

Dementia care during the coronavirus (COVID-19) pandemic



The impact of the coronavirus (COVID-19) poses unprecedented challenges for care services and, in particular, on vulnerable groups such as people living with dementia and their families and carers. The situation can sometimes change daily, and it will be important for all organisations to share resources, guidance and best-practice examples as they become available.

Precautionary measures

We are becoming familiar with the terms 'shielding', 'isolation', and 'social distancing', along with the need to effectively clean our hands, but what does this really mean, particularly for people living within residential care settings?

The [Health and Social Care Standards](#) very clearly sets out what people who experience care should expect, and during this time the same high standards of care and support should be provided. During this time, services should be completing regular assessment of risks for individuals who live in care homes and for staff and try to reduce these so people stay safe. This may mean people who live in care homes are encouraged to spend more time in their own rooms.

Hand hygiene

It is important that services take all necessary precautions to mitigate the spread of infection within and throughout the care home. One such measure is that people are offered adequate provision and opportunity to wash their hands throughout the day.

People who live with dementia may require additional practical support to achieve effective hand hygiene due to a number of reasons, such as:

- being unable to locate handwashing facilities
- being unfamiliar with the best available guidance on handwashing techniques
- being unable to recognise bathroom fixtures (soap and paper towel dispensers)
- reduced recognition of need.

It is extremely important that staff support individuals to achieve good hand hygiene aligned to current best practice. Services should consider the effectiveness of signage for handwashing facilities throughout the home. Are there enough pictorial and written cues or signs throughout the home, placed at an appropriate height to direct individuals to handwashing facilities?

Staff should adopt a person-centred approach to support people to maintain good hand hygiene, which must be clearly documented within the plan of care. For some this may be a simple verbal prompt, for others, staff may have to demonstrate or provide physical support to achieve this. We appreciate that during this time, some of these additional notes to care plans may be more abbreviated but it is important that all staff know how best to support the person living with dementia.

Shielding

Some people who live in care homes may be at a higher risk of severe illness from coronavirus because of other health conditions they live with. Health Protection Scotland and NHS Inform have published a list of individuals who this may affect and have provided clear [guidance](#) about the need to shield during the pandemic. Care staff should know people's medical history and should encourage those who fall into this category to spend time away from larger group gatherings, such as going to the lounge or dining rooms. This is for the person's own protection and to reduce the risk of getting the virus. However, people have the right to decide for themselves whether they follow this guidance. We would advise that people talk about how they feel about whether to follow the guidance or not, including their family and staff in the conversation. Care staff should make a record of the outcome of these conversations in the person's care and support plan so everyone is aware of the decision, along with communicating to colleagues during each shift handover.

Decisions regarding shielding may pose an ethical dilemma for services, particularly for individuals living with dementia who rely on a welfare guardian or power of attorney to make best-interest decisions on their behalf. It is important that services work with legal proxy advocates to ensure the best interests of individuals are established and maintained. If a conflict of interest arises, services should follow best-practice guidance to reach consensus. Services may find it useful to refer to the Mental Welfare Commission for Scotland's good-practice guide '[Supported Decision Making](#)' to help explore this further.

There is a potential risk for individuals, who are spending increased amounts of time shielding, to experience poor mental health or increased stress and distress. It is therefore extremely important the service undertakes regular assessments and actions, aligned to the Health and Social Care Standards, to mitigate risk.

Isolation

If someone who lives in a care home is suspected or confirmed as having coronavirus, the service must work to reduce the risk of others becoming infected. Staff should encourage the person to isolate as much as possible in their own room.

Supporting and encouraging someone to spend time in their room may pose an ethical and practical challenge for care services, particularly where the person lives with dementia and they may not understand the reasons for the request. The [Mental Welfare Commission](#) has produced comprehensive guidance for services to use, underpinned by a human rights approach. All decisions to limit the free movement of a person must be reasonable, proportionate and justifiable. There must be clear and effective lines of communication aligned to the Health and Social Care Standards during the decision-making process, which should be underpinned by information already known about the person. All decisions taken must be clearly documented within the care and support plan. If the decision has been taken to limit an individual's movements this must be reviewed on an ongoing basis, with a clear rationale for continuation.

It is important to remember that any limitations put in place must be the least restrictive for the person and used for the shortest period necessary. For example, before implementing an environmental barrier, such as a stair gate, we would expect to see that the person is encouraged to spend time in their room through:

- verbal cues and reminders
- being provided with opportunities to engage in meaningful activities which have relevance
- an increased staff presence and frequent staff interaction
- use of pictorial signs to remind the person not to leave their room.

Using environmental barriers should always be the last resort and should be strictly time limited to prevent them from becoming routine practice. We would expect that when such measures are taken, staff engage in a debrief session afterwards, and all decisions are clearly documented within the person's care and support plan.

We recognise that not all homes will have en-suite toilet facilities and this may pose a challenge to isolation. Where this is the case, the service should set aside one of the communal toilet facilities as close as possible to the person's bedroom, solely for their use. For people living with dementia, it is extremely important that sufficient signage is in place to direct them to the toilet facilities. The service must ensure that effective and regular cleaning is completed in line with infection control processes to limit the spread of infection.

There is a potential for individuals who are spending increased amounts of time in isolation to experience poor mental health or increased stress and distress. It is therefore extremely important the service undertake regular assessments and actions aligned to the Health and Social Care Standards to mitigate risk. It is important that where individuals experience increased stress and distress as a result of isolation, a person-centred approach is taken by staff who know their strengths and abilities. We would expect to see a detailed plan of care which addresses the person's psychological needs and highlight how situations should be managed. To help staff understand effective approaches, the NHS TURAS website contains specific modules on this subject. Interventions should be highly personalised, and any blanket approaches should be avoided.

Social distancing

Social distancing is what most of us are using to protect ourselves from catching the coronavirus. We can see the measures that are being taken to protect us and others throughout our communities. People who live in care homes should currently be encouraged to keep two metres away from others who live in the home. However, there are times when this may not be possible, particularly during some care activities. When staff are unable to keep two metres away from people who live in the home, they must take every precaution to limit the risk of coronavirus by wearing 'Personal Protective Equipment' (PPE) in line with current guidance.

We recognise for some people, this may increase anxiety and create a barrier to good communication. However, it is important to keep everyone as safe as possible. Further information is available in the section 'Considerations for communicating while using PPE'.

It is important to remember that when individuals are shielding, isolating or social distancing, they should continue to feel connected to others and the outside world. Further information is available in the section 'Keeping families and residents in touch with each other when visiting is restricted'. The service must ensure that people continue to maintain as active a life as possible through participating in a range of recreational, creative, physical, and learning activities. These can take place both inside the home and, if available, the garden. Some studies have shown that an increase in sunlight can support better immunity for individuals living in residential care settings. Accessing the outside can also have positive benefits to people's mental health. We have developed a poster on the 'Enriched Model of Psychological Needs' which can be used by staff to explore different needs linked to meaningful occupation.

We would expect to see that services are responsive to staffing provision to support good mental wellbeing for those who live in residential settings, ensuring sufficient staff are working each day to provide opportunities to engage in meaningful interactions and occupation.

Testing

Currently Public Health are undertaking surveillance testing within care homes. For any tests to be completed, consent must first be obtained. We would not expect to see people living with dementia excluded from this process without a valid reason. Services must ensure they contact any legal advocate, such as power of attorney, to gain consent when an active Adults with Incapacity Certificate (Section 47) is in place prior to testing. We would not expect testing to be completed on any individual who refuses, regardless of capacity. If situations arise whereby an individual living with dementia refuses a test, but their legal advocate consents, we expect the service to put in place strategies to mitigate risk of infection spread, such as 14-day isolation, and attempt to retest at a later time.

Considerations for communicating when wearing personal protective equipment (PPE)

Studies have shown that PPE can create barriers to effective communication, particularly for people who live with dementia and those with hearing problems. Staff and visitors wearing facemasks, visors, gloves and aprons may appear frightening to people, particularly if the reason and context is difficult to understand.

Facemasks pose a particular challenge to communication. A large part of communication between people is based on the understanding of non-verbal cues. This is particularly important for some people living with dementia or who have hearing problems. If only eyes are visible, it makes it difficult to correctly read emotions. This can easily lead to misunderstandings, anxiety, anger or embarrassment.

Over recent months, many care professionals have found ways of communicating effectively while wearing face masks. This has, for example, shown the importance of smiling and communicating with your eyes.

The use of clear and self-aware body language is an important tool in dementia care in general. It is even more important when wearing facemasks. Clear, calm gestures like pointing or modelling what you are trying to say, for instance, shaving or washing gestures, can be helpful for some people. Using laminated pictures or pictorial cards is an option, as well as using pen and paper. Staff could also show their face from a safe distance before putting on the facemask. It is important that staff assess the impact wearing PPE has on individual people and develop clear and planned communication strategies. Any material used for an individual person should be left in their room or cleaned in accordance with current guidelines.

We would also expect that relatives are supported by services to understand how to effectively communicate while wearing PPE.

Visiting restrictions during the coronavirus pandemic and their potential impact

To protect residents and staff from coronavirus, visits to care homes by family and friends are currently restricted. There may be differences between care homes in how they implement visiting restrictions, based on their individual circumstances and risk assessments. Care homes should ensure that their approach to visiting is in line with Scottish Government guidance, transparent and clearly communicated to families, staff and residents. Any restriction should be lawful, proportionate, reasonable and flexible enough to react to individual circumstances

In most cases family members will only be allowed to visit if they are the nominated next of kin and the situation is exceptional, for example, if a resident is nearing the end of their life. Providers should be mindful of the potential impact of visiting restrictions on physical and mental health. Family visits often provide opportunities for physical activity, mental stimulation and additional nutrition or hydration. Being part of a family or seeing friends is an important part of maintaining a sense of self and identity and can provide much needed feelings of happiness and reassurance. Services should assess people's individual needs for stimulation, reassurance and activity and update their care and support plans accordingly.

Some people living with dementia may find it particularly hard to comply with or remember concepts like shielding and social distancing. Some may feel very lonely and frightened if they are asked to stay in their room. People living with dementia may also be less able to communicate their anxiety, ask for emotional support or adhere to instructions and safety measures. All these factors may lead to them having an increased risk of developing stress and distress symptoms, including delirium.

Acute and prolonged symptoms of stress and distress, including withdrawal and depression, should be recognised as emergencies and visiting restrictions should be reviewed as part of the treatment plan.

The COVID-19 pandemic has brought enormous challenges for care services, people living with dementia and their friends and families. The emergency measures, guidelines and restrictions had a severe impact on living and working in care homes. It has led to many examples of extraordinary

professionalism, adaptability, co-operation and compassionate dementia care. However, we also saw that the pandemic had a disproportionately severe impact on vulnerable groups, including older people and those living with dementia and their families.

Whilst some restrictions to protect people's health and life will continue, it will remain equally important to ensure each restrictive measure will be continually assessed and evaluated to ensure it is proportionate and necessary.

Services should continue to be guided by the human rights based principles of the Health and Social Care Standards and ensure that people are respected as individuals and treated with compassion and dignity at all times.

Existing human rights legislation, but also relevant guidance and comments from organisations like the Scottish Human Rights Commission or the Mental Welfare Commission can form a helpful basis for policy and decision-making

<https://www.scottishhumanrights.com/media/2063/covid-19-ehric-submission.pdf>

Keeping families and residents in touch with each other when visiting is restricted

Being restricted from visiting loved ones in a care home during this pandemic is naturally distressing for everybody involved. It is important that everybody follows the current guidelines to keep residents and staff as safe as possible. At the same time, it is important to acknowledge and respect people's needs for social contact and mental health, as well as their human rights.

Although some visiting can now occur in care homes, there may be specific situations which result in tighter restrictions being reapplied. In that case Care homes should advise residents and families of alternative ways to stay in touch. The opportunities will differ depending on the individual resources and circumstances in each care home. Providers should support staff to be innovative and creative within the existing guidelines.

In addition to phone calls, many care homes may be able to facilitate video calls through using communication applications such as Skype, WhatsApp or Zoom. Families should be enabled to hand in necessary equipment, like computer tablets, where required. People's care and support plans should explain how they will be enabled to stay connected.

Every care home will have periods of time where staff are naturally very busy, for example around mealtimes. Families should be advised of these times and supported to find out what the best time for calling their relative is, or to arrange set times.

Many providers have now also set up social media feeds to give families an inside into current life and activities in the care home. This can be helpful and reassuring. When using social media feeds, services should be mindful that families will expect to see people in the service adhering to social

distancing and PPE guidance. If footage shows the service deviating from that, this should be clearly explained.

The use of psychoactive medication as part of seclusion or isolation

The coronavirus pandemic and the necessary measures services need to take to keep people safe should not mean deviating from the guidance on supporting people living with dementia who experience stress and distress. Good practice of assessing and treating stress and distress should remain firmly based on the principles of the Health and Social Care Standards:

- dignity
- compassion
- inclusion
- responsiveness
- wellbeing.

The principles of the [Adults with Incapacity \(Scotland\) Act 2000](#) and the [Mental Health \(Care and Treatment\) \(Scotland\) Act 2003](#) also provide a useful ethical decision-making framework for making decisions.

Pressure on staff resources, working with unfamiliar staff, carer stress and the possible need for seclusion or isolation will likely lead to difficult individual situations and decisions. It can be challenging to balance the needs for preventing and controlling infection with individual needs, in particular for a person whose ability to understand and follow reasonable instructions is limited by dementia.

The basic principles of how to approach the assessment, psychosocial and medical interventions of stress and distress in dementia should still be applied. Further information is available in the [‘Promoting Excellence Framework’](#). This means staff should use a compassionate and empathic approach to determine the main causes of distress for the individual, plan interventions that respect the individual person and take their abilities and psychological needs into account. Do not assume that distress is a symptom of dementia and do your best to work with the person who is distressed, their family members and staff who know them well to find out how best to keep them calm and relaxed.

Ensure that physical causes for distress, like pain, are properly assessed and eliminated, using assessment tools that are appropriate for the person’s communication abilities. If psychoactive medication is introduced or changed as part of an intervention, the service needs to ensure that the usual standards for inclusive decision-making are followed. The reasoning and expected outcomes should be clearly documented and the need for the medication should be regularly reviewed.

Decisions should be made on an individual basis and should take the principles of the [Health and Social Care Standards](#) as well as the principles of human rights. Staff should consider if the planned intervention is:

- reasonable
- proportionate
- justifiable.

Human rights remain central to our response to the coronavirus (COVID-19) pandemic. Many of the protection measures being implemented to reduce the risk of infection are necessary but may have substantial human rights implications. It is important that any restriction does not discriminate against a particular group of people, like people living with dementia.

Decisions and interventions should be kept under regular review and any restrictive interventions should only be in place as long as they are absolutely necessary. Staff should always consider a less restrictive alternative wherever possible. Services should ask for specialist support where necessary through the GP or local community mental health teams.

The Mental Welfare Commission for Scotland (MWC) has produced [comprehensive guidance](#) for services to use, underpinned by a human rights approach. This guidance also contains examples and details for difficult situations, like seclusion or restraint.

Changes to legislation

The [‘Coronavirus \(Scotland\) Act 2020’](#) emergency legislation came into force in April 2020. It is important for services to understand how this may influence care and support, particularly for individuals living with dementia.

Schedule 3, Part 2 of the Act describes interim changes to existing legislation related to vulnerable adults, with particular reference to the [‘Adults with Incapacity \(Scotland\) Act 2000’](#).

Most individuals with a diagnosis of dementia who live in care homes will have in place a [‘Section 47 certificate of incapacity’](#). The duration of these certificates should not exceed three years in normal circumstances. However, in the current situation, and aligned to the emergency legislation published, any certificate which becomes out-of-date is automatically extended for the duration of the legislation.

Some individuals who have a Section 47 certificate in place, may also have a legal proxy advocate (welfare guardian/power of attorney). A time limit to decision-making capabilities is sometimes applied for welfare guardians. However, under the emergency legislation, this time limit is removed for the duration of the legislation. When guardianship orders are renewed, again a time limit to these is normally applied (five years). Should the date of expiry for these occur during the emergency legislation, they are automatically extended for the duration of the legislation.

It is important to note that care services' responsibilities to ensure best-interest decisions are maintained is unchanged. Services should follow the normal processes where they feel people with decision-making capabilities are not advocating in the best interest of the individual.

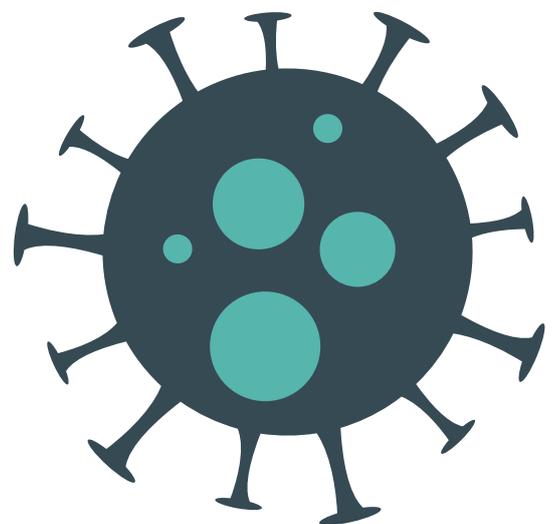
Staff support

We recognise and appreciate that during the coronavirus pandemic, staff will be working extremely hard to ensure the rights of people are maintained. It is well recognised that good person-centred care comes from staff-centred support. Therefore, it is important that services provide staff with the necessary tools to maintain their resilience during this challenging time. To help staff explore their thoughts and feelings during this challenging time, we have developed a poster on the [Enriched Model of Psychological Needs](#). NES have also developed podcast resources which focus on psychological first aid, and we would advise staff and services to access these.

The Scottish Social Service Council (SSSC) has developed comprehensive resources to allow staff to explore their emotions, feelings and anxieties during this time. These resources are available on their website. We would advise services to develop strategies that allow staff to discuss and reflect on how they are feeling and explore ways that resilience can be achieved. For example, it may be worthwhile to have a daily debrief following the shift handover to allow staff to express what challenges they have faced and celebrate good outcomes. The Scottish Government has also launched a [National Wellbeing Hub](#) for all staff in health and social care.

Useful links

- [Adults with Incapacity \(Scotland\) Act 2000](#)
- [Coronavirus \(Scotland\) Act 2020](#)
- [Health and Social Care Standards: My support, my life](#)
- [Health Protection Scotland](#)
- [Mental Welfare Commission for Scotland](#)
- [NHS Education Scotland](#)
- [NHS Inform](#)
- [Promoting Excellence Framework](#)
- [Scottish Human Rights Commission](#)
- [SSSC - Staff wellbeing resource](#)
- [National wellbeing hub](#)



Headquarters

Care Inspectorate
Compass House
11 Riverside Drive
Dundee
DD1 4NY
Tel: 01382 207100
Fax: 01382 207289

Website: www.careinspectorate.com
Email: enquiries@careinspectorate.gov.scot
Care Inspectorate Enquiries: 0345 600 9527



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