

Response to the Scottish Parliament Covid-19 Committee Call for Evidence, October 2020

About Dementia is a five-year project, funded by the Life Changes Trust and hosted by Age Scotland. We bring together people affected by dementia with professionals in the public and third sectors to influence change around policy and practice in Scotland. This response relates to the following questions in the Covid-19 Committee's Call for Evidence:

- Do you think that the Scottish Government needs these emergency power;
- Where the powers have been used was this clearly communicated;
- Where the powers have been used what impact did these changes to the law have on you or your sector;
- Could other measures have been used to better support you or your sector to respond to the challenges posed by the pandemic;
- Any other comments you wish to make;

The impact of Covid-19 on people living with dementia

In About Dementia's response to the Committee's call for evidence in May 2020 we stated that the pandemic had already caused an unprecedented impact on people living with dementia. We would like to reiterate the concerns we raised at that time of people living with dementia, their family members and unpaid carers who remain anxious about the consequences of the pandemic both currently and for the future.

Information provided to About Dementia by people affected by dementia indicates that the adverse effect of Covid-19 and the lockdown measures introduced to address the crisis has been significant for people affected by dementia.

Do you think that the Scottish Government needs the emergency powers?

About Dementia recognises that the Covid-19 pandemic clearly poses a public health threat that may justify restrictions on certain rights, such as those that result from the imposition of quarantine or isolation and which may limit freedom of movement. We urge the Covid-19 Committee, however, to ensure that human rights such as non-discrimination, transparency and respect for human dignity are maintained at all times to limit any potential harm that may come from the imposition of broad measures, such as those imposed on care homes in relation to visitation rights.

About Dementia also requests that the Committee ensure that The Siracusa Principles, adopted by the UN Economic and Social Council in 1984, be applied in relation to any care home restrictions permitted in Scottish Government guidance. These Principles specifically state that restrictions should, at a minimum, be:

- provided for and carried out in accordance with the law;

- directed toward a legitimate objective of general interest;
- strictly necessary in a democratic society to achieve the objective;
- the least intrusive and restrictive available to reach the objective;
- based on scientific evidence and neither arbitrary nor discriminatory in application; and of limited duration, respectful of human dignity, and subject to review

A particular issue brought to our attention during the first six months of lockdown has been failures in preventing inhuman and degrading treatment. This is especially recognized in relation to the need for proportionality with regards to restrictions on residents. It has been brought to our attention that residents with dementia were locked in their rooms for weeks at a time to avoid the spread of Covid-19. However, it has to be recognised that care homes are residential properties and not clinical settings which makes proportionality vital. Any restrictions should, therefore, be short term and involve consultation with individuals and/or their Powers of Attorney.

Incidences of where human rights have not been met have also been raised with us by carers in relation to being able to wash, go to the toilet or go to sleep. Carers have requested that the Scottish Government and Local Authorities be made fully aware of these ongoing challenges, to have these recognised as breaches of rights and have them acted upon.

Where the powers have been used was this clearly communicated?

It is very often the case that people do not have any choice when becoming a carer and that it is simply expected that they will take on this role. In general carers are not asked what other responsibilities they have and what their needs are. This can be challenging for carers who recognise that liberty may need to be curtailed in order to protect person they are caring for. This is never an easy decision and appears to have become more difficult during lockdown. Carers have reported to About Dementia that people living with dementia have been restrained in order to enforce lockdown rules and that carers are having to make difficult decisions without clear support or guidance.

Unpaid carers have reported having to provide more care for their loved ones during the coronavirus outbreak because their local care and support services have been reduced or closed. Often the withdrawal of services was not communicated effectively, if at all.

The withdrawal of social care services by local authorities has impacted severely on people with dementia and About Dementia has heard from carers that this has resulted in a growth in crises situations. About Dementia was informed that those who were assessed as low priority for social care were the first to have care withdrawn and that these individuals are increasingly those who are in crisis and are now in the high risk category. Unpaid carers fear that due to this reduction in care they will have no choice but to undertake more support for loved ones with more complex health conditions in crisis situations.

This situation is said to have resulted in unpaid carers feeling overwhelmed and worried about what will happen to the people they care for if they have to self-isolate or become ill. Information on such situations has been reported to us as being insufficient.

In short, evidence has been provided to us which indicates that use of Covid-19 powers have not been clearly communicated when they have been used.

Where the powers have been used what impact did these changes to the law have on you or your sector?

Evidence provided to About Dementia indicates that there has been a hugely adverse impact on family life with loss of contact between a person living with dementia and their carer being a significant part of this. The loss of community and routine activities, which are vital to people living with dementia, is proving to be very challenging. This is especially true for people in care homes but is also the case for those living in the community who would previously have attended day centres or activity clubs.

Losing regular care workers and being supported by unfamiliar people reduces the ability of people living with dementia to build relationships or trust. This is especially crucial when carers are undertaking intimate tasks.

The wearing of masks is difficult for people living with dementia, as is staying physically distant. There is direct discrimination in the way that the Covid-19 legislation has been constructed, although this is partially acknowledged in the exemptions. The current regulations have impacted on people with hearing impairments as it is not possible for someone who requires to lip read to do so if the person speaking is wearing a mask. For someone with dementia it can be difficult to remember why face masks are necessary and why physical distancing is happening. This can be distressing.

People affected by dementia have highlighted concerns that the focus on the physical prevention of the symptoms and spread of Covid-19 has prevented adequate consideration of the psychological impact on people with dementia. There is a great deal of concern amongst people living with dementia, their unpaid carers and families that the psychological impact of lockdown measures under the Scottish Government's powers is something which will have a long term effect on them and that it must be addressed now. With group settings not being possible respite opportunities are lost. Individual calls are taking place but these are not an adequate substitute. The personal contact element of support has been lost.

Could other measures have been used to better support you or your sector to respond to the challenges posed by the pandemic?

About Dementia believes that the role of carers has been expanded during lockdown, not only replacing what has been lost due to the withdrawal of paid support services but taking on additional family responsibilities at the same time. With post-diagnostic nurses being redeployed to frontline Covid-19 duties this has

left a huge gap in support and many carers have reached crisis point. Accessing frontline services has also led to a reduction in the availability of respite. The question of what will be put in place to cover respite needs until respite services are re-established has to be asked.

It should be recognised that the 3rd sector has responded well to the coronavirus lockdown and has responded quicker because the staff and volunteers were already on the ground and knew the needs of their local areas. This does not mean it was not difficult. In some areas local authorities stopped classifying people as being critical which meant a loss of support or additional support that became required has not been available.

Some carers have still been going to work but care support has been withdrawn. This has resulted in people living with dementia not being provided for at times if 3rd sector support has not been available. Carers have been stoic, getting on with what confronts them and coping with the situation. They have, though, become increasingly frustrated. The economic impact is known to be falling disproportionately on women, especially older women, who are more likely to be providing care. About Dementia are keen for this situation to be highlighted and addressed and the opportunity seized to encourage employers to be more carer friendly.

Questions have been raised about re-accessing services after lockdown. These will only return gradually so additional volunteers will have to be sought and mobilised as the lockdown eases.

In the early weeks of lockdown we heard cases where with buildings being shut it had not been possible to access Adult Carers Support plans which are retained in offices. This left individuals to make their own arrangements. Carers assessments are already required but should be mandatory. These are too often ignored. There has to be accountability if these assessments are not undertaken or not effectively implemented.

Issues around the provision of financial support, such as Self Directed Support, have been raised with About Dementia by carers who were unaware of financial support which may have become available. Carers have stated that had they known about additional financial assistance they might have been able to make better arrangements. Emergency funding (e.g. the Life Changes Trust's Individual Awards Scheme) which would allow people to purchase small items that will make them feel better should be considered. About Dementia believes that the ability to purchase small items can make a big difference to the mental well-being of people living with dementia.

About Dementia recently undertook a survey of people affected by dementia which indicated that carers had experienced a significant loss of support after lockdown with the closure of day care and befriending services most often noted. The befriending and social contact which has been adversely affected by the lockdown has to be replaced during the easing process. We, therefore, call on the NHS, Health

and Social Care Partnerships, and Civil Society in Scotland to recognize the impact of the digital divide, take rapid and creative action to safely reintroduce services to ensure people living with dementia can participate and do not become permanently locked out of society. Smaller and shorter social group meetings, complying with social distancing requirements, would still provide a degree of respite to carers and should be supported where possible.

Great loss has been experienced during the pandemic but normal grief and bereavement process have not been possible, We could be facing an epidemic of unresolved grief in future so consideration of this issue should be undertaken.

Any other comments you wish to make?

As mentioned above, over the six weeks from the 21st of April to the start of June 2020 About Dementia invited people living with dementia, carers and professionals working with people affected by dementia to complete an online survey about how Covid-19 has affected them. In particular the survey focused on the support people receive or provide, and if or how this has changed as a result of the pandemic. With the information obtained we produced a report titled 'Locked down but not forgotten: Experiences of people affected by dementia living in Scotland during the Covid-19 Pandemic'. [Here is a link to that report](#) which we hope the Covid-19 Committee will find both interesting and informative.

About Dementia would like to restate its belief that there is much to be gained from accessing information from the lived experience of people affected by dementia during the Covid-19 pandemic. It is then vital that this learning is integrated into existing practice. We would urge the Covid-19 Committee to promote the involvement of people affected by dementia in the development of guidance on supporting them during the pandemic crisis.