



COVID-19: The Hidden Impact

A report on the impact of the COVID-19 pandemic on people with dementia and carers living at home

About Alzheimer Scotland

Alzheimer Scotland is Scotland's national dementia charity and our aim is to make sure nobody faces dementia alone. We do this through providing support and information to people with dementia, their carers and families, campaigning for their rights and driving forward dementia research.

We have over 9,000 members, over 90,000 Dementia Friends and we are supported by over 1,000 volunteers. We employ around 450 full and part-time staff, mainly in our service-provision projects across Scotland.

We have Dementia Resource Centres in 21 different locations across Scotland. These centres provide a safe and friendly environment for people with dementia and their carers to access support and take part in a wide variety of groups and activities.

Based within the Dementia Resource Centres are a network of Dementia Advisors, funded by Alzheimer Scotland. Dementia Advisors work with people with dementia and carers often prior to diagnosis and, in some

occasions for carers, after their loved one has died. They provide tailored support, information and advice as well as signposting to other organisations and agencies. They also work in local areas across Scotland to raise awareness of dementia and help communities understand how to become more dementia friendly.

We also employ a group of Dementia Link Workers across Scotland who are commissioned to provide at least one year's post diagnostic support for those people who have newly received a diagnosis of dementia.

We provide a Freephone Dementia Helpline, which is available 24 hours a day, 7 days a week providing information and emotional support to people with dementia, carers, families, friends and professionals.

Making sure nobody faces dementia alone.

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May/June 2021 update



The 31st May 2021 marks the beginning of Dementia Awareness Week in Scotland. The devastating impact on the lives of people with dementia, their families and carers of the past 14 months of the COVID pandemic means that Dementia Awareness Week this year is perhaps more poignant than any previous year. It provides an opportunity to reflect on the past year and consider how we as a country recover and look to the future. This is why we have chosen the theme: Hidden Voices; Hidden Impact; Hidden Cost: Let's talk about dementia.

We want to highlight the direct and indirect harms of living in a time of a global pandemic and the public health restrictions put in place to prevent the spread of the virus. We also want to highlight the gaps in our health and social care system which meant we were not prepared for the devastation this pandemic has wrought on so many lives. People with dementia and their families and carers have been disproportionately affected. Here we set out what we are calling on the Scottish Government to do to support our community to recover from the pandemic. Dementia must be a national priority, with national and local leadership, accountability and investment which ensures people living with

dementia, their carers and families receive the highest quality of care, treatment and support throughout the illness – in every setting – and are never so exposed should we ever experience a similar crisis.

We have re-published our COVID-19: The Hidden Impact; a report on the impact of the COVID-19 pandemic on people with dementia and carers living at home first published in November 2020. The report sets out the evidence we gathered from the tens of thousands of people with dementia and their families and carers we continued to support throughout the last year, and the impact of the pandemic and the public health restrictions on their health and wellbeing. The report made a series of recommendations for the Scottish Government and others, as well as highlighting other areas of priority where we had called for action.

We have since updated our support statistics to include the timeframe between March 2020 and April 2021. We have also added a section to explain what action has been taken since the report was first published, and what action we are asking the Scottish Government to take now.

What has happened since we published the COVID-19: The Hidden Impact Report

In the months since we first published the report, we have learned even more about the impact of this global pandemic. The cautious optimism of last summer gave way to another period of uncertainty over the winter months when we experienced another national lockdown in response to the substantial rise in COVID infections, hospitalisations and tragically many more deaths. We have also seen the roll out of a national vaccination programme, and more recently a relaxation of public health restrictions as infections have reduced.

This prolonged period has kept families apart, disrupted all of the things we have taken for granted and which keep us well. For people with dementia and their families and carers, this has been nothing short of devastating.

Since this report was first published, the Scottish Government have since consulted on, published and began to implement the Coronavirus (COVID-19) - dementia and COVID-19: action plan. The plan, published in December 2020, sets out 21 commitments for a national response to the pandemic to support recovery for people with dementia and their carers. These include commitments which respond to some of the

recommendations we made in The Hidden Impact report and the other priorities we highlighted. These include commitments to:

- Support increased diagnosis rates to mitigate against the disruption to dementia diagnosis services during the pandemic;
- Continue to support the delivery of, and increase access to, the national guarantee that every person diagnosed with dementia is offered high quality person centred post diagnostic support;
- Commission a study as part of work on excess deaths during the pandemic (this work is in progress) and a study to examine the use of psychoactive medication in care homes during the pandemic;
- Work with health and social care partnerships to support the physical rehabilitation for people with dementia and their carers through implementation of the Framework for Supporting People through Recovery and Rehabilitation;
- Support and monitor the reopening of Adult Day Services for the benefit of people with dementia and their carers.



In addition to these commitments, the Scottish Government have responded to concerns we raised about significant emerging needs throughout this pandemic. They have provided funding for Alzheimer Scotland to establish a new national counselling service for families and carers of people with dementia who are experiencing loss, bereavement, anxiety and emotional distress, and this team is now operational. They have also provided short term funding to establish a new Action on Rights Team to support those living in care homes and their families and friends to support meaningful contact after so many months of limited or no contact. This new team offers emotional and practical support on the care home visiting guidance to empower families and carers to have informed discussions with care home staff and, where necessary and appropriate, to liaise directly with care home staff responsible for visiting arrangements to help facilitate visits. The team works with families to support meaningful contact in a way that helps avoid, or when necessary, resolves conflict. Since the Action on Rights team was established in February, it has worked with over 110 families of people living in care homes to support them to successfully arrange meaningful visits.

Since 2019, Alzheimer Scotland have been campaigning for Fair Dementia Care for people with advanced dementia to end the inequalities they face. Many people with advanced dementia do not currently have equality of access to the specialist health and nursing care they need. Our campaign aims to end the injustice they face in paying for care for what are health needs arising

from a progressive and neurological disease process. The pandemic has further exposed these inequalities, and we have called on the Scottish Government to commit to delivering Fair Dementia Care by increasing Free Personal and Nursing care payments so that people with advanced dementia no longer have to pay for health care needs. This was the key focus of Alzheimer Scotland's election campaign during the Scottish Parliamentary elections to finally deliver Fair Dementia Care.

In February 2021, the Scottish Government published the Independent Review of Adult Social Care. Alzheimer Scotland welcomed this report - we believe that it presents a compelling, positive and transformative vision for Adult Social Care in Scotland.

The Scottish Government have committed to implementing the report's recommendations in full, including establishing a new National Care Service, ending all non-residential care social care charging, and increasing the Free Personal and Nursing care payments to those in care homes to a level that equates to the national care home contract care costs. This appears to be closely in line with our Fair Dementia Care campaign and election pledge. Whilst we fully welcome these recommendations, it is likely that implementation will take several years. We will continue to campaign to end this inequity now on the basis that people with advanced dementia do not have time to wait. They need and deserve urgent action now. Please see 'Vision for the future' section, which sets out what action we are calling on the Scottish Government to deliver.



Our vision for the future

Hidden Voices, Hidden Impact, Hidden Cost

People with dementia and their families have been significantly impacted by the COVID-19 pandemic, and the subsequent measures put in place to mitigate the spread of the virus. Almost every component of what could, and should, be a good system of personalised care and support for people with dementia and their families has been shattered. For well over a year, with the exception of residential forms of care, almost all direct community support has been delivered exclusively by families themselves.

There is no doubt that there has been a good level of digital based support introduced, which was enabled by local authorities agreeing to the flexible use of their commissioned funds and registered services being allowed to adapt their support. This level of pragmatic partnership working, alongside the commitment of frontline staff to develop new skills and abilities in digital and online based care, has been invaluable in helping many people cope and get through this pandemic.

However it would be wrong not to recognise that, as a result of the pandemic, the fundamental foundations of high-quality person-centred care from the point of diagnosis to end of life that we have been promoting and advocating for many years, has been decimated.

The principles of a timely early diagnosis and high-quality post diagnostic support which builds on an individual's own natural support networks, their hopes, strengths and ambitions, have been the bedrock of practice which have enabled people to live well with dementia. Over the last year, this has simply not been able to be fully delivered. The Scottish Government estimated that around 20,000 people will be diagnosed in 2020 and we know that prior to the pandemic fewer than 50% of this group were offered post diagnostic support. There is a community of people waiting to be diagnosed, as well as those individuals newly diagnosed, who have not had the opportunity to properly come to terms with the illness, to build a strong level of resilience and any form of meaningful self- management. If we do not quickly respond to their needs we will simply be accelerating the level of crisis and need for formal care services, such as care homes, to a level that

we have not seen for decades, and perhaps never seen before.

Add into this those individuals who were managing to live well, using their well developed self-management approaches, attending community groups for peer support, therapeutic activities and expert advice on how to live well with dementia. They have experienced immense levels of loss, isolation and a disconnection from vital support which kept them well. We know that many of their needs have dramatically increased and they now need high levels of formal support – support which is simply not available. Families are filling this void, not just for this group but also for those with more advanced illness. Families – and not just primary carers – are essentially holding all of our social care infrastructure together. We owe them a great debt. Worryingly, many extended family members which have helped fill this void might not be able to do this for much longer, many people will be returning to work soon, furlough will come to an end and this extra level of available care will more than likely sharply decline.

When we consider the well-documented effect of the pandemic on people with dementia living in care homes, the immense and quite unimaginable pain that they, and their families, have gone through, the number of Covid related deaths and the deeply concerning excess deaths which have been reported of people living with dementia, one can only fairly and reasonably conclude that there has been a disproportionate impact on our community.

We do not believe that these issues can be resolved without a major change in the way local services are delivered and commissioned by Integrated Joint Boards. We believe that given the impact on this community, it would be wrong to leave the responsibility for recovery solely to local areas, and now is the time for the Scottish Government to establish a dedicated Dementia Directorate. This Directorate should be resourced with an adequate budget and empowered to support local Integrated Joint Boards, compliment their existing services in key delivery areas such as post diagnostic support, community services such as specialised Day Services and personalised individual support, increased carer respite and much needed community based Advanced Care Services.

We believe that this Directorate should in future become a core component to the new National Care Service, although we see no reason why it cannot be set up in advance of this service being established as a direct response to the pandemic. There are over 90,000 people living with dementia in Scotland. For too long, we have toiled to transform high-quality, innovative and progressive national strategies and commitments to support them well into local practice and services. For too long, dementia has been hidden under a mental health banner, or perceived as an older person's care issue, seen as something we can deal with in a generic way. There is more than enough evidence of how unsuccessful this has been prior to the pandemic, and we can no longer rely on seeking to influence, support or help shape local implementation of this. It is time dementia is given an independent and core position within our national structures and government. People with dementia and their families need – and deserve – a national response to this, one that must be led by the Cabinet Secretary for Health with a new dedicated Dementia Directorate capable of meeting this community's needs in partnership with local areas.



Executive Summary

This report focuses on the impact of the pandemic on people with dementia living in their own homes in the community, and the families and carers who support them. It sets out the evidence Alzheimer Scotland has gathered from the tens of thousands of people with dementia and their carers we have supported throughout this crisis, about the impact of the pandemic, and the unintended harms to their health and wellbeing caused by the measures intended to keep them safe from the virus.

The report also sets out the urgent requirement to address these harms by responding to the increased levels of need through the safe remobilisation of community supports for people with dementia and their carers. This is necessary to better balance the need to protect them from COVID-19 and the harms that the restrictions in our communities are causing.

The report concludes by making recommendations to Scottish Government, Health and Social Care Partnerships and other key stakeholders about how Scotland can ensure that the increased needs of people with dementia and carers are prioritised, to mitigate against the harms of this pandemic in the coming months.

What we did

We used a combination of desk-based research methods to review literature that was emerging at the time about the impact of the COVID-19 pandemic on people with dementia and carers. We reviewed the information that we had collated from what people with dementia and carers have been telling our 24 hour Freephone Dementia Helpline and our frontline staff in the thousands of contacts they have had throughout this crisis. We also reviewed responses from two surveys that we asked our Dementia Advisors and Post Diagnostic Support Link Workers to complete in August and October. The survey asked them to tell us how the people with dementia and the carers they have been supporting in the community have been impacted by the COVID-19 pandemic, and the public health restrictions.

What we found

- Increased frailty and a decline in mobility, and increased mental health issues such as anxiety and depression, were the most prominent health issues
- People with dementia and their carers have been negatively impacted, directly and indirectly by the COVID-19 pandemic
- The disruption to daily routines, social interactions, and health and social care support has had a negative impact on the physical and mental health of people with dementia and carers
- The disruption of community-based therapeutic and activity groups run by Alzheimer Scotland and other third sector organisations has had a negative effect on people with dementia and carers
- Faster cognitive decline and acceleration of the progression of the symptoms of dementia
- An increase in the complexity of needs of people with dementia
- Difficulty among people with dementia in understanding and complying with the need for the restrictions in their daily routines and social interactions
- Increased and substantial stress and distress among people with dementia because of these factors
- Carers have taken on the additional responsibility for supporting relatives and friends with dementia often alone and with little or no support, and no meaningful respite breaks
- Carers are experiencing significantly higher levels of stress as a direct result of trying to manage the increased needs of those they care without support and meaningful respite
- Carers are experiencing a significant decline in their physical and mental health due to the demands of caring for people with increasingly complex needs
- Clear evidence that the public health measures intended to prevent the spread of COVID-19 infections are causing harm to people with dementia and carers.

Recommendations

1. The safe remobilisation of small-scale therapeutic day service provision continues and is given the appropriate support by public health
2. Health and Social Care Partnerships act urgently to ensure that people with dementia and their carers have access to an assessment or reassessment of the changes in their levels of need
3. Health and Social Care Partnerships ensure that carers of people with dementia are better supported by have accessing to appropriate levels of respite care
4. Health and Social Care Partnerships work to safely reinstate social care that has been reduced or stopped due the pandemic, at a level which reflects the current levels of needs of people with dementia and their carers
5. The Scottish Government establishes a dedicated national Post Diagnostic Support fund, to double the capacity of Scotland's Health and Social Care Partnerships to offer high quality personalised post diagnostic support to every person diagnosed with dementia in Scotland
6. As a matter of priority Health and Social Care Partnerships ensure access to diagnosis or, where necessary develop appropriate alternative diagnostic processes for as timely and early a diagnosis as possible.



Introduction



The COVID-19 pandemic has given rise to a crisis unprecedented in recent history. The virus and the measures put in place to prevent its spread have impacted on all aspects of society. We are learning more each day; not only about the nature of the virus itself but of the direct and indirect harms it (and the measures put in place to fight it) are causing.

There is an estimated 90,000 people living with dementia in Scotland – approximately 60,000 of whom live in the community. Each of these people, to different degrees, rely on their daily routines, social interactions, community-based groups and activities, and formal health and social care services, as a way to maintain their wellbeing and live as independently as possible in their own communities. All these supports have been disrupted as a direct consequence of this pandemic and the public health restrictions.

Like many other organisations, Alzheimer Scotland has had to transform the ways in which we support people living with dementia, their families and carers to comply with the restrictions which have been in place. This includes providing alternative support for those who benefit from Alzheimer Scotland's Day Care services commissioned by Health and Social Care Partnerships. We are grateful for the ongoing support of local commissioners which enabled us to continue to support those with the most complex needs during this period when Day Care Services have

been closed. Alongside this our 24 hour Freephone Dementia Helpline staff and volunteers, local Dementia Advisors, Post Diagnostic Support Link Workers and other colleagues have supported thousands of people with dementia, their families and carers, using innovative and alternative approaches throughout this crisis. **Details of these contacts are set out in the tables on page 7.**

Through these contacts we have heard first-hand how this crisis is impacting on people with dementia and carers as they struggle to cope without their usual formal and informal support networks and routines which help them stay well.

We reviewed the information that we had collated from what people with dementia and carers have been telling our 24 hour Freephone Dementia Helpline and our frontline staff in the thousands of contacts they have had throughout this crisis. We also reviewed responses from two surveys that we asked our Dementia Advisors and Post Diagnostic Support Link Workers to complete in August and October 2020.

In addition to the evidence we gathered from these contacts and surveys, we also carried out a review of literature that was emerging at the time relating to the impact of the COVID-19 on people with dementia and carers and other groups. Several studies have been published since the start of the UK wide lockdown in late March 2020.



Between the beginning of lockdown on 23 March until the end of March 2021, Alzheimer Scotland provided:

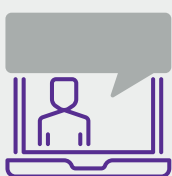
49,236

therapeutic interventions (excluding post diagnostic support). This includes:



5,016

online groups which have been attended by people with dementia and carers.



2,357

wellbeing home visits to help reduce social isolation, support wellbeing and reduce carer stress and distress



6,925

video calls



6,338

enquiries



30,804

telephone calls where support was provided



3,030

activity packs to support people with home activities

Alzheimer Scotland Dementia Post Diagnostic Support (PDS) Link Workers provided:

61,677

contacts with
people with
dementia and
their carers



2,715

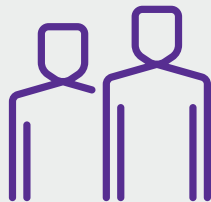
digital peer support
groups, digital cafes
and online one to
one support



Post diagnostic
support to over

5,760

people with dementia



They also made

10,101

referrals or
contacts with other
professionals



Alzheimer Scotland's 24 hour Freephone Dementia Helpline received:

8,861
calls



Lasting

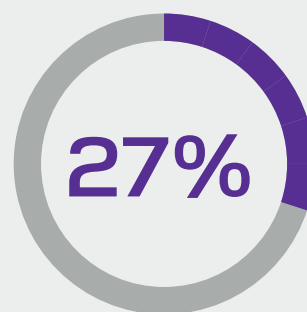
74,317

minutes in total
(which represents
28 full days of
support during
this time period)



552

email enquiries to
the E-helpline



The Helpline has experienced
an average of 27% more calls
during the pandemic. The
average length of calls has also
increased by 27%

COVID-19



The COVID-19 pandemic has devastated the lives of many millions of people across the globe. Public health measures to restrict the spread of the virus are vital. However, we also now know that the measures to prevent the virus spreading cause unintended harms. These harms are increasingly understood, as demonstrated by the First Minister Nicola Sturgeon who, on 7 October 2020, said:

“We have a duty to balance all of the different harms caused by the pandemic. We must consider the direct harm to health from the virus – which must be reduced ... And we have to consider the wider harms to health and wellbeing that the virus – and the restrictions deployed to control it – are having on all of us.”

The Scottish Government acknowledge the growing evidence of the direct and indirect harms of the pandemic in what it describes as the Four Harms of COVID-19 (Scottish Government (2020).

These are:

- the direct impact of COVID-19
- other health impacts
- societal impacts
- economic impacts.

There is increasing evidence that people with dementia and their carers are negatively impacted by each of these four harms. The impacts are wide-ranging, but they can be described within a framework of human rights, encompassing economic, social and cultural rights (Scottish Human Rights Commission, 2020). The effects on people with dementia arise from:

- High incidence of multi-morbidities, with vulnerability to infection which increases the risk of severe illness or death from COVID-19
- Age-related factors, including the increased incidence of dementia with age
- Increased anxiety, confusion and stress and distress arising from difficulty in understanding the nature of the pandemic, and the imposition of rules, regulations and guidance impacting on everyday life
- Isolation from the loss of normal social contact and interactions with family and carers
- Reduced stimulation due to cessation of activities
- Increased stress on family and carers, impacting on relationships
- Reduction in household income
- An already overstretched social care system.

All of these factors interplay to cause harm: excess mortality (Public Health Scotland, 2020), both as a direct result of contracting COVID-19, and indirectly because of the restrictions in place to manage the pandemic (Saurez-Gonzales, et al, 2020); a rapid deterioration in the symptoms of dementia, loss of cognitive function and skills with a decreasing ability to manage safely at home and stress and distress, not just for the person with dementia but also for their families and friends who have tried to fill the enormous gap in the person's life that has resulted from the disruption to the supports they normally rely on.

Several studies (Alzheimer Society, 2020a, 2020b; Carers UK, 2020; Giebel C, Lord K, Cooper C, et al. 2020 Giebel C, et al, 2020) highlight the negative impact of the disruption in health and social care services on the health and wellbeing of people with dementia and carers. Almost half of people living with dementia had experienced significant cognitive decline and worsening of the symptoms of dementia, and only 20% had experienced no change (Alzheimer Society, 2020a, 2020b). Similarly, several studies show that the majority of carers had taken on additional caring responsibilities in the absence of the usual health and social care, and other informal supports that they relied on prior to the pandemic (Age Scotland, 2020; Alzheimer Society, 2020a, 2020b, Age UK, 2020; Giebel C, Lord K, Cooper C, et al. 2020). Almost half of carers had experienced a significant decline in their emotional wellbeing and mental health and additional strain on their relationship with the person with dementia they are caring for (Alzheimer Society 2020b). A strong theme from the emerging literature is the impact

on carer's resilience, with many reporting that they are exhausted and struggling to continue to care for themselves as well as the person with dementia they care for (Alzheimer Society 2020b). Over 40% of those who receive a care and support package reported this having been reduced or stopped since the beginning of the pandemic (Alzheimer Society 2020a). There is a correlation between the disruption to health and social care services, and a detrimental impact on the realisation of human rights (Scottish Human Rights Commission, 2020) and the wellbeing of people with dementia and their carers (Giebel C, Lord K, Cooper C, et al, 2020; Giebel C, et al, 2020). This growing evidence reflects the four harms described by the Scottish Government (Scottish Government, 2020) and is consistent with what we have found through the many thousands of contacts we have had with the people we have supported throughout this crisis. The next section describes our findings.

It draws on the information we have collated from the two surveys we carried out, and from the many thousands of contacts our frontline staff and Helpline volunteers have had with people with dementia and their carers. The findings set out the key emerging themes of the impact pandemic and the public health measures. They include what our frontline staff and volunteers have told us what have observed and what they've heard directly from the thousands of contacts they have with people with dementia and carers. It also includes what people living with dementia and carers have told us directly.



What we found: impact on people with dementia



The most prominent issue arising for people living with dementia living in the community is the substantial decline in their physical and mental health. Alongside that, many are reporting rapid, higher levels of cognitive decline and increased symptoms of dementia. The increased isolation of not being able to continue their daily routines and see family and friends, combined with the disruption in social care services such as Day Care and care at home, and other community-based supports which provide therapeutic value, have had a substantially negative impact on their wellbeing.

There is a clear picture emerging of overwhelming levels of stress and distress and agitation for many people with dementia, who are often unable to understand the reasons for the restrictions in their lives as well as the ever-changing guidance. There is evidence that this is causing an increased tension in relationships with family and carers which is adding to an already stressful situation for many carers. Because of this, and in the absence of the supports they may normally rely on, we are also seeing an apparent increase in people with dementia moving to care homes sooner than would otherwise be necessary. Given the impact of COVID-19 in Scotland's care homes this is a measure of the increased levels of need of people with dementia, and the pressure carers are experiencing.

The following sections highlight the key themes we have identified:

Declining health of people with dementia

Increased frailty and a decline in mobility, and increased mental health issues such as anxiety and depression, are the most prominent health issues that have affected people with dementia.

What our staff and volunteers told us

"The longer the pandemic continues, the impact on the physical health of the people with dementia I support increases. Lack of social stimulation such as meeting up with family and friends, accessing personal interests; attending groups and receiving one-to-one support has a detrimental effect. This contact is imperative to their mental and physical wellbeing which are interlinked- if one area is affected it impacts on the other"

"Day Care has come up frequently – people deteriorating because they don't have the routine of attending Day Care twice or three times a week, and it being a really noticeable decline"

"There seems to be a reluctance to contact GPs for any physical health concern as a lot of people feel the message is to stay away from the GPs unless completely urgent. A few people with dementia and their family/carers have waited longer or until things have worsened before making contact with the GP"

"Some people's mobility appears to be affected. They're unable to partake in as much physical activity as before due to restrictions preventing attendance to exercise groups, Day Care or walking in their community due to shielding"

"There appears to be reduced physical functioning mostly due to reduced activity levels outside the home. This is leading to loss of strength, balance and stamina. I have increased referrals to Occupational Therapy for mobility assessments and to mitigate falls risks"

"Pretty much every single person that I've worked with throughout this entire lockdown period has mentioned the deterioration in the person with dementia they are caring for. I don't think there's one family I could name that hasn't brought that up"

Cognitive decline and acceleration of symptoms

COVID-19 restrictions have also impacted the cognition of people with dementia, and in some cases accelerated their dementia symptoms. As a separate concern, this has caused friction and affected relationships between the person and their family and carers.

What our staff and volunteers told us

"A lot of people are reporting that they are seeing a real progression of symptoms in the person they care for and a decline in their condition"

"I've noticed rapid deterioration in some cases, due to isolation and lack of stimulation. Low mood, depression, stress, confusion, hallucinations, disorientation. The general trend is fast cognitive decline"

"There seems to be an increasing number of people with dementia losing motivation to do anything. People wanting to just stay in bed, or sleep in their chair"

"I've had a few people talking about how lonely they feel. This is not necessarily just people who live alone, it includes those living with family who miss the outside contact with others"

"There is a lot of frustration for people with dementia who are being told about the rules but don't fully understand about the virus"

"The lack of social contact has impacted on people with dementia's mood and cognition"

"I feel that it has more significantly impacted on the mental health of people with dementia's carers and family, which is in turn impacting on their own mental health. I have noticed an increase in tensions and friction for families"

"On my caseload mental health is the most notable issue. In one area we had a very active dementia community and many individuals no longer have access to the natural networks/peer support which was so valuable pre-COVID-19"

"I have noticed an increase in the number of people entering long term care throughout the current pandemic. In my opinion many of these admissions were premature and could possibly have been avoided if appropriate support was available"

Changes to medication of people with dementia

There is some evidence from our frontline staff and volunteers of changes in medication for people with dementia. This was more prominent during the most severe period of lockdown. Reports of changes or increased prescribed medications is varied.

Where an increase is reported, it is to alleviate stress, agitation and behavioural changes. In the survey we carried out in October there were some reports of attempts to explore non-pharmacological interventions before medication is prescribed as a last resort.

What our staff and volunteers told us

"I have a few cases where medication was introduced to manage low mood. Working closely with the Community Mental Health Team has enabled Link Workers to try alternative options before the introduction of medication"

"The introduction of medication to support anxiety issues and/or changes in medication as a result of the pandemic have been widespread"

"There have been a few occasions when this has been the case. We have encouraged those supporting the person to look to non-pharmacological routes first such as music or other purposeful activities. For many this has not helped as much as it could have, and this has led to looking at a medication route. It has been low numbers, but as you can imagine that has been a big issue for the person and their quality of life"

Changes in the support provided to people with dementia since the start of the pandemic

Changes to health and social care provision have had a significant impact on people with dementia and their carers.

What our staff and volunteers told us

"What callers to the helpline are telling us on many occasions is that services and supports are not available at this time due to COVID-19 restrictions, and with NHS-24 they are unable to get through or have to wait extremely long times on hold due to the demand on their service"

"Services are now being reinstated but under a new model. Day Care staff are now offering outreach visits. A few people have had periods of respite in local care homes and the local commissioned service has started a home visiting service again"

"There has been no Day Care since March, over the summer some of this has been replaced with one-to-one services but not to the same level. There is practically no residential respite available and no replacement. I have had a trend of families just using savings to pay privately for social support for the person living with dementia in order to give the carer a break as they cannot wait for Health and Social Care assessments"

"Some family carers have reduced or cancelled home support due to fear of the virus. Most have not asked for these to be recommenced. Some carers under severe stress have declined the offer of support for the same reason"

"The absence of Day Care and community groups means that carer stress has increased and people living with dementia have been at risk of cognitive and physical decline and depression due to social isolation"

"Day Care has come up frequently – people are deteriorating because they don't have the routine of attending Day Care twice or three times a week, and it being a really noticeable decline"

"The main stressor has been the disruption to daily routine and the support to live well, with many of the supports they view as lifelines having been reduced or withdrawn entirely"

"I have noticed an increase in the number of people entering long term care over the current pandemic. In my opinion many of these admissions were premature and could possibly have been avoided if appropriate support was available, and therefore enabling the person to remain living in their own home for the foreseeable future"



What we found: impact on carers

By far the most significant theme which is emerging is carer stress. The vast majority of calls to our 24 hour Freephone Dementia Helpline and to our Dementia Advisors are from carers. For many, the decline in their mental health has also affected their physical health, especially if they already had a pre-existing medical condition. This has made it increasingly difficult to maintain their caring responsibilities.

Family members and friends have taken on the responsibility of caring for people with dementia, often alone and without the support from the family, friends and support services that they rely on to help them in their caring role. Many are struggling to balance their caring role with other family and work responsibilities, often with little or no opportunity to access respite support which can give them a break from caring or time to themselves.

What our staff and volunteers told us

"I have seen an increase in carer stress due to the lack of respite options such as Day Care and not being able to have family visit to provide this"

"We've had an increase in calls to our Helpline later in the evening and throughout the night by carers who were at breaking point, unable to cope any more"

"I'm noticing high levels of stress, carers feeling helpless and overwhelmed. Some carers are at breaking point, with no hope to a way out or respite. The situation is increasingly worse now"

"Carer stress is the top enquiry I'm getting"

"Every single day carer stress is what's coming through. It's overwhelming and it is a pressure cooker out there"

"Existing health issues for carers are being exacerbated by the current pandemic due to lack of practical and social support. Carers are physically doing more for the person they support in regards to personal care support, mainly due to reduction in family support and reduction in care packages"

"The waiting time for hospital treatments and operations delayed has had a negative on people. Carers have also delayed their operation dates as no one else is available to provide care to person who has dementia during recovery time"

"Carers are ignoring their own health issues. Many were waiting on planned procedures that didn't happen. Now that the NHS is opening up it is raising issues about getting cover if someone needs to go into hospital. Families are having to step in and provide the cover. Respite is very difficult to access and there needs to be almost a crisis point for people to get this put in place"

"Social care seems overstretched. Resources have been too little for what is needed for so long and the pandemic has increased the pressures in the system to breaking point"

"The situation for those in the community who care informally for someone with dementia has clearly worsened during the pandemic and continues to do so. This, in my view, is causing people to reach crisis point earlier and more severely than may have occurred"



What people with dementia and carers told us

The prolonged lack of access to day services has had a significant adverse impact on my mum's functioning. Her dementia appears to have progressed rapidly in the months since March 2020 and, although we will never know for sure, I am convinced that the social isolation and lack of stimulation has been a major factor in her decline. The impact on her partner has been very marked. He has done his very best to provide the social and cognitive stimulation she has been missing, as well as every other aspect of her care that he provides, but he is an elderly man himself and he is clearly exhausted,

increasingly overwhelmed and distressed. This population are unable to make use of digital options and face-to-face input is essential for them. I have no doubt that the lack of day services will hasten mum's need for nursing home care far sooner than any of us would have expected or wanted. COVID-19 will be with us for a long time to come and we must do better at balancing the needs of vulnerable and disabled people living in the community, with the need to keep them, and staff, safe. The quality of life of people living with dementia, and their carers, has been devastated by lack of service provision.

My husband Graham was diagnosed with Alzheimer's Disease in 2015 at the age of 67. We lived in Glasgow at the time, and in 2017 moved to Prestwick, partly for me to be nearer work, and partly because we were aware of the excellent dementia friendly services which were available in the area. Since moving here, Graham has taken part in lots of activities delivered by both Alzheimer Scotland and Dementia Friendly Prestwick. This has helped him to feel part of the wider community, and he has enjoyed keeping active and meeting new people. Since lockdown started, these activities have understandably been curtailed and most services have managed to establish some form of online support. While this has been really appreciated, and I know the hard work that goes in to maintaining these services online, they haven't always been the best way for Graham to access support. Since lockdown there has been a definite deterioration in Graham's condition, and he finds it difficult to concentrate on any online discussions; this has been the same for family get-togethers. The social support and interaction which was available through activities prior to lockdown was invaluable and definitely made an impact on Graham's mood – it helped to make him feel part of a community.

Since lockdown started Graham's condition has deteriorated generally, but his speech has been the area which has been most impacted. This has been difficult for both of us as he gets frustrated and, as I'm still working full-time, I don't always have the time to spend with him in interacting. We have been provided with

additional hours self-directed support, to help Graham to access social activities, which we are grateful for. I'm just aware that there are very few physical, social activities that Graham will be able to access in the current situation. While the last seven months have been difficult for everyone, and we are lucky in lots of ways, it has taken its toll, both on Graham's condition, and in added stress of trying to work from home and maintain some sort of routine and activities. I think mostly, although he isn't aware of it, he misses the friends and the social interaction that he has had on a weekly basis since we moved here.

I think that being able to access some physical and face-to-face support would make a huge difference to Graham (and me). As well as providing additional social stimulus for Graham it would also provide some sort of additional structure to the week. From a caring point of view the additional physical support can't be underestimated – it would mean that I would know that he was safe, and interacting with others, which also has a positive effect on his mood.



From a husband

“ The lack of face to face supports have been missed however knowing that I have my video calls weekly has helped enormously with my sanity.”

A person with dementia

“ I have noticed an increase in confusion/memory loss. The pandemic is having such an impact on my everyday life, where I can go, who I can meet. My schedule was so important to me, having a coherent plan helped maintain a level of stability. The uncertainty of the future was already part of my mind set due to my diagnosis and now the pandemic has compounded these feelings and I fear even more so for the future. I've lost my confidence, my sense of purpose.”

From a husband

“ Alzheimer Scotland Online support has been invaluable to my well-being.”

From a partner

“ The impact of coronavirus has changed how we spend our daily day. The Day Care services that my partner attended were a breath of fresh air for both of us. She met people and shared many laughs and sing songs, many new friends were made. The getting out and mixing with other people was so much appreciated and welcomed. I benefitted with time to do things on my own that I couldn't do before. I would also like to say both services have provided an outreach support during this difficult time.”

What this tells us

People with dementia living in the community and their carers rely on the natural support networks around them, as well as a mix of informal and formal health and social care support. Each of these supports have been disrupted by the pandemic.

There is an estimated 60,000 people with dementia who live in the community. We believe that there are three areas where disruption to the supports they rely on have contributed to the harms highlighted in this report.

People receiving or are entitled to receive dementia post diagnostic support; including those who have not yet been diagnosed or referred for support due to the pandemic.

During the crisis many people with dementia have continued to receive post diagnostic support in alternative ways using telephone and online contacts. However, while this has been valuable, for many individuals the impact of this is a significant reduction in their ability to live well with dementia and to build resilience and skills to cope with a complex progressive illness. We believe that many will need an additional period of post diagnostic support beyond the one-year guarantee to help them live as well as possible for longer. During this period there has also been a substantial disruption to dementia diagnosis services and the subsequent referrals for post diagnostic support. The Scottish Government estimated that approx 20,000 people would be newly diagnosed during 2020 (Scottish Government, 2016). This disruption means that potentially several thousand people have not had a diagnosis or been referred to post diagnostic support, who otherwise would have. In addition, the latest post diagnostic support performance data shows that, of the estimated 18,000 people diagnosed with dementia in 2017/18, only 7,605 (42.3%) were referred for post diagnostic support (Public Health Scotland, 2020b). The combined impact of the existing gaps in post diagnostic support, and the disruption during the pandemic has contributed to the declining wellbeing of people with dementia and carers. Post diagnostic support will play a critical role as we transition from this pandemic, but it will need to be given a greater priority level nationally and locally.

People with dementia and carers using informal supports such as the wide range of community based therapeutic and group activities run by Alzheimer Scotland and other third sector providers.

Alzheimer Scotland and other third sector partners provide and fund a wide range of community based therapeutic and group activities in communities across Scotland. All of these have had to stop to comply with the public health restrictions during the pandemic. In previous years Alzheimer Scotland's dementia cafés had over 32,000 attendees, 6,000 people with dementia participated in activity groups, and there were over 25,000 attendances at groups to support people with dementia and carers. The loss of these has created a substantial gap in the supports that play a vital role in the lives of people with dementia and carers, many of whom may not yet be known to, or using, social care services. Alzheimer Scotland has introduced alternative and innovative ways using telephone, digital and other solutions. While this works well for many people with dementia and carers, there are a group of people who do not have access to the technology needed or are unable to benefit because of their particular needs. In the absence of these face-to-face supports many people who have not needed more formal health and social care support are developing unpredicted and unexpected levels of need because of declining physical and mental health and an acceleration of the symptoms of dementia.

People with more advanced dementia and carers with more advanced illness, who receive health and social care support such as care at home, Day Care or respite services.

It is estimated (although it known to be underestimated) that approximately 12,000 people with dementia receive non-residential social care (Scottish Government, 2017) who are living with advanced dementia (Alzheimer Scotland, 2019). These include self-directed support options, care at home, Day Care services and respite services. The cessation of Day Care and changes to care at home support, including where people have opted to voluntarily reduce or withdraw from social care support to reduce their risk from COVID-19, as well as the impact on carers, have contributed to a significant increase in the complexity of their needs. There is some evidence that this has led to an increase in the numbers of people with dementia being admitted to hospital or moving to care homes.

In conclusion, we are entering the winter months with a second wave of COVID-19 infections and further public health restrictions are being introduced. These restrictions are likely to remain in place for the foreseeable future and we cannot ignore the evidence of the impact of these restrictions on people with dementia and those who care for them.

Dementia post diagnostic support needs greater priority and investment nationally and locally, if we are to have the capacity to ensure that those who have not fully benefited from it during this pandemic are offered an additional period of support; meet the demand of the thousands who have been delayed in getting a diagnosis, or referred for post diagnostic support, during this pandemic; and make significant progress in closing the existing gap in this crucial support.

There is a clear need to address the gap left by the cessation of the community based therapeutic and activity groups run by Alzheimer Scotland and other third sector partners. These supports help many people to remain well without the need for formal social care and provide vital support and respite for carers. The growing body of evidence demonstrates that the absence of these community supports is a major contributing factor in the declining health and wellbeing of people

with dementia and carers. Alzheimer Scotland, like other organisations, have adapted to use innovative digital and telephone solutions as an alternative to the community supports we provide. These play a vital role both now and in the future, but they do not replace the value of human intervention, nor are they accessible to everyone. It is crucial to continue to safely remobilise small scale Day Care, as well therapeutic and community-based activities, to continue to support people with dementia to live as independently as possible within their own communities and support the wellbeing of carers.

It is vital that we understand the changing levels of needs for people with dementia and carers through assessment and reassessment of their current levels of need. This will ensure that people with dementia with the most complex needs have access to the health and social care services they need.

If we are to mitigate against the harms that people with dementia and their carers have experienced throughout this pandemic, we must act now to safely remobilise these crucial supports. Unless we do there is a significant risk that health and social care services will be overburdened with avoidable and cost intensive care home admissions and hospital admissions.



Other priorities

Throughout this pandemic Alzheimer Scotland has worked with other stakeholders to raise the issues that people with dementia, their families and carers are reporting, with the Scottish Government in order to find solutions to how we can better balance the need to protect people from the virus with the harms of the restrictions put in place to prevent it spreading.

In addition to keeping the Scottish Government informed of emerging issues for people with dementia and carers, Alzheimer Scotland has called for Scottish Government Ministers to act in several key areas which have emerged throughout this crisis.

We have called on the Scottish Government to:

- Take urgent action to understand the reasons why people with dementia are disproportionately represented in the deaths from coronavirus and the excess deaths during this pandemic
- Acknowledge that the pandemic has further exposed the inequalities Alzheimer Scotland highlighted in our Delivering Fair Dementia Care Report, and to work towards Fair Dementia Care by ensuring that people with advanced dementia living in care homes do not have to pay for care, which is clearly health care. We have proposed that the Scottish Government commit to increasing the existing Free Personal and Nursing care payments so that they equate to the actual cost of personal and nursing care
- Provide a named individual to support families and carers of people with dementia who live in care homes so that they can be equal partners in the care of their relatives or friends and support better decisions and communication between care homes and families around safe visiting.



Recommendations

1. The safe remobilisation of small-scale therapeutic day service provision continues and is given the appropriate support by public health
2. Health and Social Care Partnerships act urgently to ensure that people with dementia and their carers have access to an assessment or reassessment of the changes in their levels of need
3. Health and Social Care Partnerships ensure that carers of people with dementia are better supported by have accessing to appropriate levels of respite care
4. Health and Social Care Partnerships work to safely reinstate social care that has been reduced or stopped due the pandemic, at a level which reflects the current levels of needs of people with dementia and their carers
5. The Scottish Government establishes a dedicated national Post Diagnostic Support fund, to double the capacity of Scotland's Health and Social Care Partnerships to offer high quality personalised post diagnostic support to every person diagnosed with dementia in Scotland
6. As a matter of priority Health and Social Care Partnerships to ensure access to diagnosis or, where necessary develop appropriate alternative diagnostic processes for as timely an early a diagnosis as possible.



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