

# **Alzheimer Scotland**

## **Response to The Scottish Government's Dementia and COVID-19 Recovery and Transition Plan**

### **Introduction**

Alzheimer Scotland welcomes the opportunity to provide feedback to the Scottish Government's Dementia and COVID-19 Recovery and Transition plan. The response is informed by people with dementia and carers as well as the views of our staff and helpline volunteers who have supported tens of thousands of people with dementia and carers during this pandemic. Over the past week our local teams hosted a series of online sessions to gather feedback. These sessions involved:

- 150 carers and people with dementia engaged in 31 discussions (mixed one to one and group sessions) (Appendix A)
- Two helpline staff and eight helpline volunteers (Appendix B)
- 200 local Alzheimer Staff in 13 group sessions (Appendix C)

The collated responses from each of these three groups are included in the appendices. This response sets out an overview of the themes from this feedback and includes additional observations from other senior colleagues.

### **General Comments**

The Scottish Dementia Working Group and National Dementia Carers Action Network have had the opportunity to provide feedback via events hosted by the Scottish Government's Dementia Policy Team. In addition, Alzheimer Scotland colleagues have participated in workshops planned and facilitated by the Scottish Government Dementia Policy Team

With the help of our colleagues Alzheimer Scotland was able to host a significant number of sessions for people with dementia and carers, staff and volunteers in little over a week. Nevertheless, it is important to reflect feedback from a number of carers who were unable to participate in these sessions because of their caring role and the limited time to consider the plan and respond. They felt that they needed more time than the process allowed, and that the timescale was too short.

Alzheimer Scotland recently shared with the Scottish Government our COVID-19: the hidden impact report. The report sets out the growing evidence of the impact of the pandemic on people with dementia and carers living at home and makes several recommendations aimed at balancing direct and indirect harms of the pandemic. It is our view that this evidence based report should be reflected in the plan.

There is a general theme from the sessions we hosted that some of the commitments contained in the plan need to be more specific and measurable.

Alzheimer Scotland welcome the plan and agree with the general aims and areas of focus. However, the feedback we have collated highlights several areas where the plan can be strengthened. These are set out below.

**Evidence of impact on people with dementia and carers**

It is our view that the plan needs to include stronger evidence and acknowledgement of the impact of the pandemic on the lives of people with dementia and carers. This includes recognising the disruption to the health and other support services they rely on. The Scottish Government has published a Mental Health – Scotland’s Transition and Recovery plan which includes a comprehensive evidence section. The absence of evidence and recognition of the direct and indirect impact of the pandemic is a key theme from the feedback from people with dementia and carers. This is important because, as a public facing plan, people with dementia and carers need to know that the Scottish Government’s plan both recognises and responds to their lived experience. We recommend strengthening the evidence section.

**Support for a timely diagnosis and post-diagnostic community support.**

This section does not sufficiently reflect that the national post diagnostic support guarantee is not being delivered and that the most recent performance data demonstrates that more than half of those who have received a diagnosis of dementia have not been offered post diagnostic support. This was the case before COVID-19. During the pandemic both diagnosis and post diagnostic support have been disrupted. Those who have received post diagnostic support have not been able to fully benefit and may need further period of support. The commitment needs greater clarity about what specific action(s) will be taken to ensure the capacity to deliver post diagnostic support to those who are entitled to be offered this crucial support, to address the existing gap in delivery and meet the additional demand of those who have been impacted by the disruption to diagnosis and post diagnosis support and have either not been offered it or fully benefitted from it during the pandemic.

**Safe Remobilisation of community based supports.**

The impact of the disruption to community based supports such as day care and other formal and informal community based supports people with dementia and carers rely on is a key theme of the feedback we have collated. So too is the changing and increased level of needs of people with dementia and carers. The feedback we have collated highlights the need to safely and rapidly re-mobilise the services which people with dementia and carers need. The plan also needs to reflect the need assessment and respond to the increased levels of need.

**Support for carers to be equal partners in care.**

There is clear evidence that many carers are struggling with the additional caring responsibilities that are a direct consequence of this pandemic and the public health restrictions. This is strong theme in our feedback from carers, our helpline volunteers and local colleagues. Aside from a few exceptions most have reported that they do not feel that they are regarded as equal partners in care, valued for and supported in their caring role, or part of any discussions or decisions about their role in caring for their family member or friend. This is reflected in their experiences of restrictions in care home and hospital, lack of respite or alternative supports where day care or other services have been disrupted. These experiences are reflected in some of the scepticism contained in the feedback from carers about the ability to deliver on the commitments.

### **Improving the hospital experience**

We welcome the ongoing commitment to continue to co-fund the national dementia/nurse consultant and further cohort of dementia champions. The contribution of the Alzheimer Scotland Dementia Nurse Consultants is rightly acknowledged. However, it is equally important that the plan also acknowledges the role of other health professionals who have also made a substantial contribution to supporting to people with dementia, and carers in hospitals, care homes and in their own homes.

### **Recovery and Rehabilitation**

The plan does not reflect the critical role of rehabilitation in ensuring that people are appropriately supported during their recovery so that they can regain their health and wellbeing. People living with dementia may require specific and targeted rehabilitation support, either following recovery from the virus or as a consequence of an exacerbation of other health issues due to isolation, physical deconditioning, cognitive decline or reduced access to health services. There is an emerging international evidence base on a variety of rehabilitation interventions for people living with dementia and we need to build on good practice and capacity within the healthcare system and to explore innovative models, adopting a multi-disciplinary and multi-agency approach to meet the needs of people with dementia.

We acknowledge that the Scottish Government has recently published the Framework for supporting people through Recovery and Rehabilitation during and after the COVID-19 Pandemic. However, this is not referred to in the plan. Given the evidence of the impact on people with dementia and carers it is important, in our view, that rehabilitation needs a specific commitment.

### **Digital**

Digital is one of the key principles of the Rehabilitation Framework but there is limited reference in the plan for the potential for digital, and other technologies to provide solutions for many people with dementia and carers.

During the pandemic the use of digital supports has increased dramatically for people with dementia, carers and practitioners. Near Me and other video conferencing platforms have helped to maintain connections for service delivery and therapeutic interventions and have provided the means to reduce loneliness and isolation, improved wellbeing and resilience. They have also given many carers the ability to remotely connect with others, including those they care for. For many this has helped reduce stress and provide peace of mind.

This value of digital technologies is also reflected in the feedback from people with dementia, and carers. However, many have not been able to benefit and need greater support to get connected, find the right solutions for them and to become more confident. The consumer digital landscape changes so quickly that it is difficult to keep up with and requires practitioners with a different set of skills to support

people with dementia and carers to find the best options for them that can deliver meaningful support.

The feedback we received also acknowledges that some people did not feel able to benefit from or use digital technology at all and didn't work for some people with dementia or that while it helped greatly it did not replace human face to face support.

Digital technology has played a significant role during this pandemic and will continue to do so in the immediate period of recovery and in the long term. We acknowledge the work being driven by other relevant digital strategies such as the Technology Enabled Care (TEC) Programme and Scotland's Digital Health and Care Strategy. However, given the relevance to recovery from the pandemic digital solutions need greater emphasis in this plan.

### **Fair Dementia Care**

We acknowledge the desire to have a transition and recovery plan for dementia which focuses on recovery from the pandemic and not existing national dementia strategy or other relevant commitments. However, this pandemic has exposed existing inequalities including those highlighted in Alzheimer Scotland Fair Dementia Care report and campaign. During the pandemic people living in care homes with advanced dementia, who have been unable to have contact with family and friends or engage in the routines or activities normally available to them are still paying substantial contributions to care home fees. Those at end of life and who have sadly died from Covid, or other causes, during this period continued to be required to pay for their care. We understand that there is an independent review of adult social care ongoing which may make recommendations relating to how social care is funded and paid for in the future. However, we do not know what recommendations will be made and any recommendations relating to paying for social care are unlikely to be implemented any time soon. It is our view that the inequalities we highlighted in the Fair Dementia Care report need to be addressed now and that a commitment to work towards delivering fair dementia care should be included in this plan.

## Appendix A: People with Dementia and Carers

### Dementia and COVID-19 - The Scottish Government's Recovery and Transition Plan – Questions for people living with dementia and carers

How well does this paper accurately reflect and respond to the lived experience of dementia during COVID so far? What's missing?

The feedback from people with dementia and carers have been mixed.

Five people we asked felt that the paper does accurately reflect and respond to lived experience

However, a larger number of respondents were more critical. They felt that there was a gap between what is said in this paper and experienced reality.

“The paper does not reflect the anxieties encountered by carers and those with dementia being unable to access any clinical support during these past months. Dementia is a deteriorating condition and follow up, advice and support regarding medication and treatment have been lacking during Covid”

“Personally it does not reflect my experience so far there is no recognition of how services were cut off quickly with little understanding of how this would affect someone living with dementia and their understanding of why they were closed . No acknowledgement that closure of groups in the community could and did have severe consequences for Dementia sufferers and their families.”

“There seems to be a wide gap between the lofty words of the Scottish Government and the reality of what has happened since March....Forgive me if I feel the tone of this plan is idealistic and self- congratulatory. It is my experience that although Alzheimer Scotland, the Carers Association and organisations such as Tide are doing wonderful work, little has been done by the Scottish Government to "ensure people with dementia have their rights and dignity upheld”

“I found a small part of it self-congratulatory in tone, and therefore inappropriate and unmerited, considering the number of care home deaths, after people were discharged from hospital without testing”

“I found lots of words and it talked and talked but did not say anything to me. It is like listening to them talk but they don't answer anything or tell me anything. I didn't get any answers, nothing is clear cut. It just didn't hit the mark. I am no more enlightened after reading than I was before.”

Some people with dementia and carers who read the paper struggled to understand it and would have preferred it to be written in plainer English.

“Not a dementia friendly or carer friendly ‘read’ in places: some very long sentences, poorly punctuated.”

Many who responded also said that the paper does not consider or the difficulties many people with dementia have had in understanding COVID rules, and the anxiety it causes both the person and their carer.

"I've lost confidence. I want to go out independently but I can't. I want to do the right thing but I don't know what the right thing is, so I'd rather do nothing than get it wrong."

"Mum has had difficulty taking on board the fact that, in some situations, masks are a necessity. She doesn't really understand why my brother, other family members and friends can't visit and that she can't be taken to cafés and other trips out"

"The Scottish Government have not done enough to support us through this situation. Their guidance is so vague and changes all the time making it very difficult for me to keep up-to-date, so I worry that I will do something wrong."

**The paper recognises that the majority of people with dementia live at home. What 'quick wins' can we include that will make a positive impact during to people's quality of life at home during the next year?**

The feedback provided many suggestions on what can improve people with dementia and their carers' quality of life can be improved. They are listed below in the order of most mentioned or discussed (i.e most supported) to least.

**Relaxation of restrictions to enable in person meeting, acknowledge the importance of socialising and social stimulation (50 responses).** Most often respondents stressed the importance of re-opening day services. Many carers believe as closure of day services have negatively impacted people with dementia and carers,

"The best "quick win" for people's quality of life at home is to get as much human one-to-one involvement as possible and where possible meet up with other like-minded carers."

"I didn't realise how much I depended on day services until they stopped, I am sure I would have been able to keep my husband at home longer with regular periods of respite for me and support for him"

"Safe ways of setting up groups without compromising safety is essential as the longer they are off the less likely the person living with dementia will want to go back as they have become reliant on their carer which in itself will bring on other issues"

Similar to the previous point, many carers asked for **support to carry out day to day life, without the person they care for (15 responses).** For example, to go shopping or run errands. This could take the form of respite, or help with shopping, or priority status at supermarkets.

"would like if we had some small chances to get out, so someone coming to be with PWD, wanted to be able to get out to hairdresser when they opened, some kind drop off service for PWD"

"They said that the most difficult thing has been not being able to have anyone into the house. Carer finds this limiting because if she has to go for an appointment, PWD has to go with her."

"Introduce priority food shopping for carers"

12 people who responded to this paper asked for better **Communication of what support is available, provide clear and comprehensive information to people with dementia and carers, without having to go looking for it themselves.**

I feel that we get conflicting information from GP, Psychiatrists, social work etc. They all give different information on how to get services or if services are even available"

“Information was in short supply, on how support could be given to sufferers and carers. In our case, this was not an issue, but could have been to individuals without family support. We were unaware of the support line, so maybe it could have been advertised more.”

“Hard to get advice about what relates to dementia and what is not as no professional contact in person”

“I feel that if you want or need advice or support you must go looking for it yourself and it can be a minefield and difficult to decipher. Luckily, I can use the internet etc. but worry about older carers & couples who are less able and often I am still very confused about the guidelines and what is available.”

Another priority area for people with dementia and carers is ensuring that **access to support, whether social care or healthcare is timely and the level of support is sustained** (12 responses)

“Our carers have been great and having a care package put in place during lockdown has been a huge bonus for us as we live so far away ... I’d hate for it to be changed or scaled back as she is used to the carers now”

“The diagnosis triggered a prescription for medication but that got delayed during lockdown and Mum only started taking it in early August. The consultant had also referred Mum to be seen by an OT but that has still never happened.”

“My husband was in respite and needed to see a GP, due to the location of the facility which was outside our home council boundary, the GP serving the facility would not come to see him as my husband wasn’t local to the area, likewise his own GP wouldn’t visit, as it proposed going out of his area, this meant that no one would be prepared to visit him”

Other “quick wins” mentioned by respondents included **continuity of people providing care at home (5) more support with transport to visit appointments (4), support to attend online groups (4)**

**What can we do in the short term to mitigate the impact of reduced access to timely diagnosis and to post-diagnostic support during the pandemic?**

Many of the responses to this question also relate to the answer to the previous question regarding **access to support, whether social care or healthcare is timely and the level of support is sustained**. In addition, respondents also brought up that **after diagnosis, greater certainty over how long it will take to receive PDS**

“My husband was given a diagnosis of dementia at the start of the year. There has been no visit or contact and I was given some books to read. He has deteriorated over the year and I need someone to speak to about it, why was the PDS (NHS) team stopped during COVID, this is when we needed it most”

“I feel that the responsible statutory service has not adequately communicated the plan for the one year of Post Diagnostic Support to which I am entitled. I appreciate that support cannot start immediately but would feel reassured at least were I to be informed of an approximate timescale and provided with a more detailed outline of what support will entail”

**What issues of equality or discrimination have been highlighted by the pandemic and what can we do in response?**

Respondents raised the challenges that many people with dementia and carers are having with the shift to using more technology for healthcare and support services. It needs to be emphasised not everyone can use it, not everyone likes it. People should not be penalised for this and alternatives should be available. In-person services should resume as quickly as possible

“my wife finds it very difficult if there are a few people on the [video] call at once, it’s confusing for her... I need to help”

“GPs must be accessible and have face to face contact with carers during this time as it is a traumatic experience and stress and anxiety cannot be reduced by a phone call.”

“My husband has dementia and is hard of hearing, he can’t understand what is being said over the phone. I also don’t have IT access, so digital appointments are not use – the NHS needs to get back to seeing people sooner rather than later”

“I am not sure I would have considered [technology] had I known how time consuming and stressful it was going to be. I consider myself to be fairly good with technology/IT but this has been extremely trying at times”

“Too much of the support given at the moment is digital, it’s very off putting, above our heads and we just don’t want to use it. It doesn’t feel “real”, it very confusing for me and I don’t have dementia, person with dementia gets very confused very quickly with delays in speech and if more than one person is talking.”

Carers also raised the concern that the restrictions around care home visiting are affecting “Residents rights – the right to a family life – this is being deprived to care home residents at the moment due to extreme visiting restrictions. There has also been a deterioration in the health of my wife due to her being confined to her room, and lack of visitors, activities, exercise, spiritual support, hairdressers, opportunities to exercise etc. She has lost a lot of confidence and can no longer walk.” Respondents seemed unclear as to what can be done to address this situation given the inconsistent implementation of government guidelines.

“Carer felt that the government moved forward and gave guidance to care homes on how to start safely opening the home, however at local level this has not happened. Especially in privately owned and run care homes who appear ‘to interpret the rules to suit them’ also ‘no-one appears to be monitoring or policing what is happening”

“It has been a nightmare for me not being able to visit my wife in the care home. Government guidance on care home visiting during the pandemic has improved but it has not been implemented very well by the care home.”

**How well do the commitments in the paper support family carers to be equal partners in care?  
How can this be improved?**

Carers generally do not feel that they are being supported to be equal partners in care. Carers have talked about the fact they are forbidden from seeing their loved ones, and are not listened to by care providers- both in hospitals and care homes. There is scepticism whether the guidance in this paper will change that.

“I don’t see how I can be an equal partner if I can’t even see him (in the care home) or touch him.

I have many concerns that I am raising but nothing changes and I am not able to do anything about it.”

“Carers have had no equality in the care of their loved ones, The Scottish Government have written their reports, but care homes are doing their own thing and setting their own guidelines”.

“How can I be equal in my husband’s care when I cannot access the ward. He is unable to tell the doctors what is wrong. There are so many different people on the ward too, so trying to speak with the same person is difficult”

“Carer not being allowed into medical appointments, PLWD had a panic attack during the appointment and this could have been prevented if carer allowed to be with him.”

These examples where carers do not feel that they are treated as equal partners in care create stress both for the people with dementia and the carers. Conversely, the few examples that we know about where carers have felt like equal partners, they seem a lot less stressed and felt the outcomes have been better for the person they care for.

“When person with dementia was in hospital, I was kept informed of everything. I could not visit as it was early on in the pandemic when everything was most disturbed but at one point when he was quite unsettled they brought him to the door of the ward and I was able to speak to him from 2 metres back. The hospital suggested it as a means of helping him settle. It didn’t make a difference, but they did try.”

“Carer spoke about being an equal partner in care with PWD’s GP. She said that his GP always involves her, speaking to PWD first and then speaking to her. The GP also checks with carer how she is doing.”

Another issue which needs to be addressed is that almost no carer was aware of or recognised any of the supports listed in the paper. Only one carer that we have spoken to mentioned receiving any support from Connecting Carers. The lack of support was disappointing to carers as they admit they do need help.

"I try to be as positive as possible as I am his main carer, but it can be hard, and the support just isn't out there when we need it"

"Any sort of respite would be good. I have asked and been told no respite available at all"

I have health problems of my own but I am just told to get on with it

"You are made to feel guilty if you do not reduce your partner's package of care"

"Extra funding for short breaks for carers - what is this? Only Time 4 Me funding at the moment, which is a small amount of money."

"I am really tired as my Mum's care package was cut even before lockdown started so it has been an exhausting struggle to look after her since March. I have been unable to work because of the cuts in the care package. As the Scottish Government didn't take any action regarding the cuts it has had a really negative impact on me emotionally, physically and financially. I feel that the SG has just ignored unpaid carers. Frankly I was not aware of any SG or other support being made available to unpaid carers during the pandemic."

Similar to being recognised as "equal partners", carers are sceptical that they will receive support that the paper claims exists.

"Carers feel like everyone else is getting more funding except them"

"focus on communication and increasing awareness of "services available". Without sufficient funding to support, resource and adequately staff these services, awareness alone lacks any substance as the ability of these organisations to carry out their admirable work to support carers in their demanding role is limited."

"I struggle to understand how the Scottish Government will meet the commitments in the paper unless they put in a lot more funding"

**We want to reflect the extra pressure COVID has placed on the dementia workforce. How can we best reflect this and what should we do differently over the next year?**

Respondents have asked for extra resources to be available for care homes and care home staff.

"recruitment for a larger workforce as the pandemic and lockdown has highlighted a shortfall particularly in staff."

"During this pandemic it has highlighted that Care Home staff are not recognised as professionals and their salary reflects this."

Some respondents also asked for more training for hospital staff to be more aware of how to help people with dementia.

"I wonder how much medical staff in hospitals know about dementia, as some really don't understand about the condition and how it can effect someone"

"Never heard of dementia champion during stay"

"I actually heard several nurses declare that they had had no training in Dementia care. Surely this could be easily addressed."

"Hospital staff have no idea of supporting someone with dementia whether earlier or later in their diagnosis."

**What additional comments do group members have?**

**Alzheimer Scotland**

Throughout many of responses we received, there was a lot of praise for the work of Alzheimer Scotland, and other charities and community organisations.

“Alzheimer Scotland have been involved from the start of COVID keeping in touch and doing their best with calling me on the phone and there are groups online. A lot of other agencies took weeks if not months to get back in touch”

“I feel the telephone support from Alzheimer Scotland has been invaluable, you know us like family, and we can phone you anytime. You are so reliable with your calls every week other services have just dipped in and out with sporadic calls.”

“The only support for mum has been from Alzheimer Scotland with the weekly befriending call. I am not aware of any Govt support – no one else has been in touch in any way. GP services have been shocking – not had any experience with hospital but have not been made aware of any guidance?”

“I know I can phone Alzheimer Scotland at any time if needed, but as far as government or local Authority help, it seems non-existent? Alzheimer Scotland are the only support I’ve used.”

“If I hadn’t had the Alzheimer Scotland Helpline, and specialist help, I wouldn’t have managed.”

## **Technology**

The paper acknowledges the importance of technology in keeping services running, and how much this has been valued. Many, particularly in remote areas, have found technology particularly helpful and hope it is used into the future.

“ensure that all the support network and on-line activities introduced during the pandemic continues. Both the support network and on-line activities are amazing in my local community and so beneficial to supporting people with dementia and carers through this unprecedented time.”

However, this is not universal. We must also acknowledge there are many that are putting up with technology and stress it is not an adequate replacement for face-to-face meeting.

“Support from online groups is good but really missing face to face contact.”

“Digital groups have been a good means of keeping in touch, but we need to be meeting people face-to-face now.”

“The online support has been a lifeline for us over the last 9 months as I’ve been shielding, but I do miss the face to face support of the physical groups. My husband has also missed this.”

“A mixture of online support and groups physically meeting would be best. We are rural and if the weather is bad the online groups would still be great.”

There also those that do not like using it in any circumstance, or cannot use it, as discussed previously. Therefore, these people are not getting any support, emphasising the fact technology is by no means a replacement for services that were in place before the pandemic.

## **General Feedback of the Paper**

Some respondents felt the paper does not feel tangible or immediate. It is vague without specific or achievable aims, or information of how these goals will be achieved.

“From a carer’s point of view this document is very much looking to the future and doesn’t feel very immediate. Glad the government is “striving” however and will take “action”. “

“How do we avoid such deaths in the future? I can’t see where this is detailed.”

“The ‘what’ is clearly delineated but not sure how you could make these admirable commitments SMART. Not easy certainly when the future is so uncertain.”

“I found the paper full of commitments but no practical way of how they are going to achieve them feels to me like talking a good game”

## Appendix B: Helpline Volunteers

### Dementia and COVID-19 - The Scottish Government's Recovery and Transition Plan – Questions

#### 1. How well does this paper accurately reflect and respond to the lived experience of dementia during COVID so far? What's missing?

##### Feedback-

Collective view that the paper is aspirational and reads in a positive tone, however there is not enough acknowledgement of the hardship and exceptional difficulties people with dementia and their carers have experienced thus far. There is a particular lack of focus on care homes and excess deaths. There continues to be a massive gap between policy and the lived experience of people with dementia and their carers.

- Dementia has been a national priority in Scotland since 2007. Are we meeting all commitments in the current Dementia Strategy 2017 - 2020. What gaps still exist in the Strategy? The paper states that Scotland leads the way but then states too few people get the help. This is a contradiction in terms. Perhaps it is time to take a closer look at ourselves and be more frank about what we see. Timely diagnosis (only 64 per cent receive early diagnosis) and associated help and support should, in 2020, be the priority. Action required: The Government must invest in health and social care systems (the economic impact is more on the social care than health care) to improve diagnosis as per their National Dementia Strategy and The Standards of Care for Dementia in Scotland. What additional funding is available to meet these targets set out by Government in the current Strategy in 2017?
- Fair and efficient financing and provision of social & community care services is essential to ensure high quality care is given to people with dementia and their families/carers.
- Care Homes: People living with dementia in care homes are unaware of Covid and do not understand why their families have been prevented from visiting them. Their families suffer the sadness of not seeing their loved ones. The consequences of the lack of visits on people living with dementia with no family contact could cause an increase in states of agitation, anxiety, depression and deteriorating health. It would seem that even highly controlled visits have been banned. Weekly testing of both care staff and relatives should be a priority so that visiting can resume as soon as possible. The Government have promised this for several months but has not been implemented. As far as I know, care staff currently have a weekly COVID test? (NOTE: Government announced this week that testing will be expanded in coming months for care home visitors and staff); It seems very slow and therefore the testing programme in care homes is not providing the level of support to enable relatives to visit. It is not unreasonable to expect this to have been dealt with by now. It would appear PCR testing will be provided to facilitate Christmas testing but this needs further clarification from the Health Secretary.
- Care Homes must treat residents as individuals and risk assessments made before preventing relatives from visiting. There must not be a blanket ban on visits.

**2. The paper recognises that the majority of people with dementia live at home. What ‘quick wins’ can we include that will make a positive impact to people’s quality of life at home during the next year?**

Utilising the support and willingness of volunteers to spend time with and support people with dementia who are experiencing stress/distress, loneliness and isolation. Increase support to frontline workers with a strong focus on their mental wellbeing. Workers are describing feelings of exasperation and burn out. By looking after the workforce we enhance the quality of life for people needing support at home.

**NB: Upset was caused by the term ‘quick win’ this came across as a crass and insensitive way to ask this question and goes back to the point that it does not appear to acknowledge or appreciate the utter devastation people with dementia and their carers have experienced at this time.**

Refer to Dementia Strategy 2017 -2020 and in relation to COVID, we need to ensure people living at home with dementia receive quick access to healthcare and social care via their GP surgeries/other dementia experts. It is not always possible for Carers to arrange a telephone consultation and surgeries should have district nurses available to visit people at home. District Nurse visits/Dementia Nurses need to be involved in this over the next 6 to 12 months to clear the backlog of dementia annual reviews. GP surgeries/memory clinics etc to work more closely with Alz Scotland to help provide appropriate support in the community. Alz Scotland play a major role in the care in the community for people living with dementia and their carers and this should be increased.

To reduce isolation and loneliness, and the recognised mental health issues this causes, COVID quick testing (currently being undertaken in Liverpool) should be available for people looking after our citizens who are living with dementia. The vaccination programme which we all hope will begin in early 2021 is not mentioned in the report? Consent issues/POA. The paper is vague and lacks detail. Action required: Closer collaboration between GPS/memory clinics/social services and Alz Scotland. Results of memory tests given at clinics should be shared with relatives. Do we have adequate numbers of Dementia nurses? Do we have enough link workers who are crucial in supporting families in the community? Check dementia care recruitment gaps to achieve goals set out in Dementia Strategy.

**3. What can we do in the short term to mitigate the impact of reduced access to timely diagnosis and to post-diagnostic support during the pandemic?**

There needs to be more awareness of PDS amongst practitioners. The Helpline receive a large proportion of calls from individuals and family members who have a diagnosis but are completely unaware of their right to PDS. We receive many calls from people who are concerned about dementia but are not being listened or responded to by their GPs and therefore do not have access to a timely diagnosis. More awareness raising and support needs to be given to those key stakeholders and better relationships built to ensure that dementia is a priority within health and acute settings.

More closer collaboration is needed between GPs, health and social care etc and Alz Scotland in the work in the community and ensuring no-one is left alone to deal with dementia. The paper mentions

access to PPE for carers and time off for carers? Who pays for care when the unpaid carer is taking time off? There is no actual detail.

**4. What issues of equality or discrimination have been highlighted by the pandemic and what can we do in response?**

Targeted support – to BAME communities. We must understand health inequalities and improve the populations health. Do we need to train people to increase their knowledge and skills so we are delivering services that reduce health inequalities.

**5. How well do the commitments in the paper support family carers to be equal partners in care? How can this be improved?**

**6. We want to reflect the extra pressure COVID has placed on the dementia workforce. How can we best reflect this and what should we do differently over the next year?**

Feedback-

**Communication needs to be better. We would always have a spike in calls whenever significant announcements were made by ScotGov as there was always a distinct lack of clarity on what this means for PWD and their carers.**

The wall to wall press and TV coverage of the COVID epidemic and the BBC programme “Disclosures” in July, has shown the public perfectly clearly the extent to which the medical and dementia workforces have been stretched. Banning visits in care homes could cause burn out for the care staff as they have to cope with the consequences of families prevented from seeing their loved ones.

The tragic deaths of our elderly in care homes clearly indicates the need for closer cooperation between political decision makers and medical and dementia experts.

In the UK care staff jobs have been poorly paid, with little job security and no career prospects meaning that there is a high turnover of care staff and a reliance on temporary workers.

**7. What additional comments do group members have?**

Feedback-

**Dementia Prevention reference seems a bit disjointed more clarity on this and possible not in the right place.**

“After such a tragic year for our elderly and vulnerable citizens, now is the time for the Government to better serve the needs of people living with dementia and acknowledges the substantial contribution of unpaid carers.”



## Appendix C: Feedback from local staff

### Dementia and COVID-19 - The Scottish Government's Recovery and Transition Plan – Questions

How well does this paper accurately reflect and respond to the lived experience of dementia during COVID so far? What's missing?

**Feedback was received from over 200 members of Alzheimer Scotland staff who support people with dementia, their families and carers:**

It was felt that the report captures a lot of what is being reported locally and nationally

Purpose of Report: 'to continue to get the right care....' Not everyone has had access to the right care. The plan should be about supporting people to know what they are entitled to and having some means to achieve this

Responding to the Pandemic: People do not recognise these actions and responses as all having taken place.

The report highlights that people have to fight their way through this individually.

People's real experiences are missing and the voices of people living with dementia (either living at home or in a care home).

People's stories on video would send a powerful message - equally PLWD and carers.

#### General Comments on the Paper

- There is a huge gap between the policy guidelines and implementation/practice.
- The services and support people receive vary by locality
- It reads well, however details in paper not always been seen in practice, communication between services and the people with dementia and their carers has at times been disappointing.
- Does not reflect accurately the lived experience of dementia during COVID so far. Largely people feel that they have been 'left to get on with it', and the responses from the Government feel largely tokenistic.
- I am not sure the paper fully addresses the real practical issues on the ground for families in terms of removed or reduced local services that were a lifeline for people and the devastating impact this has had ( the wording is that "people have been unable to benefit" ) I don't personally think that goes far enough to measure the extent of decline in PWD or carer's health and difficulty experienced
- I think in practical terms on the ground for families (and staff), there is not currently a sense of early intervention or brain health (not just prevention but delaying effects for people already diagnosed), more one of firefighting where access to support is at crisis point as so much of what was available for people in these early stages has gone and for people further on, what might have been thought of as a positive choice (ie short

break outside the home, care home placement, assessment in hospital) is now seen as a last resort due to people's fear of all that comes with isolation and limited visiting access.

### **Visiting Hospitals and Care Homes**

Experiences of loved ones being able to visit a person with dementia in hospital are mixed, some able to visit while others not. There is also frustration from carers, when they are allowed a hospital visit, but when their loved one is moved to a care home this is less likely. There is some distress for families trying to visit at end of life in care home. Most people not being able to visit in hospital in past few weeks, unless end of life.

- The delivery & interpretation of hospital visiting guidance not made clear and can vary from area to area, depending upon area tier – it has not been a good experience for people
- There need to be more guidance for families on safe hospital visiting
- Hospital visiting guidance is available but have to look hard for it especially early on in lock down
- Hospital visiting not so problematic and more structured than care home visits.
- Virtual visiting in care homes isn't happening
- Disparity in information between hospital and care home
- Requires clear and concise guidelines that can be easily accessed and adhered to across the board.
- Care home visiting guidelines are confusing and are implemented differently depending on interpretation. Varies from one local authority to another.
- Guidance for visits to care homes has been interpreted very differently by different homes so people have very different levels of access to their relatives with dementia
- care home only offered to half hour visits and can't predict when end of life will be
- Carers are suffering guilt if loved one dies alone

### **Shielding**

- People living with dementia have been confused whether or not they are in the 'shielding' group
- Many understood the reasons but were unsure how to access support (huge credit to local communities/neighbours here for the work they did at the beginning of lockdown). Shielding was a struggle for all I contacted mostly due to lack of stimulation and contact, loneliness and boredom.
- Clarity required, shielding categories and what is available i.e. social work home care - if you were already linked into this then who would coordinate your needs
- Dementia was not mentioned/included as a vulnerable group unless there is a co-morbidity with COPD, cancer, asthma etc

### **Healthcare**

- People with dementia need to attend medical appointments e.g. flu jab alone, medical questions being asked of a person with dementia who is unable to answer them.
- Regarding the flu jab, some being told no flu jab until February. A carer received the jab free of charge but the PWD had to pay
- Consultations being done over the phone. One carer was asked if they thought their husband's medication needed increased. No face to face diagnosis or reviews.
- Lack of human contact – can't see people behind masks, lack of human touch.
- Lady with dementia having to make her own way into hospital.
- Another carer had to leave her husband at front door of hospital and go straight back to her car. Not knowing whether or not he had made it to the ward. Changed now and people getting back into hospitals. Differing experiences ward to ward and hospital to hospital.
- Carers not given enough information about loved ones. Communication between hospital and carer is extremely bad. Carers waiting at home on calls from Doctors/nurses re their loved ones.
- Carer feedback - "they really don't care about people with dementia - some staff have little knowledge of how to support someone with dementia in hospital"
- There are limited dementia champions in Glasgow QEH

#### **Social Contact/ Befriending/ Community Groups/ Day care**

- No real focus on non-essential services e.g support and peer groups...we know this early intervention helps to keep people engaged, active and independent with lower level needs
- Therapeutic groups seen as a lifeline to PLD & their carers, but not closed due to restrictions
- Doesn't appear to be any substitution or replacement for day/community services in forms of support. Those with families have been feeling very guilty about the loss and lack of social stimulation and been powerless to change this.
- The lack of physical contact is frustrating
- I have had staff and families ask why I cannot go out to see them when befrienders/nurses/support workers etc can
- People need more human face to face contact
- The majority of Befriending services will only support people who do not have dementia or who are in the very early stages and have no social, communication needs.
- Telephone befriending is not suitable for all people living with dementia as it can cause confusion, not understanding where the person on the phone is and sometimes putting down the phone and walking away to find them. As people living with dementia may not have capacity, telephone prompts and asking questions to assess their wellbeing can have misleading results.
- The reopening of Day Care was a difficult and long drawn out process.
- Although it's great that Day Care is open again, people are missing other things. Groups, face to face support. No planning around meeting face to face in a controlled environment i.e. a coffeeshop. Seen a huge decline in PWD in early diagnosis.

### **Support for Carers**

- Carers are stressed, respite is only given when a carer is at crisis point.
- Earlier intervention to stop people going into care earlier than they should.
- There are limitations to virtual support. Carers feel socially isolated and require practical help, social contact to give the carer a break.
- Carers are angry and upset and feeling desperate due to the lack of clarity and inconsistencies.
- Families feel angry, let down & have lost trust, feel abandoned
- The majority of Carers who are presently in desperate need of a break would not be eligible for support for their loved ones from local befriending organisations or voluntary day care. They often need to support the person to engage in phone and video calls, which is valuable for the person living with dementia but offers no break for the carer.
- Friends, neighbours and informal carers can be negatively impacted from the stress of caring for someone living with dementia, and during covid, shielding for themselves or the person has increased this strain, some people have not been able to understand covid and restrictions and have continued to call at neighbours doors putting people at real fear of transmission of covid.
- Clearer guidance for carers in accessing and accepting support would be useful. Many are still reluctant to allow family, close friends or neighbours to help them as they are scared of 'breaking the rules'
- I am not sure families been so aware of all the government's initiatives or background work described in the content of the paper. One family carer told me that she felt she had no value. Another carer who had view of the paper said she had not heard of the Clear your head campaign.
- It is good hear the acknowledgement on Mental Health for carers but it is not clear what services are going to be available to address the trauma some family carers have been through early on in lockdown, being unable to visit family in hospital or a care homes. Feel there are some real gaps in acknowledging the emotional impact on individuals.
- Counselling services stretched massively and there is not much counselling available for older adult services
- Carers feel they have fewer rights than ever and are encouraged to be grateful for what they have
- Don't want to put loved ones in respite as four weeks often leads to long-term care
- Attention needs to be paid to how carers will deal with the emotional impact of COVID in the months and years to come
- Carers know they should be equal partners, the responsibility is on the professionals to include them, it is not the carer's responsibility to fight to be included.

### **Support for people with dementia**

- Only crisis interventions are available
- National guidance for support that should be available is not reflected at local authority level. For example, only home care available at the moment with a small case of URGENT one hour visits for people reaching crisis.

- The offer of other services is very limited and the guidance how to access is unclear. As a locality we continue to do wellbeing calls and online activity groups but the local feedback from the people we support is that they have just been left to get on with it. Some have been resilient but many have gone into long term care quicker than would have been expected. Many have felt very much on their own.
- A recovery plan should also include access to services. I've not seen anything on transport
- Supporting the retention and re-design of services and supports

**8. The paper recognises that the majority of people with dementia live at home. What 'quick wins' can we include that will make a positive impact to people's quality of life at home during the next year?**

A range of suggestions were received from Alzheimer Scotland and the below provides a summary of the most common:

- The reassurance of consistent contact from a named individual/allocated worker/befriender or companionship service – this is something that those supported by Alzheimer Scotland staff have appreciated and there is a feeling that this would be beneficial for all people living with dementia at home who want it.
- Additional support for the use of technology, such as provision of devices and reliable broadband and guidance/signage to assist with the usage.
- For those for whom technology will never be a solution direct funding to access offline resources, such as DVDs and activity packs that alleviate boredom and increase activity and interaction at home, would make a huge difference.
- Routine is important, as is getting out of the house and human interaction (face to face) so the re-opening of group activities and therapeutic interventions, even on a small scale, would be hugely beneficial to both people living with dementia and their carers.
- Increased length of home visits by paid carers to be extended – this would allow greater time for more stimulating support and therapeutic input from existing paid carers and would also offer some respite to family members/carers whilst posing no increase in risk. Where families have now got access (usually via a carer team) to a weekly (or more frequent) 2/3 hourly visit, this has made a huge difference,.
- Review eligibility criteria for people to receive support at home in order that early intervention can take place to avoid crisis situations
- Primary care rehab services for people with dementia living at home to address increased frailty and decreased mobility that has arisen during the pandemic
- Provide funding for the reprint of Living Well with Dementia booklet.

**9. What can we do in the short term to mitigate the impact of reduced access to timely diagnosis and to post-diagnostic support during the pandemic?**

A range of suggestions were received from Alzheimer Scotland and the below provides a summary of these:

- There are not enough Link Workers to follow up on PDS therefore more funding is require to increase the number and improve access to PDS.
- Improved signposting and a more flexible PDS pathway is required to recognise that Link Workers are providing support for longer as it can be difficult to close cases when there is a lack of alternative support. It will also be necessary to recognise that during the pandemic that some people will have missed out on receiving a full PDS service so will require this for longer.
- More skilled counselling services to assist with coping with stress and emotional difficulty.
- Provide a phone call two weeks after diagnosis for light touch support and answer any burning questions
- Raise awareness of PDS and the fact that even while going through the pandemic we are still able to signpost to and help with accessing such vital supports as Attendance Allowance, benefits checks, Council tax reductions etc.
- At the initial time of diagnosis people need time to absorb the information and come to terms with the diagnosis, therefore allow GPs to make PDS referral at a later stage if appropriate.

**10. What issues of equality or discrimination have been highlighted by the pandemic and what can we do in response?**

**What additional targeted support should be reflected in the paper? How can we best respond to the disproportionate impact on BAME communities? What additional equalities issues have been highlighted by the pandemic and what should we do in response?**

Feedback-

- A fairer balance requires to be struck between controlling infection and applying restrictions with greater account being taken to the impact of the restrictions, particularly for people living with dementia, their families and carers.

- Issues around equality of access to digital (including reliable broadband) means people are missing community support so the provision of digital befrienders to go into homes would help address this.
- Rural isolation has been exacerbated during the pandemic with issues regarding access to appointments and the limitations of telephone and digital solutions, so more outreach in rural areas could help address this.
- People living with dementia have been sent home for hospital without proper assessment, such as following falls, whilst others have seen support packages withdrawn at the outset of the pandemic with no suggestion of them being reinstated as the situation has improved.
- Blanket decisions have been made for and on behalf of people with dementia and carers without reference to them or recognition of individual circumstances – a person-centred approach to guidance and restrictions is required going forward, particularly in relation to care home visiting.
- A disparity in the allocation of SDS budgets for social support or in relation to access to services and respite has been experienced both across and within local authority areas. A fairer, more consistent approach to accessing services and budgets is required.
- Family carers have been particularly affected during the pandemic by the withdrawal of care packages and closure of day services and respite. Action is required to ensure care packages are fully reinstated and day services and respite remobilised, even on a small scale basis.

**11. How well do the commitments in the paper support family carers to be equal partners in care? How can this be improved?**

Feedback-

- Respondents commented that the term 'equal partner in care' is not evidently captured in the paper and that whilst the commitments make sense their impact is limited as they are more suggested guidance than enforceable requirements.
- It was noted that family carers are not referred to in either section of the recovery plan.
- Guidelines require to be consistent and not open to interpretation
- H&SCP staff should receive specific dementia training
- For family carers to be equal partners in care they require to be involved in decision making regarding their loved ones whether in hospital or care home settings or providers of at home services.

- Carers don't appear to be getting the extra allowance that the report suggests, and the criteria for carers allowance is very difficult to meet.
- Communication between the care home and families could be improved in the form of a designated person to liaise with carers. Another issue around communication is not having a dedicated social worker, resulting in carers having to outline their situation multiple times.
- Staff reported working with a number of people who do not identify with the term 'carer', preferring to be recognised as husband/wife/daughter/son. Staff also noting the volume of people in extended families who contribute to the care of their family member with day to day tasks.
- Staff's understanding of the Short Break Fund is that it's time limited and on a first come first serve basis, and noting that carers don't have the confidence to go on a break at the present time, or the ability to (due to restrictions).
- Reports from carers who have lost trust in the system and feel they have lost any choice or autonomy they may have had. Due to restrictions, carers feel equal partner status is impossible due to lack of communication with care home staff, and the loss of communication and connection with their family member. Carers report to feeling let down by the void between what is supposed to be offered/available and what is actually available.
- Staff noting the reference to a marketing campaign and questioning investment in such activity versus investment in service provision.
- Investment in adequate services and respite opportunities would inevitably support the dementia workforce.
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- Re carer respite, staff noting small, regular amounts of 2-3 hours per week are just as important and impactful as one or two weeks, and more funding is required to support this.

[reference our living well and hospital care consultations carried out 2019/2020 for user feedback on partners in care and living well with dementia](#) – what does this mean????

**12. We want to reflect the extra pressure COVID has placed on the dementia workforce. How can we best reflect this and what should we do differently over the next year?**

During discussions, frontline staff from across the organisation shared their frustrations about how challenging and difficult it was, and still is, to not be able to support people in the way they need at a time when support has never been more needed, many of whom have no support system or social worker. There is a real sense of sadness – 'time is of the essence with people with dementia, you can't bring back that time once it's lost'. Staff also acknowledged that shift

from providing practical support to emotional support, and the difficult conversations that took place. There was some reflection on how quickly they all adapted to using new technologies, learning and upskilling quickly in order to offer support in different way. Staff acknowledged they were making huge adjustments and showing resilience for the people they support at a time they were also having to be aware of their own health and wellbeing. Staff noted that communication from Alzheimer Scotland has made them feel very connected throughout the pandemic,

**Funding**

- Greater investment in PDS/Link Workers

**Increase in respite provision**

- In terms of companionship support workers rather than residential respite, people might be able to manage for longer at home without carers reaching breaking point - widely recognised that most people wish to remain for as long as possible in the place where they feel safe eg home.

**Access to Flu Jabs**

- Despite being part of the Health and Social Care sector, several staff had problems accessing the flu jab

**Participation**

- Opportunities to contribute to conversations regarding commissioned services and be able to have an input re what staff can contribute as a skilled workforce and the services they can provide.

**13. What additional comments do group members have?**

**Anticipatory Care Planning**

How do we ensure this is done in an appropriate way and handled sensitively in future?