the investors and owners from that private sector
 24 that have built up our whole long-term care estate.
 25 Now, they will be experiencing significant pressures

1 in terms of being viable, and we are already seeing many
 2 care homes not able to sustain the current challenges
 3 that they are facing financially. But what is also
 4 important to understand is that many, many individuals
 5 are actually self-funding these environment, to quite
 6 considerable sums, and what actually we would argue is
 7 that we need to just take a pause and think really
 8 carefully about how we design and fund and invest in
 9 this going forward.

10 I feel that the opportunity, if there are any
 11 opportunities through the new National Care Service,
 12 would be to take a very detailed, close look at what
 13 happened during this pandemic, to mitigate and rule out
 14 all the potential risks of scale and start to design
 15 an alternative approach to long-term care for people
 16 with dementia. Now, that is not impossible, but it
 17 needs a very, very high level of commitment and it will
 18 need substantial resource. Our long-term care
 19 commission we hope will produce some starting
 20 discussions and some solutions for that. We certainly
 21 won't be the implementers of it but we feel that, as
 22 a society, to step back from this and not seek to
 23 transform these environments, both physically and from
 24 a financial perspective, and not to commission and think
 25 more statistically about this, it would be a huge

1 mistake.

2 Q. I think the point you make in paragraph 91 is that, in
 3 your view:
 4 "There should be a task force redesigning care homes
 5 making them COVID safe to make sure all these rights are
 6 protected."
 7 If we are looking, Mr Simmons, as indeed this
 8 Inquiry will be, at certain recommendations, would it be
 9 your view that a sensible recommendation would be
 10 something along those lines?

11 A. I think so, Mr Gale. I think what I would want to say
 12 is I think, as I mentioned earlier, a lot of pressure
 13 was put on our care home providers and staff who were
 14 doing a really powerful and fantastic job in the midst
 15 of very difficult circumstances, so this is not
 16 a criticism of them in any shape or form, but I do think
 17 that a system that relies on economy of scales to make
 18 it viable when that economy of scale is actually the
 19 greatest risk factor of COVID in a pandemic, somewhere
 20 in the middle of that I think you have to have a really
 21 clear and honest position and say: that's not right, we
 22 need to look at this.
 23 Now, we have 1,000 care homes. I am not suggesting
 24 for a minute that we start closing care homes, but over
 25 time right now we should be designing and building and

1 commissioning things and that should be led by
 2 a strategic approach to commissioning, not left to the
 3 market. So we should be, as a sort of, you know, a new
 4 National Care Service or as a local and health social
 5 care partnership determining through good quality data
 6 what we think we will need and commissioning that in
 7 a way that is much, much safer and entirely different
 8 from what we probably have at the present time. If we
 9 don't do that then we are just leaving ourselves open to
 10 exactly the same risks, the same likelihood of potential
 11 excess deaths for people with dementia in a way that is
 12 entirely wrong in my opinion.
 13 Q. Thank you.
 14 THE CHAIR: Can I just pick up on those last two answers you
 15 have made. I understand exactly what you are saying, in
 16 the very broadest generalisation, the estate, the 1,000
 17 care homes, or however many they are, have been designed
 18 with a different purpose in mind, and that has been
 19 shown by the pandemic, on the basis of your evidence, to
 20 be inadequate. I think it was in paragraph 89. Can we
 21 just go back to paragraph 89. You say:
 22 " ... they should be built in such a way that you can
 23 isolate individual parts of the home to make sure people
 24 are not denied access ..."
 25 So there is a design issue. You have also indicated

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1 that perhaps smaller units rather than larger units
 2 would be better. Then in paragraph -- the taskforce
 3 one, paragraph 91:
 4 "There should be a taskforce redesigning ..."
 5 And you have elaborated upon that very clearly and
 6 cogently. Plainly this Inquiry is concerned with if
 7 there are any recommendations about these matters.
 8 Another way of approaching the same problem might be
 9 a regulatory regime, because one could through
 10 regulation provide criteria which require to be
 11 fulfilled in relation to care homes, smaller separate
 12 units and so forth and so on. Would you accept that is
 13 an alternative that could be considered?
 14 A. I think, my Lord, the current guidance from the
 15 Care Inspectorate is moving towards that very nature of
 16 advice. I think that that is also slightly
 17 problematic because --
 18 THE CHAIR: Most policy is.
 19 A. Yes, but what you are actually -- so what you are
 20 relying on then is that -- it is this point of -- so you
 21 might have the sector that owns a large estate of
 22 care homes based on economy of scale getting new
 23 guidance to really transform the nature of that, and the
 24 difficulty might be that, as you go smaller, your costs
 25 go higher --

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1 THE CHAIR: No doubt.
 2 A. -- and affordability -- so this is where I think it
 3 cannot be left to the market to determine the future of
 4 the long-term care estate, it has to be determined by
 5 investment and strategy and commission.
 6 THE CHAIR: That, with respect, is a tendentious point in
 7 that others might have different views in relation to
 8 that, which might be, for example, regulation as
 9 I suggested.
 10 A. Yes.
 11 THE CHAIR: That is fair enough. Yes, Mr Gale.
 12 MR GALE: Thank you, my Lord. Just two other points,
 13 Mr Simmons. In paragraph 92 you have indicated your
 14 support for Anne's Law, but you caveat that by saying
 15 that it is being watered down a little. Obviously you
 16 know what Anne's Law is and you know what clause 40 of
 17 the bill provides.
 18 A. Yes.
 19 Q. What would you suggest?
 20 A. I think it should be -- it should just be enacted as
 21 a separate piece of legislation; just moved forward. It
 22 shouldn't be left to secondary legislation. I think the
 23 case is well made now in the position we are in just
 24 now. It should become law.
 25 Q. Thank you. Finally, paragraph 93, you express the view

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1 that:
 2 "Dementia just got lost."
 3 Lost by whom?
 4 A. As I explained, what seemed to happen, and should have
 5 happened, in my opinion, was that dementia, given the
 6 evidence that we've got in terms of the number of people
 7 who died with dementia, the excess deaths that were
 8 there, the experiences that we have outlined, we never
 9 really got a clear pathway through from the diagnosis,
 10 to post-diagnostic support, to integrated care, to
 11 advanced care and around that all the hospital and
 12 care home experiences. We should have had
 13 a directorate, in my opinion, running that and dealing
 14 across the various other issues. What happened was that
 15 it was sort of any particular focus might be on, say,
 16 for example, the care home visiting, that wasn't dealing
 17 with dementia, that was dealing with a specific issue.
 18 Although people might feel that that was dealing with
 19 dementia, it wasn't, and what seemed to happen was we
 20 got into dealing with that particular bit of guidance or
 21 this particular piece of guidance and it was moving at
 22 a sort of rapid pace, and my view is that actually we
 23 should have been sitting looking at how, from the very
 24 earliest point of diagnosis to advanced stage dementia,
 25 we were going to look after people during this pandemic

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1 and doing that going forward. So when I say it got
 2 lost, the strategy of and a vision of how we tackle this
 3 and go through it just was not there in the sense
 4 that I describe it.

5 Q. Mr Simmons, I am very grateful to you, as is the Inquiry
 6 generally, for the information you have given us.
 7 I would ask you: is there anything you feel you haven't
 8 said or that you would like to say at the end of your
 9 time giving evidence?

10 A. I think one area I didn't really touch on that I perhaps
 11 should have done was perhaps the hospital-based
 12 experience of people. You know, we have spent a lot of
 13 time talking about the care home environment. There
 14 were as difficult experiences for people going into
 15 hospital, and I think it would be remiss of me not to
 16 mention that, Mr Gale. I feel that we had made some
 17 very good progress in Scotland tackling the problem of
 18 dementia within acute hospitals or general hospitals.
 19 We had ten Care Actions, we had dementia champions, we
 20 had consultants, nurses and AHPs, that we were jointly
 21 funding with the Scottish Government to improve that
 22 whole arena and probably our experience now of that is
 23 that we have lost significant ground, and it is an area
 24 that, on reflection, I think the Inquiry will obviously
 25 consider and look at, but the experiences of people with

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1 dementia going through hospitals at the height of the
 2 pandemic and thereafter has been very challenging.

3 Q. Just so that I understand that, how do you feel that
 4 ground has been lost in that context?

5 A. What we had previously was a high-level commitment to
 6 what is called ten Care Actions. We had substantial
 7 investments in our programme called Promoting
 8 Excellence, which is a training framework for people, so
 9 that everyone in an acute — well, everybody in the
 10 health service and social care would have the right
 11 level of dementia skilled training to do their job. We
 12 also had a champions programme, which was a — like
 13 a really detailed course of study that helped someone
 14 understand dementia and apply improvements within the
 15 hospital environment. We also had what was called the
 16 Focus on Dementia team, which is a big Health
 17 Improvement Scotland project, all looking at improving
 18 hospital care. That seems to all have stalled, Mr Gale.

19 MR GALE: Mr Simmons, I am very grateful to you. Thank you
 20 very much indeed.

21 THE CHAIR: Thank you, Mr Simmons. You have obviously taken
 22 great care in the preparation of your statement and your
 23 evidence and I am very grateful for the way you gave it
 24 this morning. It has been very helpful.

25 THE WITNESS: Thank you, my Lord.

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1 THE CHAIR: Yes, 2 o'clock.
 2 (12.46 pm)
 3 (The short adjournment)
 4 (2.00 pm)
 5 Statement of Dr Jennifer Burns (read)
 6 THE CHAIR: Good afternoon, everybody.
 7 Mr Gale.
 8 MR GALE: Thank you, my Lord.
 9 As I indicated earlier, my Lord, this afternoon is
 10 going to be a read-in of the statement of
 11 Dr Jennifer Burns. The reference is SCI-WT0572-000001.
 12 She has provided this statement and, as my Lord will
 13 see from paragraph 2, she does not wish to give evidence
 14 at the public inquiry, but she has agreed that it be
 15 read and recorded.
 16 Given its significance on a number of points, I took
 17 the view that it would be useful for this to be read
 18 into the Inquiry notes, and also to be made public in
 19 this way.
 20 As my Lord will see, her name is Jennifer Burns.
 21 For present purposes, she is 62 years of age, her
 22 address is known to the Inquiry. She retired from
 23 full-time NHS employment on 30 November last year,
 24 although she has remained available for a certain amount
 25 of locum work over the winter until April of this year.

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1 Her academic and professional qualifications are
 2 contained in paragraph 4, and paragraphs 5 and 6
 3 summarise her specialist interests. As my Lord will
 4 see, her interests have been largely in geriatric
 5 medicine. In 1995, she was appointed as a consultant
 6 geriatrician at Glasgow Royal Infirmary, and she worked
 7 there until her retirement on 30 November of last year.
 8 My Lord will see at the bottom of paragraph 7 that
 9 she has held a number of roles in the British
 10 Geriatric Society, including as being the Chair of the
 11 Scottish Council of the society from 2012 to 2014, and
 12 then she was elected as President, first of all as
 13 President Elect from November 2018 to November 2020, and
 14 took over as President from November 2020, until
 15 finishing the role on 17 November 2022. So, for present
 16 purposes, my Lord, she was in place as an office-bearer
 17 of the British Geriatric Society during the whole of the
 18 pandemic.
 19 At paragraph 8, she sets out the background of the
 20 British Geriatric Society, and I will just start reading
 21 from there:
 22 "... [it] is a UK-wide Medical Society. It
 23 represents all four home nations with individual
 24 Councils. UK wide, we have over four thousand members
 25 and about ten per cent of them are in Scotland.

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1 The society is a multidisciplinary membership
2 organisation which healthcare professionals join on
3 a voluntary basis. The majority of consultants
4 specialising in geriatric medicine working in Scotland
5 are BGS members.”

6 I will just use the abbreviation BGS:
7 “The [BGS] has the aim of improving healthcare for
8 older people. It supports its members through
9 education, training, and the provision of guidance to
10 support its members deliver better care.”

11 It supports and encourages research. It does policy
12 work to support and spread good practice beyond the
13 members of the society, and to influence national
14 policies and programmes for older people’s healthcare.

15 Non—members can access many of its key reports.
16 They can attend conferences, access the Society’s
17 website, use its reports and tools and undertake
18 education and training.

19 “In geriatric medicine, most of our consultants will
20 work in acute care hospital settings, but some will work
21 across acute and community care. We recognise that
22 a lot of care of older people is across all specialities
23 and in primary care. The [BGS] is keen to liaise and
24 support across many different specialist areas, as
25 overall older people are the population group that use

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1 health and social care services the most.”

2 It has never advised the Scottish Government at any
3 time formally, and it does not sit on any Scottish
4 Government—led government boards. Throughout the
5 pandemic, it was meeting with other medical specialities
6 throughout the Royal College of Physicians of London,
7 and this allowed for sharing of experience and helped
8 guide best practice. The senior officers of the
9 Royal Colleges would have meetings with the Chief
10 Medical Officers.

11 “In Scotland, the Chief Medical Officer appointed by
12 Scottish Government is supported by a number of deputies
13 and clinical directors to provide advice to the
14 Government. During the pandemic Professor Graham Ellis,
15 who was a consultant geriatrician in Lanarkshire, filled
16 this role. He later became Deputy Chief Medical Officer
17 for the Scottish Government during the pandemic. BGS
18 was able to contact and liaise with him informally on
19 issues relating to older people.”

20 Paragraph 14 is significant, we suggest, my Lord:

21 “... BGS, were never asked formally to give an input
22 or advice to Scottish Government. Going forward, in
23 a future pandemic, if the Scottish Government wanted to
24 strengthen their team, they could ask us to be part of
25 that.”

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1 She then deals with communication and guidance:
2 “As clinicians, [the BGS] had regular updates and
3 guidance on management of Covid both from the Government
4 and in our health board area. The BGS was focusing on
5 supporting its members, encouraging research and
6 producing guidance in our specialist area. For example,
7 [it] recognised the impact of Covid in older people,
8 particularly those living in care homes, as likely to be
9 significant. [It] aimed to augment the guidance for
10 those involved in caring for residents in care homes
11 (both carers, nurses and medical professionals) who
12 might develop Covid.

13 “BGS produced a range of recommendations from
14 picking up symptoms options for treating, to proactive
15 planning for what might happen if someone got Covid. It
16 was recognised that at the start of the pandemic there
17 were no effective treatments for this new virus.
18 Consideration was given to whether those patients would
19 benefit from hospital care and what could we provide in
20 the care home that might replicate what somebody might
21 get if they were in hospital. Many people who were
22 living in care homes do not want to be hospitalised and
23 if their care can be provided in a care home then that
24 is very often the preferred option ... BGS suggested
25 that we look at provision of enhanced medical care

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1 within care homes. The aim was to support services to
2 be proactive in developing those services, for example
3 oxygen concentrators to allow safe delivery of oxygen,
4 that might not routinely be there, certainly not across
5 the whole of the NHS. Most the Scotland would not
6 automatically have access to that.

7 “The BGS guidance on managing Covid in care homes
8 was published, then revised three times over the
9 pandemic and was one of our most downloaded documents.
10 It was available on [the BGS] website and circulated to
11 [its] members.”

12 And it was entitled “Managing the COVID—19 pandemic
13 in care homes for older people”.

14 There are a number of footnotes to Dr Burns’
15 statement, my Lord, and some of these documents are
16 contained within those footnotes. It was first
17 published in March 2020 and last updated on
18 18 November 2020.

19 “There was a lack of peer reviewed scientific papers
20 on the impact of Covid on older people and care home
21 residents in the first wave, so the understanding of the
22 range of symptoms patients had at onset of the illness
23 was limited.”

24 The practitioners were relying on the information
25 they were getting via the media to some extent about the

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1 effect the virus had on people in care homes in Italy.
 2 There was a recognition that the virus would have
 3 a devastating effect on people in care homes.
 4 Practitioners weren't sure what was happening or going
 5 to happen in Scotland or in the UK:
 6 " ... but we could see there was a real and
 7 significant threat, and that older people would be very
 8 vulnerable, particularly older people who were living
 9 with frailty . Frailty is a distinctive health state
 10 relating to the ageing process in which multiple body
 11 systems gradually lose their in-built reserves. Around
 12 10% of people over 65 have frailty, rising to between
 13 a quarter and a half of those over 85. Older people
 14 living with frailty are at risk of adverse outcomes
 15 after even apparently minor challenges to health such as
 16 infection . People living in care homes are likely to
 17 have more advanced levels of frailty ."
 18 I just pause there, my Lord. I think this morning
 19 Mr Simmons made some reference to frailty, and also when
 20 Dr Croft gave evidence, your Lordship actually asked him
 21 about frailty , so that does give a little more
 22 explanation.
 23 THE CHAIR: Yes.
 24 MR GALE: "The BGS wanted to support research into the
 25 impact of Covid infection on older adults with frailty .

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1 We shared information on multi-centre trials gathering
 2 this data amongst our members and many teams
 3 collaborated to undertake this work across the UK."
 4 And the references are given.
 5 "The published data now confirms the link between
 6 higher mortality and morbidity and advancing frailty ."
 7 She then deals with feedback from members on
 8 guidance:
 9 "We did not have any formal feedback from surveys or
 10 other sources on the utility of the guidance, but
 11 certainly our impression was that our members were
 12 pleased that we had produced the guidance and there was
 13 a gap in what was available in relation to support for
 14 care home residents and their health care teams. The
 15 fact that the guidance was reviewed three times was
 16 testament to the fact that we were reacting to feedback
 17 and from the evolving evidence. As time went by and
 18 there were options for different treatments and testing
 19 coming in, then we included that in subsequent versions.
 20 The guidance remains the most downloaded publication of
 21 all time [on the BGS] website."
 22 There was then some guidance for hospital settings:
 23 "BGS produced a range of tools and templates to
 24 support those managing patients in [the] hospital
 25 setting to augment other guidance. In the hospital

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1 setting, in addition to symptoms of cough,
 2 breathlessness, fever it was common for older adults to
 3 present with delirium (acute confusion), loss of
 4 appetite, falls or syncope, gastrointestinal symptoms
 5 and deterioration in function. This is common to other
 6 illnesses presenting in older people. It was recognised
 7 by clinicians working in acute settings that testing
 8 needed to expand to cover atypical presentation to allow
 9 accurate diagnosis and infection control measures. It
 10 took some time for this to be implemented as the
 11 evidence of this atypical presentation took time to
 12 appear."
 13 She then deals with the Scottish Government's
 14 response to the pandemic:
 15 "It was challenge challenging to manage this
 16 pandemic with limited understanding of the effect of
 17 this new virus on the Scottish population. Looking back
 18 now, the lack of universal testing and the delay in
 19 recognising the variation of symptoms in older people
 20 left older people exposed to under-diagnosis in the
 21 early stages of illness . The mortality rate from Covid
 22 infection is very age dependent and higher if you are
 23 frailer and have complex co-morbidities as was the case
 24 with many hospitalised older people and care home
 25 residents. Delay in recognising this may have

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1 challenged measures aimed at infection control.
 2 "In any future pandemic we need to identify and plan
 3 for those who are most vulnerable to poor outcomes. Age
 4 and frailty are two of the main factors identified post
 5 Covid and people who are being supported in care homes
 6 or older people in hospital settings with other health
 7 problems exemplify this. Planning should focus on
 8 support to minimise the spread of infection and to
 9 deliver a high standard of care for those with the
 10 infection . It would have almost been impossible to
 11 prevent the spread of Covid in care homes because people
 12 need care, and they are cared for by individuals who had
 13 exposure to Covid in the community.
 14 "Impact on health service
 15 "The health service is stretched at the moment, but
 16 we are seeing the development of services outside
 17 hospital. This is known as Hospital at Home in Scotland
 18 or virtual wards in NHS England. During the pandemic
 19 this was well developed in some health boards such as
 20 NHS Lanarkshire and NHS Fife but not universally
 21 available. This allowed people to access additional
 22 assessment in homely setting including support in
 23 care homes. It was possible to deliver treatments such
 24 as IV fluids , oxygen therapy and if needed other
 25 treatments that traditionally would have required

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1 hospital admission. This is recognised as a useful
 2 addition to the health service and has been
 3 progressively rolled out over the years of the pandemic.
 4 "The Care Inspectorate Scotland look at the quality
 5 of care to ensure it meets high standards. They provide
 6 inspection reports for the Care Home Sector and where
 7 improvement is needed, they support services to make
 8 positive changes. This is an important scrutiny
 9 mechanism. However, in the fast-moving pandemic the
 10 sector needed additional support to manage infection
 11 control and deliver enhanced care for residents. This
 12 resulted in more oversight from health boards with
 13 tracking of infection outbreaks and support to roll out
 14 for example staff and resident testing and ultimately
 15 vaccination. These changes need to be supported as
 16 people living in care homes benefit from enhanced
 17 support from health service teams.
 18 "In terms of impact on the health service, the NHS
 19 and care home sectors have always been stretched.
 20 Vacancy rates were always high before Covid, but ..."
 21 Dr Burns suspects that they are even higher now,
 22 although she doesn't have any figures on the care home
 23 sector.
 24 "The impact on members of BGS of working through the
 25 pandemic was significant. Guidance was changing quickly

1 at the start of the pandemic and that came with its own
 2 challenges. BGS undertook a survey of its members'
 3 experience during the first wave of the pandemic in the
 4 autumn of 2020 and have published the feedback in our
 5 Through the Visor report."
 6 Which again is referenced:
 7 "The survey asked questions of people's experience
 8 of access to viral testing, availability of PPE for
 9 staff, and patient movement in hospital settings as well
 10 as impact on the individual members. [The] feedback on
 11 the survey reflected the concerns of the individual
 12 members. There was a frustration surrounding delays in
 13 testing, the quality of the tests and what level of PPE
 14 was available to staff. [BGS] carried out a second
 15 survey in spring 2021 ..."
 16 And followed that up as a published Through the
 17 Visor report.
 18 "BGS provided the Inquiry with a copy of our two
 19 Through the Visor reports, summarising the experience in
 20 the working environment."
 21 My Lord, I confirm that we have those and have
 22 considered them.
 23 She then deals with transfer of patients from acute
 24 hospitals to care homes:
 25 "BGS were reviewing the guidance from the

1 Governments in England and Scotland on discharge to
 2 Care Homes. [BGS] recognised that people have a right
 3 to be in their home/care home and if that individual did
 4 not have to be in hospital you would not want them to be
 5 in the hospital. Early in the pandemic BGS noted in
 6 'Managing Covid in care homes' that if residents were
 7 discharged back to care homes when testing positive for
 8 Covid they should be isolated in their own rooms for
 9 14 days. We also advised all new or return admissions
 10 to a care home setting should be isolated from other
 11 residents for 14 days. Later versions of the guidance
 12 indicated that testing within 48 hours of hospital
 13 discharge was required and to seek advice from the
 14 Public Health teams on managing previously positive
 15 patients.
 16 "Around mid-April 20 more routine and asymptomatic
 17 testing patients for Covid had been introduced within
 18 hospitals. It was clear that patients should be tested
 19 before discharge to care homes. The benefit of this
 20 approach allowed us to identify if somebody had or did
 21 not have Covid and public health advice was then
 22 followed. There remained a risk that individual
 23 patients could be incubating Covid and have at the early
 24 stages a negative test, so isolation of residents for
 25 14 days post discharge to care homes continued to be

1 supported in our guidance.
 2 "The medical profession learned during the pandemic.
 3 An example of this was the risk of discharging patients
 4 from hospitals to care homes without testing. By the
 5 20th April 2020 patients were being tested to attempt to
 6 prevent infectious patients being discharged into
 7 care homes in Scotland.
 8 "We must acknowledge the vulnerability of the
 9 care home sector. There would however be patients who
 10 would test negative and then go back to the care home
 11 and still have Covid because that's the nature of the
 12 virus. It doesn't always present with a positive test.
 13 So, the additional advice of suggesting a period of
 14 isolation for a resident after discharge to care home
 15 was appropriate and I believe we did get there in
 16 Scotland. Access to suitable testing seems to have been
 17 the limiting factor in rolling out more universal
 18 testing for this situation and for hospital admissions."
 19 With regards to testing, Dr Burns says she can't
 20 comment on any variances across Scotland, but what she
 21 can say is:
 22 "... that the technology was evolving rapidly and
 23 the length of time it took to get a result reduced over
 24 the first few months and ultimately we had point of care
 25 testing."

1 She then deals briefly with impact on acute
 2 settings. She says:
 3 "We didn't have the capacity to do universal testing
 4 initially on all hospital admissions."
 5 As she has mentioned previously:
 6 "... not everyone who had Covid showed symptoms and
 7 some had atypical symptoms, so not everyone was tested
 8 who were admitted and that was the reality in most acute
 9 hospitals. Some patients had typical symptoms who met
 10 criteria for testing and others did not. The learning
 11 in that was very rapid ..."
 12 As she refers to earlier .
 13 "Older people are major users of hospital services ,
 14 and they were not universally tested in the beginning
 15 and until we got that type of testing it wasn't possible
 16 to have a true understanding of the impact of the virus
 17 on different groups and to organise safer routes through
 18 hospitals for them."
 19 She is unable to comment on what the delay was for
 20 the availability of testing. That would need to be
 21 answered by a Public Health team or a virologist.
 22 She then deals with the impact on people living with
 23 dementia in care homes:
 24 "A very high percentage of people living in
 25 care homes have dementia either diagnosed or not

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1 formally diagnosed. In a care home you would normally
 2 have a mixture of physical and mental disability to meet
 3 the requirement for 24hr care. Patients with dementia
 4 were more likely to suffer delirium, if acutely unwell
 5 with illnesses such as Covid, leading to a more confused
 6 and agitated state and it can be hard to keep them safe
 7 in an environment. Conversely, delirium can cause
 8 people to become very sleepy and to stop eating and
 9 drinking. This is medically described as hyperactive or
 10 hypoactive delirium. A study published in [the journal]
 11 Age and Ageing which followed older patients with Covid
 12 admitted to hospital showed mortality increased
 13 independently with both age and increasing frailty and
 14 although delirium was not independently associated with
 15 increased mortality it was linked with prolonged
 16 hospital stays and poorer functional recovery, so more
 17 survivors needed enhanced care after the illness .
 18 "The BGS guidance 'Coronavirus: Managing delirium in
 19 confirmed and suspected cases', published in March 2020,
 20 did explore the issues of managing cases of delirium
 21 linked to Covid infections. It include guidance on
 22 screening for delirium, linked to previous SIGN
 23 guidelines, and provided support for staff on the role
 24 of medication. But it also highlighted the challenges
 25 of managing physical isolation of infected patients. We

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1 understood these difficulties from a range of clinical
 2 experiences working with people pre and during Covid who
 3 had dementia and delirium.
 4 "With regards to difficulty accessing resources –
 5 The major issue would be increasing staff ratios in
 6 wards and care homes to provide more one to one care.
 7 "BGS recognised that those patients dying from Covid
 8 were more likely to need high quality end of life care
 9 and summarised resources from a range of providers in
 10 our resource 'COVID–19: End of life care in older
 11 people'."
 12 Again referenced.
 13 "This signposted to NHS England's clinical guide for
 14 'Management of Palliative Care in Hospitals during the
 15 coronavirus ...'"
 16 That is reference to another document.
 17 "Clinicians accessed these resources to guide best
 18 practice across hospital and community settings.
 19 "Our members did feed back to us that they were part
 20 of supporting not only patients/residents but also
 21 families of people who were affected during the pandemic
 22 and this was a taxing role for them."
 23 She was asked how the clinicians supported care home
 24 residents' families :
 25 "This would be largely about communication on

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1 diagnosis, prognosis and treatments ..."
 2 And this was given remotely in the main.
 3 She makes then some comments on rural care homes and
 4 hospitals. She doesn't have any information from
 5 members regarding rural areas, but she is aware of a new
 6 service set up in Forth Valley via networking. There it
 7 was developed:
 8 "... an acute hospital at home service for care
 9 homes in particular. It was led by a local general
 10 practitioner who was supported by geriatricians and
 11 palliative care. Forth Valley Health Board would know
 12 more about that as they were part of the commissioning
 13 organisation.
 14 "There are workforce shortages in geriatric
 15 medicine, which are felt more in rural health board
 16 areas. For example at this point there was only one
 17 geriatrician permanently in Dumfries and Galloway. This
 18 limits the reach of the specialist service so it is
 19 harder for them to innovate and deliver care across
 20 a whole health board area."
 21 She then deals with accessing services across the
 22 board:
 23 "During lockdown, there was obviously a real
 24 reduction in face–to–face interactions. Many
 25 interventions would normally have been face–to–face and

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1 it was not possible during Covid in the same way as
 2 previously. Rehabilitation after illnesses such as
 3 broken bones or after falls is known to improve outcomes
 4 and quality of life so although some remote advice was
 5 offered, it took time to reintroduce this element of
 6 face-to-face activity. It has improved steadily but
 7 some services have not resumed due to staffing demands
 8 in other more acute areas. This does disadvantage older
 9 people who may already have lost ground due to periods
 10 of isolation during the pandemic.

11 "There was huge innovation in developing remote
 12 consultations. I think it was one of the successes and
 13 remains a useful part of what can be offered."

14 She says that she knows:

15 "... a lot of speech and language therapists were
 16 able to do a lot more work on phones and on computers
 17 which was obviously dependent on the individual being
 18 able to use the technology.

19 "As geriatricians, we offer Acute Care but also
 20 outpatient care and day units where [such clinicians]
 21 would receive interventions from the multidisciplinary
 22 team. That stopped for many months as it was not
 23 possible, relying as it did on people coming in groups
 24 and shared transport. Going forward more patients now
 25 attend with support from family members but there is

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1 some resumption of hospital transport."

2 The BGS records suggest not all services have
 3 resumed. The impact of that, she suspects:

4 "... we do see when you ask older people. Age UK
 5 undertook survey[s] published in July 2021 looking at
 6 the impact of lockdown on older people and they see more
 7 issues with mobility deteriorating and mental health
 8 deteriorating."

9 She says she does not think that prolonged lockdown
 10 had a negative effect on the health and well-being of
 11 older people who didn't contract COVID.

12 "As we redesign services going forward, we need to
 13 make sure that access is good for people with disability
 14 and older people. There were delays in accessing some
 15 healthcare services and memory clinics which has led to
 16 a backlog and now it is in recovery mode."

17 She was asked what could have been done better until
 18 vaccination was successfully introduced:

19 "... there was a risk of hospital visits and so risk
 20 assessment was required before restarting business as
 21 usual ..."

22 She is not sure what could have been done
 23 differently there.

24 "It must have been difficult for people who were
 25 developing dementia and waiting on a diagnosis and for

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1 their family members supporting them. They might not
 2 have been able to access the support that they normally
 3 would have got.

4 "Alternatives to face-to-face have changed some of
 5 the outpatient model of the NHS and how it runs now.
 6 Within my speciality, the issues the patients have are
 7 not always best met by video consultation. This is
 8 particularly true for new patient visits or for
 9 conditions that require physical examination. However,
 10 it can be suitable for follow up consultations."

11 She would want to see a new patient face-to-face if
 12 she could, but some of her colleagues will use it,
 13 particularly if it is in a rural area.

14 "It can also give ... the choice of whether you, as
 15 a patient want to be seen face-to-face or alternatively
 16 by video call or phone. Having that option can be more
 17 patient focussed as travel to clinic to see a doctor for
 18 perhaps a short consultation if you have a disability
 19 can be difficult. Feedback from members in rural areas
 20 is particularly positive. It can work as long as it is
 21 person centred and the patient has the options and
 22 support to ensure the access to services addresses their
 23 needs."

24 She then deals with PPE and testing:

25 "There was a lot of variation in the guidance on

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1 both testing and PPE required in the first few weeks.

2 Initially the use of PPE was only in Covid areas but
 3 then it was recommended for all patient interactions and
 4 if [sic] some high dependency settings where you were
 5 fitted with an FFP3 mask. Obviously, that was difficult
 6 for members because of how certain you could be of
 7 rapidly changing recommendations. There was concern
 8 about the level of protection afforded by the standard
 9 PPE in general Covid ward settings. This was reflected
 10 in some of the comments in the Through the Visor survey.

11 "As time passed evidence was collected on this. It
 12 is a complex area as other factors such as ventilation
 13 of rooms or wards can affect the risk of contracting
 14 Covid.

15 "When the guidance came out from Scottish Government
 16 with what they recommended to be worn, in general, we
 17 had no issues accessing it in the Acute setting. By
 18 [the end of] March 2020 in Scotland, we were wearing
 19 masks, gloves and aprons with eye protection for close
 20 contact with those with confirmed Covid. Handwashing
 21 and hygiene were always the cornerstone of our infection
 22 control.

23 "We adhered to the provisions set out in the
 24 Guidance of the Scottish Government.

25 "The lack of universal testing early on meant we

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1 were not confirming all cases as some were either
 2 asymptomatic or had atypical symptoms. This results in
 3 difficulties in infection control and in later diagnosis
 4 for some patients who would later deteriorate. As
 5 testing became nor available, we had other challenges as
 6 some patients, particularly those with dementia or
 7 delirium, found the testing difficult to tolerate. Time
 8 to test result varied dependent on the type of test and
 9 test setting. The introduction of point of care testing
 10 with immediate results improved this but often needed
 11 follow up tests to confirm the accuracy.

12 "Public Health teams will have learnt a great deal
 13 about testing and should be able to advise future
 14 pandemics on the best options to improve outcomes.

15 "Nursing staff managed to support patients with
 16 testing, showing empathy and compassion with those who
 17 lacked capacity to understand the reasons for often
 18 multiple testing."

19 She then deals with do not resuscitate orders:
 20 "While end of life care has always been an integral
 21 part of care for older people, the acute and rapid
 22 changes seen with Covid changed the pace and focus of
 23 that care. BGS supports and encourages patient centred
 24 care with sensitive advanced care planning conversations
 25 and best interests' discussions with patients and their

1 loved ones. One aspect of this is considering the
 2 likely benefits and harm from medical treatments such as
 3 CPR ... and communicating this sensitively. We had to
 4 acknowledge that this was a virus that we didn't have
 5 a treatment for with a very high mortality. If you got
 6 to a point where your heart or breathing [process]
 7 stopping with advanced Covid infection, then CPR was not
 8 going to be successful. These decisions are then
 9 documented in medical records as a communication device
 10 to other staff. It is important to explain this to
 11 patients and families. BGS guidance on End-of-Life Care
 12 in Frailty has resources to support healthcare
 13 professionals in managing these often difficult
 14 conversations.

15 "Understandably, this can be difficult and
 16 unexpected for some patients and families. It is so
 17 important that concerns are alleviated with good
 18 communication and trust in the health professionals
 19 providing care. A decision not to undertake CPR should
 20 also be part of a plan to describe what treatments are
 21 available and might be useful and these can be
 22 documented in records in the form of 'Treatment
 23 Escalation Plans' or in Anticipatory Care Planning
 24 records.

25 "The benefits of having advance care discussions are

1 to enable a more dignified death with a focus on symptom
 2 control and patient wishes."

3 She then goes on to deal with changes to roles and
 4 impact on BGS members:

5 "Some staff did get moved out of day units or had
 6 changes to shifts. Extra on call and ward provisions
 7 were required to meet the challenges. We captured some
 8 of this experience in our two surveys on the membership
 9 in 2020 published in Through the Visor reports. These
 10 reflect the strain on our members. Mortality was high
 11 in some wards, and providing care in these settings was
 12 very challenging ... for all our members.

13 "There were also positive experiences in that people
 14 felt that they were making a difference and pulling
 15 together as part of a team. Some of the innovations and
 16 technology improved as did the fast-moving pace of the
 17 evidence and the continuous learning and ability to
 18 contribute to research. There were negative and
 19 positive comment."

20 She suspects:

21 "... there is still an impact on our members ..."

22 She doesn't have direct evidence of that
 23 specifically .

24 "The membership itself was mainly frontline NHS
 25 staff. They were first line responders when the demand

1 for the job was at its peak. There was concern for the
 2 patients and concern amongst the staff for themselves.
 3 There was anxiety about whether they were adequately
 4 protected with PPE. We did ask if people had time off
 5 or sickness absence and there was higher than usual
 6 sickness absence rates. There was significant Covid
 7 related illness among staff. This was before vaccines,
 8 so some colleagues were very unwell. Some of our
 9 colleagues had also died. These anxieties about one's
 10 own health, the risk to vulnerable family members
 11 combined with the intense nature of the clinical work,
 12 was really taxing.

13 "During the first period of Covid, the difficulty
 14 was dealing with acutely unwell patients with limited
 15 treatment options and high levels of uncertainty. As
 16 the pandemic progressed with peaks and troughs there
 17 were positive changes with research offering some
 18 effective treatments and a well-managed vaccination roll
 19 out, however the duration of the pandemic required
 20 longer term resilience to continue and manage the
 21 challenges.

22 "In relation to training and conferences for our BGS
 23 members, [BGS] managed to switch quickly to a virtual
 24 model. They continued to offer education to our members
 25 at virtual conferences and webinars. Some of that

1 depended on staffing levels and access to study leave
 2 but attendances at virtual conferences increased over
 3 pre-pandemic levels. This supported continuing
 4 professional development but also allowed some
 5 reflection and learning on the pandemic. Access to this
 6 was supportive of emotional well-being by sharing
 7 experiences and networking.”
 8 She then expresses a personal view: as
 9 an individual, she continued in her full-time job in
 10 Glasgow Royal Infirmary and was involved at the BGS
 11 initially as President Elect, and then, from November
 12 2020, as President. Work as a clinician meant that she
 13 experienced all of the challenges of managing patients
 14 in acute hospital care. It was emotionally draining,
 15 and also important and rewarding, to be able to provide
 16 care for those vulnerable patients. She was part of
 17 a large multidisciplinary team of healthcare
 18 professionals, and needed to support them in this
 19 important work. Her role at BGS also meant that she was
 20 involved in meetings and providing resources for BGS’s
 21 members, and she was able to attend virtual meetings
 22 with the Royal Colleges once a fortnight and network
 23 with colleagues in many other disciplines.
 24 The next section is on impact of COVID and lockdown
 25 on older people:

1 “The Age UK survey is interesting ...”
 2 She didn’t know if Age Scotland also did something
 3 similar.
 4 “... but one of the things I captured was the term
 5 ‘vulnerable’ which was a blanket term used to apply to
 6 older people, is quite a shock for people who are
 7 happily living their lives. The report comments on
 8 anxiety related to the risks from the virus resulting in
 9 many being afraid to go out and resume previous
 10 activities even when restrictions had eased. Having to
 11 be isolated from family and close friends had an impact.
 12 We know that regular exercise, maintaining physical
 13 fitness, social interactions, and a sense of purpose all
 14 combine to build resilience and prevent disability. The
 15 lockdown affected many older people’s ability to
 16 undertake these activities and the longer-term impact of
 17 this is likely to be negative for their physical and
 18 mental health.
 19 “The rollout of vaccinations targeted older people
 20 and residents in care homes as top priority and this has
 21 been a success in giving enough protection to allow
 22 a more normal life to resume.”
 23 She then deals with restrictions, particularly in
 24 the context of end of life:
 25 “Restrictions on visiting in Acute and Care home

1 setting were more difficult to manage. It was all
 2 a balance of risk. If you had open visiting with no
 3 restrictions, there was the potential of the virus being
 4 brought into the setting. This might affect not only
 5 the individual being visited but potentially the wider
 6 population within the setting.”
 7 My Lord, I just pause there. The next paragraph is
 8 one that the Inquiry team thinks is of significance, and
 9 bears some relation to what Mr Simmons said this
 10 morning:
 11 “Care homes are an individual’s own home and as the
 12 pandemic eased restrictions eased in many settings but
 13 were slower to relax for those living in care homes.
 14 Social isolation is harmful to care home residents and
 15 can result in low mood or cognitive or functional
 16 decline. We were restricted for a lot of the pandemic
 17 for reasons that at the time I supported but on
 18 reflection and feedback from members, I consider that
 19 these restrictions were too prolonged. Visiting
 20 policies should take account of benefits and risks to
 21 the individual resident, the potential risks to the
 22 wider care home population and the current prevalence of
 23 Covid in the surrounding community. As testing capacity
 24 increased, a roll out of testing for visitors to
 25 care homes could be added to the strategy to provide

1 some reassurance.
 2 “Evidence shows that many residents in care homes
 3 are in the last months of their lives and long periods
 4 without a visitor are harmful. Whilst there is
 5 a complex balance of rights and responsibilities,
 6 campaigns such as John’s Campaign highlight the
 7 importance for the right of people with dementia to be
 8 supported by their family carers and they are
 9 campaigning to embed this in law.”
 10 She does think that it is something that needs to be
 11 thought about for the future, particularly for those in
 12 need of care.
 13 “Visiting in hospital and care homes was allowed in
 14 end-of-life situations but deciding when somebody is ill
 15 enough to warrant a visit was difficult as patients’
 16 conditions can change quickly and health care
 17 professionals had to make judgements on this in
 18 care home and hospital settings. Sadly, it will be
 19 inevitable some families didn’t get the warning in time
 20 and missed the chance to visit.”
 21 There is then a section which I will simply take as
 22 read on literature/research by BGS, and move on to the
 23 section on guidance at paragraph 75:
 24 “We received guidance from the Scottish Government
 25 regarding changes, restrictions, PPE, testing, oxygen

1 provision amongst other things. The government were
 2 being advised by scientific advisory groups. We would
 3 then receive our guidance from the health boards but
 4 also via professional routes, such as the Royal Colleges
 5 of Physicians (London, Glasgow and Edinburgh) who ran
 6 virtual webinars fortnightly giving updates on the
 7 evidence for treatment options.
 8 "Professor Adam Gordon was the lead author in the
 9 care home guidance, and he sat on the social care
 10 subgroup of [SAGE] in England. BGS Care Home guidance
 11 was circulated to members of BGS in Scotland. The first
 12 guidance was published on 25 March 2020 and revised and
 13 updated after that."
 14 She then deals with lessons learned. Just before
 15 she completed her term as BGS President
 16 in November 2022, BGS published a paper on:
 17 "... 'Lessons learned from Covid', trying to capture
 18 what we have learned and highlight priorities for future
 19 pandemic preparedness. We highlighted 10 lessons for
 20 the future."
 21 My Lord, just at that point, perhaps I can simply
 22 refer to that document. It is footnoted in her
 23 statement.
 24 At page 4 of that document there is a summary of the
 25 lessons that she sets out, or that the BGS sets out.

1 There is one that I would particularly refer to, and
 2 that is Lesson 2. It is in these terms:
 3 "There is a need to ensure that a balance is
 4 achieved between protecting care home resident from
 5 a virus that could be fatal for them and also protecting
 6 the human rights of individuals to see their families
 7 and loved ones."
 8 That is expanded on in the narrative at page 5 of
 9 that document. If I could just read briefly from some
 10 of that. It follows on from the well-known opinion of
 11 the then Secretary of State for Health and Social Care,
 12 Matt Hancock, about throwing a protective ring around
 13 care homes. The BGS document says this:
 14 "Rules on visiting in care homes changed regularly
 15 with many families and care home operators struggling to
 16 keep up with what was allowed and what was not. Many of
 17 the restrictions in care homes remained in place long
 18 after restrictions were lifted for the rest of society
 19 and many family members became frustrated at not being
 20 allowed to visit their loved ones face-to-face, even
 21 once both the visitor and the resident were vaccinated."
 22 There is a reference to a paper. That particular
 23 paper:
 24 "... made five recommendations for Governments
 25 planning for future pandemics including the

1 acknowledgement of family visits as a human rights for
 2 care home residents and the need for better guidance for
 3 care home staff as well as improved communication with
 4 family members."
 5 Going back to paragraph 77, Dr Burns says:
 6 "If there is another pandemic, it is likely to have
 7 a similar impact on older people and those with other
 8 vulnerabilities. The full report details these in full
 9 but I would highlight the need to ensure a balance is
 10 achieved between protecting care home residents from
 11 a virus that could be fatal to them and also protecting
 12 the human rights of individuals to see their families
 13 and loved ones. Planning for the response to a pandemic
 14 should involve experts on the population most affected
 15 by the illness in question at the earliest possible
 16 stage. Services should be available and adequately
 17 funded to provide patients with the most appropriate
 18 care in the best place for them. For some patients this
 19 will be in hospital. For others, it may be in their own
 20 homes or care homes. Clinical trials must include the
 21 populations most at risk and most likely to benefit from
 22 the treatments being tested. In the majority of cases
 23 this will include older people.
 24 "As a society, we need to be more open about talking
 25 about death and dying so preparing for end-of-life care

1 isn't as shocking, particularly if one's own health has
 2 been deteriorating and for example one needs support in
 3 a care home. Opening the conversation ahead of the
 4 final days allows individuals to have a chance to
 5 express their thoughts and wishes and for those caring
 6 for them to recognise what is important to them.
 7 "Additionally, NHS and social care workforce
 8 planning must ensure that there are enough staff, that
 9 all staff have the skills they need to care for the
 10 ageing population and that staff are cared for mentally
 11 and emotionally and supported to continue to work in
 12 these roles. The workforce remains under stress due to
 13 vacancies and inadequate numbers of staff in training to
 14 replace those who retire or leave."
 15 She is keen that the Inquiry comes out with some
 16 positive suggestions. She says:
 17 "We need to address concerns and learn from them.
 18 We also need to be supporting the workforce to deliver
 19 the best care moving forward. Delivering enhanced care
 20 to those living in care homes would be an example of
 21 this. Those older people living in care homes have
 22 complex medical co-morbidities and are in the last years
 23 of life and ensuring high quality care in this setting
 24 is key.
 25 "In Scotland the pandemic highlighted the need to

1 have plans in place for managing patients who had
 2 deteriorated clinically and might be approaching end of
 3 life . Advance care planning was recommended for all
 4 older care home residents. When end of life care was to
 5 be delivered in the care home setting plans could be put
 6 in place ahead of time to have available medication to
 7 manage common symptoms. Referred to as 'Just in Case
 8 medication' prescription of medication to relieve
 9 symptoms can be given ahead of time, in preparation for
 10 changes as an illness such as Covid progresses, to avoid
 11 delays in contacting medical and pharmacy staff out of
 12 hours for example. These medications include morphine
 13 or similar opiates for pain and breathlessness,
 14 Midazolam for agitation, Hyoscine for excessive
 15 secretions, Levopromazine for nausea or vomiting.
 16 Trained nursing staff would then be able to administer
 17 medication when needed for symptoms without delay.
 18 "During the pandemic we managed to introduce
 19 services, tests and vaccinations rapidly. This pace of
 20 change has not been sustained and now the requirement is
 21 to evaluate the pros and cons of the changes and plan
 22 for the future."
 23 She signs that statement under the declaration that
 24 she believes the facts stated are true and she is aware
 25 the statement will be made available on the Inquiry's

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1 website.
 2 THE CHAIR: Very good. Thank you very much indeed, Mr Gale.
 3 MR GALE: Thank you, my Lord.
 4 THE CHAIR: I think that is the evidence for today and we
 5 are back again tomorrow morning at 10 o'clock.
 6 MR GALE: Thank you, my Lord.
 7 THE CHAIR: Thank you, all.
 8 (2.57 pm)
 9 (The Inquiry adjourned until 10.00 am on Wednesday,
 10 1 November 2023)
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