

Good practices in working with people with disabilities during COVID-19

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A. Key points

Gaps and concerns over Govt guidance re people with disabilities and Covid-19:

- In the UK-Govt earlier Covid-19 plans – people with disabilities were overlooked
- Organisations supporting people with disabilities have lost significant resources at a time when people with disabilities need more support – and hence there is a risk that essential services may have to stop
- Many people with disabilities were left off the UK Govt’s shielding scheme – meaning they could not access services and support
- The Do Not Resuscitate Orders were in some cases issued without discussion with the families – causing a high level of concern as to what treatment they would receive if they became ill – reassurance was eventually given – but it had eroded confidence
- There was concern over the pressure to wear face coverings for people who could not easily do so – hence a request for messaging was made to cover their needs

Challenges for people with disabilities re Covid-19:

Challenges - general:

- People with disabilities may have underlying health conditions that increase their risk of serious complications
- It is estimated that more than 46% of the world’s population of people over 60 years of age have disabilities
- Inaccessible information and communication that people with hearing, visual, intellectual or physical disabilities mean they may not receive key information about prevention and assistance
- It may also be more difficult for people with difficult kinds of disabilities to undertake hygiene related tasks
- They may be disproportionately affected by disruption to health and social care services

- Prejudices, stigma, and discrimination against people with disabilities, including misconceptions that people with disabilities cannot contribute to the outbreak response or make their own decisions.
- People with learning disabilities are particularly vulnerable to respiratory conditions – in 2018/19 – 41% of people with a learning disability in the UK died of a respiratory condition
- People with Downs Syndrome can be highly affected by respiratory infections, particularly upper airways infections - these are due to differences in their immune system, differences in body structures, and some illnesses that are more common in people with Downs Syndrome - when they get them there is a greater chance of them becoming seriously unwell, more likely to be admitted to hospital, and needing a ventilator
- It is estimated that 40% of adults and 36% of children and young people with a learning disability and / or with autism experience mental health conditions – and routine and carers can have a big impact

Challenges - people with disabilities in care homes:

- It is estimated that some 80% of people living in care homes have some form of dementia
- 31% of people surveyed showed a worsening of functional independence and cognitive symptoms during the first month of lockdown
- People with frontotemporal dementia and their family caregivers seemed to particularly struggling to comply with protective measures
- A ban on visits from spouses and partners in care is believed to be causing a significant deterioration in the health and wellbeing of residents with dementia
- Residents may be asked to not leave their rooms, but not understand why, staff who they know best may be away from work, and people may be frightened to stay by themselves in their rooms
- People with dementia who develop infections are more likely to develop delirium, which complicates hospital management and compromises their future cognitive health
- People with dementia and cognitive impairments may not be able to explain their symptoms and so carers need to be able to observe changes, including delirium

Good practice principles - for working with and supporting people with disabilities:

Policy and general approaches:

- Learn from the work and the experience of specialist organisations who work with and represent people with different kinds of disabilities – and engage with people with disabilities as agents of change
- Reinforce links and engagement between the organisations working with and representing people with disabilities and the governmental sector
- Share clear practical guidance that considers the needs of people with different types of disabilities, including people with different intellectual and physical disabilities
- A positive and empathetic attitude is important
- Ensure meaningful consultations with and active participation of persons with disabilities and their caregivers in all stages of the response and recovery

In care homes:

- Where a person meets the Government criteria for 'shielding', they should be prioritised for an en-suite room
- Providers should adopt a trauma-informed approach – balancing protection with reducing trauma wherever possible
- Case-by-case reviews will be needed for people who are unable to follow advice on isolation and testing – to minimise risks to other people, whilst also protecting as much as possible the rights of the person concerned
- Care is needed to not overlook symptoms of Covid through assuming they are related to a person's mental health/behavioural difficulties
- It is important to listen to the residents and their parents / carers – to understand changes and also how best to communicate with the specific person
- Provide life-saving information in accessible formats – such as braille, large print, easy to read versions, written formats or videos with text or sign language, and accessible web content
- Consider the best channels and approaches for communicating with people with different kinds of disabilities and of different ages and developmental levels
- Teach every day actions that reduce the spread of germs – such as how to wash hands properly, how to stay apart from people and wearing a face mask (where it can be tolerated)
- **Support people living with incontinence** – to: reduce their stress levels; keep hydrated; eat fibre in their diet; ensure they have access to the right products at the right time; keep a routine for toileting
- **Guidance for care staff supporting adults with learning disabilities and autistic adults** – <https://www.gov.uk/government/publications/covid-19-supporting-adults-with-learning-disabilities-and-autistic-adults/coronavirus-covid-19-guidance-for-care-staff-supporting-adults-with-learning-disabilities-and-autistic-adults>

Existing good practice tools - for working with and supporting people with disabilities:

A range of existing materials and tools already exist for people with different kinds of disabilities – these are a few good practice examples:

- **Top tips for tricky times – series of 8 top tips sheets based on challenges identified by care home staff** – related to: when residents do not understand social distancing; supporting residents at the end of their lives; providing comfort and reassurance to care home residents; hydration; using music for comfort and reassurance; supporting staff during multiple deaths; supporting families at a distance; helping care home residents with dementia to use video to communicate with their families – <https://ltccovid.org/2020/07/01/new-resource-top-tips-for-tricky-times-evidence-and-guidance-grounded-in-good-practice-and-experience-to-support-care-homes/>
- **Simple guides for people with intellectual disabilities** (available on different subjects) – [Local Lockdown Easy Read Guide](#)
- **Simple guides for people with Down Syndrome** - <https://www.downs-syndrome.org.uk/download-package/coronavirus-what-is-it-how-to-stay-safe-easy-read/>
- **Picture books - Beyond Words – picture book with no words – for explaining about Covid-19 – “Beating the Virus”:** <https://booksbeyondwords.co.uk/downloads-shop/beating-the-virus>

- Pre-written cards for when people with a learning disability cannot follow social distancing rules – <https://www.challengingbehaviour.org.uk/learning-disability-assets/goingoutcardupdates17thjuly.pdf>
- Tips on how to manage people spitting – <https://www.challengingbehaviour.org.uk/learning-disability-assets/spitting.pdf>
- Hand-washing tips – with links to videos and activities: <https://www.challengingbehaviour.org.uk/learning-disability-assets/handwashinginformationsheet.pdf>
- Hand-washing video by people with disabilities – <https://www.youtube.com/watch?v=4eY59qr2FTo&feature=youtu.be>
- How to sensitise people with learning disabilities to wear or accept others wearing a mask – <https://www.challengingbehaviour.org.uk/learning-disability-assets/sldandppeupdated30thjuly1.pdf>
- Covid tips for wheelchair users – <https://www.sunrisemedical.co.uk/blog/wheelchair-precautions-for-covid-19>
- Protocols for cleaning a wheelchair - <https://www.tn.gov/didd/for-consumers/seating-and-positioning/seating---positioning-maintenance.html>

Good practice – keeping in touch and visiting people in care homes:

- **Guidance provided by the government (updated 15 Oct 2020)** – this is based on dynamic risk assessments – first priority preventing risks of infections in care homes – enabling visits when community transmission is lower – stresses the importance of communicating the policy with families
- **Range of factors to be considered when assessing the possibility of visitors (UK Gov)** – level of care from external visitors; balance of benefits to residents vs spreading infections; number of visitors; ability to put in place practical measures to mitigate risks; the level of clinical vulnerability to Covid; the level of distress by restricting visitors (for example for people with dementia; people with learning disabilities; or autism); the level of risk in the area; the precautions that can be established during visits; the likely ability to maintain social distancing; etc.
- **Infection control measures for visits (UK Govt)** – limit to a single visitor or maximum 2; bookings to be made; a record to be kept of visitors to the home and who they interact with; no contact with other residents or staff; hygiene activities and PPE to be provided and worn; screen visitors for symptoms and contact with people who have tested positive for Covid; where possible visit to be undertaken outside or in a well-ventilated room; visitors should be supervised at all times; consider use of plastic barriers; decontaminate areas several times a day; minimise personal interaction between the resident and visitor; encourage visitors to not use public transport to visit; discuss gifts to encourage only ones that can be disinfected
- **Other safer ways care homes have used to facilitate visits:**
 - Meet in garden or outside space or purpose-built tents – allowing social distancing
 - Meet in a special visiting room – which is cleaned in-between visits
 - Speaking to each other through a plastic screen
 - Meet in the person’s room – but go there directly and do not meet other residents

- Chat through a ground floor window or patio door
- Have a drive through visit where you talk through your open care window 2 meters away
- ‘Hug’ curtains
- Glass booths / glass pods

Links for the above:

Practical examples of how care homes around the world have tried to enable visits in their facilities that, yet still very restrictive, may allow better direct interaction than video calls for many people - include:

- [“window visits”](#)
- [“car visits”](#)

Examples of strategies enabling more meaningful, private and direct interaction between residents and their partners in care:

- [Hug curtains](#)
- [Glass booths](#)
- [Glass-pod](#)
- Visits in care home open spaces (e.g. [gardens](#), [terraces](#), [purpose-built tents](#) ...)
- [Designated spaces](#) within the care home

Legal guidance – for families of people with disabilities:

- **Legal facts for people with learning disabilities** - Challenging Behaviour Foundation - <https://www.challengingbehaviour.org.uk/learning-disability-assets/faq1legalpanelupdated21stseptember.pdf>; and <https://www.challengingbehaviour.org.uk/learning-disability-assets/faq2updated15thoctober.pdf>

Government legislation:

- Easy read version of the: **Mental Capacity Act and the Deprivation of Liberty Safeguards in relation to caring for people during the Coronavirus pandemic** - https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/888422/emergency-mca-guidance-covid-19-easy-read.pdf

B. Gaps and concerns over Govt guidance re people with disabilities and Covid-19

Resources	Main lessons to take away
<p>Disability rights UK analysis of the:</p> <p>“OUR PLAN TO REBUILD: The UK Government’s COVID-19 Recovery Strategy”</p> <p>UK Government</p> <p>11 May 2020</p> <p>https://www.disabilityrightsuk.org/news/2020/may/new-guidance-fails-address-needs-disabled-people</p> <p>https://www.disabilityrightsuk.org/news/2020/may/government-issues-%E2%80%98phase-two%E2%80%99-coronavirus-guidance</p>	<p><i>“Those who are shielding due to medical conditions can’t safely return to work or school. Many disabled people have no option but to use crowded public transport. Some of us can’t exercise without human support. We are left with the feeling that the government plan isn’t about us”.</i></p> <p><i>“This plan comes less than two weeks after over 100 MPs and peers wrote to the government asking that government plans address the needs of disabled people.”</i></p> <p><i>The detailed 60 page document, “OUR PLAN TO REBUILD: The UK Government’s COVID-19 Recovery Strategy” can be found here: https://www.gov.uk/government/publications/our-plan-to-rebuild-the-uk-governments-covid-19-recovery-strategy</i></p> <p><i>The detailed guidance makes no specific reference to disabled people, but does make reference to ‘clinically vulnerable’ and ‘clinically extremely vulnerable’ people.</i></p>
<p>Disability Charity Consortium (DCC) members including DR UK say the UK’s 14 million disabled people are being “forgotten by the Government” and “allowed to fall through the cracks”.</p> <p>Ten disability charities have criticised the Government for failing to represent the interests of disabled people.</p> <p>The Consortium members are: Scope, Sense, Mind, Action on Hearing Loss, Business Disability Forum, Mencap, National Autistic Society, RNIB, Disability Rights UK and Leonard Cheshire.</p> <p>2 June 2020</p> <p>https://www.disabilityrightsuk.org/news/2020/june/disabled-people-%E2%80%98forgotten-government%E2%80%99-%E2%80%98perfect-storm%E2%80%99-puts-vital-services-brink</p>	<p><i>“Vital services for physically disabled people in particular have missed out on emergency funding so far. The DCC has highlighted a lack of a coherent strategy to specifically support disabled people through the pandemic and beyond, with many services suspended and facing a perilous future.</i></p> <p><i>Whilst some money has been made available for mental health, autism and learning disability it is nowhere near enough to match the demand for services.</i></p> <p><i>This is despite disabled people being the hardest hit by the pandemic. Many of the DCC members have submitted written evidence to the Women and Equalities Committee showing how this is the case.</i></p> <p><i>Disability Charity Consortium members say essential services may have to stop and this could lead to ‘unthinkable consequences’ for the future. Social care services are facing massive staffing and personal protective equipment purchase costs, with organisations spending up to £800,000 a month on PPE alone. Meanwhile helplines have seen calls soared by up to 80%. Charities have also rapidly digitised services and programmes to keep them running during lockdown.</i></p> <p><i>The Co-Chairs of the Disability Charities Consortium said: “Despite repeated efforts to raise the issue, it feels like the UK’s 14 million disabled people, particularly those with physical conditions, are being forgotten and allowed to fall through the cracks”.</i></p>

	<p><i>Providers of services are facing spiralling costs, a rapid drop in income from cancelled fundraising activities, but huge surges in demand as a result of the crisis, creating the perfect storm.</i></p> <p><i>Right now, we are collectively supporting millions of disabled people who are anxious, isolated and alone. Our staff are providing vital services, information and support under incredibly difficult circumstances. Sometimes we are the only place that disabled people have to turn.</i></p> <p><i>We want to be there for every disabled person who needs us, but this could soon be an impossibility. Disability charities, large and small, are at risk of disappearing at the very time that disabled people need us most. Without vital funds, we will have stark choices to make about cutting services or, in some cases, closing our doors."</i></p>
<p>Advocacy with the UK government on rights of people with disabilities</p> <p>Kamran Mallick, CEO of Disability Rights UK said:</p> <p><i>"Throughout the crisis, DR UK and other disabled people led organisations have been drawing the serious issues facing disabled people to the attention of government. In this letter to the Prime Minister, the group sets out the devastating impact of the crisis on disabled people and call for disabled people to be at the heart of recovery planning."</i></p> <p>23 July 2020</p> <p>https://www.disabilityrightsuk.org/news/2020/july/disabled-people%E2%80%99s-led-organisations-challenge-government-record</p> <p>https://www.disabilityrightsuk.org/sites/default/files/pdf/Prime%20Minister%202020-7-23.pdf</p>	<p><i>"Many disabled people were not on, or were missed off, the NHS 'shielding' scheme, leaving them with no recourse to extra support. For those that were on the shielding scheme, needing to rely on either food parcels or the goodwill of volunteers in order to eat, created a highly stressful situation.</i></p> <p><i>The reporting of deaths of people 'with pre-existing conditions' fuelled the fears of many disabled people that they were unseen, unimportant and forgotten. Indeed, as of June 2020, disabled people accounted for two thirds of all deaths in the UK from Covid-19.</i></p> <p><i>We also heard from disabled people and their families who had received letters from their GP suggesting that they should agree to a Do Not Resuscitate (DNR) order against their name in the event they became unwell with Covid-19. This naturally caused a huge amount of concern about what would happen to people with 'pre-existing conditions' who needed intensive care. Reassurances were eventually given, but by then the damage to disabled people's confidence in the treatment they would receive was done.</i></p> <p><i>The government's daily coronavirus briefing continually failed to provide a live British Sign Language (BSL) Interpreter, reinforcing the sense that the government had forgotten disabled people at a time when they were disproportionately affected.</i></p> <p><i>A return to language in government of 'the vulnerable' or 'vulnerable people' made many disabled people feel that they were seen as victims of the crisis, unable to speak for themselves or be part of the debate".</i></p>
<p>Concern over pressure to wear face coverings without exclusions</p>	<p><i>"Taking the lead from government messaging, [on 14 July] on Radio 4... both the Mayor of London and the CEO of the British Retail Consortium, used aggressive and punitive language regarding people who did not comply".</i></p>

<p>Disability Rights UK</p> <p>14 July 2020</p> <p>https://www.disabilityrightsuk.org/news/2020/july/disabled-people-still-facing-discrimination-over-face-coverings</p>	<p><i>“We would ask that government urgently recognises the need for balanced messaging, including that some disabled people cannot wear face coverings and that this should be respected. If the messaging doesn’t change, millions of disabled people will not be able to safely leave their homes. For those of us that do, we will experience, fear, anxiety, possible conflict with public and police and demands to prove our impairment/illness.”</i></p>
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C. Challenges for people with disabilities re-Covid-19

Resources	Main lessons to take away
Negative impacts of isolation and confinement	
<p data-bbox="113 331 421 636">Detrimental effects of confinement and isolation on the cognitive and psychological health of people living with dementia during COVID-19: emerging evidence.</p> <p data-bbox="113 658 421 725">Aida Suárez-González - LtcCovid</p> <p data-bbox="113 748 229 792">1 July 20</p> <p data-bbox="113 815 421 1151">https://ltccovid.org/2020/07/01/detrimental-effects-of-confinement-and-isolation-on-the-cognitive-and-psychological-health-of-people-living-with-dementia-during-covid-19-emerging-evidence/</p>	<ul style="list-style-type: none"> <li data-bbox="453 331 1410 412">• <i>It is estimated that 86% of people in care in the UK have some form of dementia.</i> <li data-bbox="453 434 1410 613">• <i>They show a worsening of functional independence and cognitive symptoms during the first month of lockdown (31% of people surveyed) and also exacerbated agitation, apathy and depression (54%), along with the deterioration of health status (40%) and increased used of antipsychotics or related drugs (7%).</i> <li data-bbox="453 636 1410 703">• <i>People with frontotemporal dementia (FTD) and their family caregivers seem to be particularly struggling to comply with protective measures.</i> <li data-bbox="453 725 1410 927">• <i>Only 2 case studies reporting strategies to support people with dementia in care homes have been produced so far. One describes a quarantine care plan for a person with FTD and the other, a mitigating strategy to ease the distress experienced by a man when his family stopped visiting during the pandemic.</i> <li data-bbox="453 949 1410 1285">• <i>People living with dementia in care homes have experienced a particularly harsh version of lockdown. Although no observational studies on the effects of confinement in care home residents have been published yet, the ban on visits from spouses and partners in care is believed to be causing a significant deterioration in the health and wellbeing of residents with dementia. It is worth noting that a study involving 26 care homes proved that it is possible to implement successful infection control measures at the same time that visits are permitted.</i> <li data-bbox="453 1308 1410 1509">• <i>COVID-19 infections will continue happening until a vaccine is developed. Learnings from this first COVID-19 wave can help the home care and day care sector prepare to minimise the disruption of their services in future waves so support can continue for people with dementia in the community.</i> <li data-bbox="453 1532 1410 1644">• <i>In care homes, evidence-based compassionate protocols should contribute to mitigating the detrimental effects of isolation and quarantine in residents with dementia (and their families).</i>
<p data-bbox="113 1682 421 1794">Impact of the outbreak on people living with dementia in the UK</p> <p data-bbox="113 1816 421 1962">Aida Suarez-Gonzalez, Gill Livingston and Adelina Comas Herrera - LtcCovid</p> <p data-bbox="113 1984 261 2018">3 May 2020</p>	<ul style="list-style-type: none"> <li data-bbox="453 1682 1426 1984">• <i>For people living with dementia in care homes, measures to prevent and control infection present particular challenges, as residents are no longer able to receive visits, the normal routines are no longer possible, staff will often wear Personal Protection Equipment (PPE) (which makes recognition and communication more difficult), and many permanent staff may be absent as they are self-isolating. Residents are often asked not to leave their rooms but may not understand why, be restless and so find it hard to stay still and become frightened at being by themselves.</i>

<p>https://ltccovid.org/2020/05/03/report-the-impact-of-the-covid-19-pandemic-on-people-living-with-dementia-in-uk/</p>	<ul style="list-style-type: none"> • Cognitive difficulties experienced by people living with dementia may make reliable implementation of preventative measures more difficult and can potentially increase their risk of contracting the virus. • Besides, people with dementia who develop infections are more likely to develop delirium, which complicates hospital management and compromises the future cognitive health of patients. • People with dementia experience greater functional loss during hospital stays and are likely to experience worse post-discharge functional recovery than those without dementia.
<p>Considerations for children and adults from disabilities UNICEF 19 March 2020 https://www.unicef.org/disabilities/files/COVID-19_response_considerations_for_people_with_disabilities_190320.pdf</p>	<p><i>“People experiencing social disadvantage and marginalization are known to be disproportionately impacted by ill-health. In the context of the COVID-19 pandemic, persons with disabilities may have increased risk for exposure, complications, and death as...</i></p> <ul style="list-style-type: none"> • Children and adults with disabilities may have underlying health conditions that increase their risk of serious complications from COVID-19 • Persons with disabilities are disproportionately represented among older populations, who are known to be at increased risk in the COVID-19 pandemic. It is estimated that more than 46% of the world’s population of people over age 60 have disabilities” • Inaccessible information and communication that people with hearing, visual, intellectual or physical disabilities may not receive key information about prevention and assistance • It may be more difficult for them to access water, sanitation and hygiene facilities and they may not have accessibility aids • They may be disproportionately affected by disruption to health and social care services • Quarantine, health facilities and transport established as part of the response may not be suitable for the needs of adults or children with disabilities • <i>“Prejudices, stigma, and discrimination against people with disabilities, including misconceptions that people with disabilities cannot contribute to the outbreak response or make their own decisions.</i> • <i>In health emergencies, people with disabilities may be less likely to be prioritized in resource allocation and priority setting”</i>
<p>Clinical guide for front line staff to support the management of patients with a learning disability, autism or both during the coronavirus pandemic—relevant to all clinical specialities</p>	<ul style="list-style-type: none"> • People with dementia and cognitive impairments may not be able to explain their symptoms and so the carers need to be observant on changes, including of delirium. For people with a learning disability, autism or both. • In 2018/19 - 41% of people with a learning disability who died, died of a respiratory condition, so they are considered particularly vulnerable.

<p>NHS England and NHS Improvement</p> <p>24 March 2020 - Version 1</p> <p>https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0031_Specialty-guide_LD-and-coronavirus-v1_-24-March.pdf</p>	<ul style="list-style-type: none"> • Gives tips on communicating with the person and their caregiver and different methods of communicating when they do not communicate verbally (see next table below).
<p>Vulnerability to respiratory illnesses</p> <p>Downs Syndrome Organisation</p> <p>13 March 2020</p> <p>https://www.downs-syndrome.org.uk/download-package/dsmig-articles-dsa-journal-141/</p>	<ul style="list-style-type: none"> • People with Downs Syndrome can be highly affected by respiratory infections, particularly upper airways infections. • When they get them there is a greater chance of them becoming seriously unwell, more likely to be admitted to hospital, and needing a ventilator. • These differences are due to differences in their immune system, differences in body structures, and some illnesses that are more common in people with Downs Syndrome

D. Good practice principles - for working with and supporting people with disabilities

Resources	Main lessons to take away
Good practice principles - policy level	
<p>Policy Brief: Disability inclusive response to Coronavirus</p> <p>United Nations May 2020</p> <p>https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2020/05/s_g_policy_brief_on_persons_with_disabilities_final.pdf</p>	<ol style="list-style-type: none"> 1. <i>Ensure mainstreaming of disability in all COVID-19 response and recovery together with targeted actions</i> 2. <i>Ensure accessibility of information, facilities, services and programmes in the COVID-19 response and recovery</i> 3. <i>Ensure meaningful consultation with and active participation of persons with disabilities and their representative organizations in all stages of the COVID-19 response and recovery</i> 4. <i>Establish accountability mechanisms to ensure disability inclusion in the COVID-19 response</i>
<p>Supporting patients of all ages who are unwell with coronavirus (COVID-19) in mental health, learning disability, autism, dementia and specialist inpatient facilities</p> <p>NHS 30 April 2020, Version 1</p> <p>This guidance has been updated to reflect changes to the case definition for COVID-19 from 18 May 2020</p> <p>https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/C0290_Supporting-patients-who-are-unwell-with-COVID-19-in-MHLDA-settings.pdf</p>	<ul style="list-style-type: none"> • <i>Where an individual is admitted who meets government criteria for 'shielding', they should be prioritised for an en-suite facility. Inpatient settings should consider the vulnerabilities of all patients they are caring for, making any reasonable adjustments to care where required.</i> • <i>Inpatient settings should reorganise wards/bays/en-suite facilities and staffing arrangements to separate these cohorts of patients, to maximise protection for the maximum number of patients. Specific local arrangements will need to be kept under regular review as the size and gender mix of these cohorts are likely to change over time.</i> • <i>Providers should also adopt a trauma-informed approach, with particular consideration of the effects of staff in personal protective equipment (PPE) providing care and support to individuals, recognising the overall aim of reducing trauma.</i> • <i>Case-by-case reviews will be required where any patient is unable to follow advice on containment, isolation and testing. Providers should decide the appropriate use of the relevant legal framework for each case, with support from medicolegal colleagues as required. Non-concordance with isolation represents a clear and obvious risk to other people. This should, in the first instance, be conveyed to the patient, helping them to understand the clinical reasons for self-isolation and testing.</i>

Good practice principles – practical level	
<p>Covid related guidance from the British Geriatric Society (BGS)</p> <p>Alistair Burns (National Clinical Director for Dementia, NHS England/Improvement)</p> <p>https://www.bgs.org.uk/topics/dementia</p>	<ul style="list-style-type: none"> • Covid-19 – End of life care - https://www.bgs.org.uk/resources/covid-19-end-of-life-care-and-dementia • Covid-19 – Dementia and cognitive impairment - https://www.bgs.org.uk/resources/covid-19-dementia-and-cognitive-impairment • Links for other support: https://www.dementiauk.org/
<p>Dementia care in care homes during the Coronavirus Pandemic</p> <p>https://www.alzheimers.org.uk/get-support/coronavirus/dementia-care-homes</p> <p>https://www.alzheimers.org.uk/dementiaconnect</p> <p>https://www.alzheimers.org.uk/get-support/coronavirus</p>	<ul style="list-style-type: none"> • Person centred care - Person-centred care involves tailoring a person's care to their interests, abilities, history and personality - https://www.alzheimers.org.uk/about-dementia/treatments/person-centred-care • If a person with dementia gets coronavirus - https://www.alzheimers.org.uk/get-support/coronavirus/person-dementia-care-home-falls-ill#content-start
<p>Impact of the outbreak on people living with dementia in the UK</p> <p>Aida Suarez-Gonzalez, Gill Livingston and Adelina Comas Herrera - LtcCovid</p> <p>3 May 2020</p> <p>https://ltccovid.org/2020/05/03/report-the-impact-of-the-covid-19-pandemic-on-people-living-with-dementia-in-uk/</p>	<ul style="list-style-type: none"> • Rare dementia practical tips - https://www.raredementiasupport.org/coronavirus-covid-19/ • Rare dementia – spoken videos of guidance for living through Covid-19 lockdowns – Hello and routines; sunlight; Stay safe part 1; Stay safe part 2; RDS Support and Stay in Touch - https://www.raredementiasupport.org/practical-tips-for-living-with-dementia-in-lockdown/ • Alzheimer’s Society - Singing for the Brain - https://www.alzheimers.org.uk/get-support/your-support-services/singing-for-the-brain
<p>Clinical guide for front line staff to support the management of patients with a learning disability, autism or both during the coronavirus pandemic—relevant to all clinical specialities</p> <p>NHS England and NHS Improvement</p> <p>24March 2020 - Version 1</p> <p>https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0031_Specialty-guide_LD-and-coronavirus-v1_-24-March.pdf</p>	<ul style="list-style-type: none"> • <i>Be aware of diagnostic overshadowing – When symptoms of physical ill health are mistakenly either attributed to a mental health/behavioural problem or considered inherent to the person’s disability or autism diagnosis. People with a learning disability have the same illnesses as everyone else, but the way they respond to or communicate their symptoms may be different and not obvious. Their presentation with coronavirus may be different from that for people without a learning disability.</i> • <i>Pay attention to healthcare passports - Some people with a learning disability and some people with autism may have a healthcare passport giving information about the person and their health needs, preferred method of</i>

communication and other preferences. Ask the person and/or their accompanying carer if they have one of these.

- **Listen to parents/carers** - The family or carer will have a wealth of information about the individual and how they have been, including any other co-morbidities and the medication the person is taking. *Listen to them as well as the person you are caring for. They know the person who is unwell best and how to look after them when they are not in hospital. They also know how the person's current behaviour may differ from usual, as an indication that they are unwell.* The family or carer may have short videos of the person to give you an idea of their usual self. But remember the carer they come in with may not be their usual carer at this unusual time.
- **Make reasonable adjustments**
- **Communication** - Communicate with and try to understand the person you are caring for. Check with the person themselves, their family member/carer or their hospital/communication passport for the best way to achieve this. *Use simple, clear language, avoiding medical terms and 'jargon' wherever possible. Some people may be non-verbal and unable to tell you how they feel. Pictures may be a useful way of communicating with some people, but not all.*
- **Understanding behavioural responses to illness/pain/discomfort** - *A person with a learning disability and some people with autism may not be able to articulate their response to pain in the expected way: e.g. they may say that they have a pain in their stomach when the pain is not there; may say the pain is less acute than you would anticipate; or not say they are in pain when they are. Some may feel pain in a different way or respond to it differently: e.g. by displaying challenging behaviour; laughing or crying; trying to hurt themselves; or equally may become withdrawn or quiet. People who are wheelchair dependant may have chronic pain. Understanding what is 'normal' for that person by talking to them, their family and carers, is crucial to helping with assessment and diagnosis. You can use pictures to help establish whether a person is in pain and where that pain is.*
- **Mental Capacity Act** - People with a learning disability and people with autism do not automatically lack capacity. *Assess capacity in line with the person's communication abilities and needs, and remember the principle of the Mental Capacity Act in making appropriate efforts and adjustment to enable decision making wherever possible.*

	<ul style="list-style-type: none"> • <i>Ask for specialist support and advice if necessary</i> • <i>Mental wellbeing and emotional distress - It is estimated that 40% of adults and 36% of children and young people with a learning disability and or with autism experience mental health problems. Change in routine can have a big effect on their emotional and mental wellbeing. A change in carers because a person's usual carers are self-isolating may also have an impact. In a hospital setting, masks and protective clothing may frighten them, make them more anxious and lead to adverse behaviours, such as hurting other people, hurting themselves and destroying property. Do not assume that this is an indication of mental illness and do your best to work with the person who is unwell, their carer or family member to find out how best to keep them calm and relaxed.</i>
<p>COVID-19 PPE: recommendations for care home workers providing support to people with learning disabilities or autistic people</p> <p>PHE with input from the National Autism Society</p> <p>28 Sept</p> <p>https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/888422/emergency-mca-guidance-covid-19-easy-read.pdf</p> <p><u>Same guidance:</u></p> <p>COVID-19 PPE: recommendations for care home workers providing support to people with learning disabilities or autistic people</p> <p>Gov UK</p> <p>28 Sept 2020</p> <p>https://www.gov.uk/government/publications/covid-19-how-to-work-safely-in-care-homes/covid-19-ppe-recommendations-for-care-home-workers-providing-support-to-people-with-learning-disabilities-or-autism</p>	<p><u>Example of recommendations:</u></p> <p>Steps can be taken to make PPE seem less frightening in several ways. It is important that in doing this you do not alter the PPE items in any way as this could reduce their effectiveness in protecting staff or the people you are providing care for.</p> <p>Care England has provided the following suggestions to help with this:</p> <ul style="list-style-type: none"> • <i>Staff may be able to greet residents without a mask through a window before entering the space where they actually meet</i> • <i>Explain that by wearing the mask you are helping other people to stay safe and that the mask is now part of your regular working clothes or uniform</i> • <i>Wear disposable picture badges showing staff without masks</i> • <i>Introduce masks by making them in an art session. This will be useful if residents need masks when going out. Have a choice of colours or fabric designs</i> • <i>Try to normalise the wearing of masks around the care home; if there are soft toys around perhaps provide masks for these</i> • <i>Play a game trying to guess what expression people are making behind masks</i> • <i>Use Makaton or British Sign Language (BSL) or possibly develop shared non-verbal signals for the expressions usually read from faces</i> • <i>Develop a matching pairs game with pictures of people with and without masks</i>

	<ul style="list-style-type: none"> • <i>Praise people when they ask questions about the masks. Answer clearly and honestly using their preferred communication method</i> • <i>Consider changing existing staff photos on activity boards or staff boards to photos of the staff wearing masks</i> • <i>Consider graded exposure approaches with the aim of making the PPE acceptable</i> <p><u>People who react with distress and anxiety:</u></p> <p><i>In exceptional circumstances, a very small number of people may have great difficulty in accepting staff wearing masks (and eye protection if relevant). Despite explanation, education and desensitisation they may repeatedly attempt to take them off, or they may react with extreme distress or anxiety.</i></p> <p><i>The severity, intensity or frequency of the behaviours of concern may place them or the supporting staff at risk of harm. A comprehensive risk assessment for each of these people identifying the specific risks for them and others should be undertaken. Under no circumstances should this assessment be applied to a whole care setting.</i></p>
<p>Covid-19 response: Considerations for children and adults with disabilities</p> <p>UNICEF</p> <p>19 March 2020</p> <p>https://www.unicef.org/disabilities/files/COVID-19_engagement_children_and_adults_with_disabilities_final.pdf</p>	<ul style="list-style-type: none"> • Provide life- saving information in appropriate multiple and accessible formats such as: <ul style="list-style-type: none"> ○ <i>Braille and large print for people who are blind or hand sight impairments</i> ○ <i>Easy to read versions for people with intellectual impairments</i> ○ <i>Written formats or videos with text captioning / or sign language for people with hearing impairments</i> ○ <i>Accessible web content for people using assistive technologies such as a screen reader</i> • Utilize the communication channels that are used by young people with disabilities • Engage people with disabilities as agents of change • Ensure that messages are disability inclusive
<p>5 steps to prevent harm to people with intellectual disabilities and their families in Coronavirus emergency</p> <p>Inclusion – Europe</p> <p>No date</p> <p>https://www.inclusion-europe.eu/wp-</p>	<p>5 steps to prevent harm to people with intellectual disabilities and their families in Coronavirus emergency:</p> <ol style="list-style-type: none"> 1. Inform clearly – about what people should do to protect themselves and others 2. Deliver information – to people with intellectual disabilities and their families 3. Help to deal with emergency – limited services and crisis plan – many day centres may be closed and families taking

<p>content/uploads/2020/03/CoronavirusResponse.pdf</p>	<p>over may be exposed to risks – such as loss of income and high levels of stress</p> <ol style="list-style-type: none"> 4. Help overcome isolation – while social distancing measures are in place 5. Protect disability rights – and related funding
<p>Talking with children about coronavirus disease</p> <p>CDC</p> <p>20 May 2020</p> <p>https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/talking-with-children.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2F2019-ncov%2Fcommunity%2Fschools-childcare%2Ftalking-with-children.html</p>	<ul style="list-style-type: none"> • Remain calm. Remember that children will react to both what you say and how you say it. They will pick up cues from the conversations you have with them and with others. • Reassure children that they are safe. Let them know it is okay if they feel upset. Share with them how you deal with your own stress so that they can learn how to cope from you. • Make yourself available to listen and to talk. Let children know they can come to you when they have questions. • Avoid language that might blame others and lead to stigma. • Pay attention to what children see or hear on television, radio, or online. Consider reducing the amount of screen time focused on COVID-19. Too much information on one topic can lead to anxiety. • Provide information that is truthful and appropriate for the age and developmental level of the child. Talk to children about how some stories on COVID-19 on the internet and social media may be based on rumours and inaccurate information. Children may misinterpret what they hear and can be frightened about something they do not understand. • Teach children everyday actions to reduce the spread of germs. Remind children to wash their hands frequently and stay away from people who are coughing or sneezing or sick. Also, remind them to cough or sneeze into a tissue or their elbow, then throw the tissue into the trash. • If school is open, discuss any new actions that may be taken at school to help protect children and school staff.
<p>People living with incontinence</p>	
<p>Supporting people living with incontinence</p> <p>Continence Foundation of Australia</p> <p>https://www.continence.org.au/new/faq-continence-and-covid-19</p> <p>COVID-19 Lockdown Continence Tips</p>	<p><u>Challenges that people living with incontinence may face during the Covid pandemic:</u></p> <ul style="list-style-type: none"> • Ensuring continuous access to incontinence pads – if suppliers get behind with deliveries • Ensuring continuous access to hand-gel to clean hands before managing their catheter [noting that soap and water is even more effective]

<p>Continence New Zealand</p> <p>No date</p> <p>https://www.continence.org.nz/pages/COVID-19-Lockdown-Continence-Tips/229/</p> <p>https://www.continence.org.nz/images/pages2/229_pages_image_2_Lockdown%20Tips.pdf</p>	<ul style="list-style-type: none"> • Less visits by health professionals providing continence care – such as nurses and physiotherapists – for example: https://www.kentcht.nhs.uk/service/continence-service/ • Increased stress – leading to increased incontinence <p><u>Tips for managing your continence during lockdown:</u></p> <ul style="list-style-type: none"> • Use helplines for people living with or caring for people with incontinence where they exist for support and advice • Work your pelvic floor every day • Drink plenty of fluids and limit your caffeine intake • Get fibre in your diet – helps to keep bowel movements soft • Keep a routine for toileting • Find the right product • Take time out to reduce stress and anxiety – Breathe deeply and repeat!
<p>Older people, UTIs (and hence incontinence) and COVID-19</p> <p>https://www.youtube.com/watch?v=0HVmOqgmXPY</p> <p>By the:</p> <ul style="list-style-type: none"> • Global Platform for the Rapid Generation and Transfer of Knowledge on COVID-19 and older adults in low and middle-income countries (GP-Older-COVID) and the • International long-term care policy network - Speakers from Argentina, Brazil, South African UK and Thailand sharing experiences and knowledge about COVID-19 and care homes www.corona-older.com 	<p>An interesting (but quite long) webinar - interesting points made re UTIs and COVID – which has relevance to the management of incontinence - on the webinar they are saying:</p> <ol style="list-style-type: none"> 1. The symptoms that older people who have when they have COVID are often different from the general population: <ol style="list-style-type: none"> a. <u>Most commonly they have</u> - delirium; diarrhoea; lethargy; falls; reduced appetite b. Fever, cough and breathlessness - are <u>not so common</u> 2. Around mins 1 hr 17 min - it starts to talk about: <ol style="list-style-type: none"> a. How older people with COVID are sometimes being mistaken for someone with an UTI b. In Brazil before the COVID-19 outbreak, the leading cause of admission to hospitals of older people was poorly managed UTIs – with high temperature as a symptom c. So now they are sometimes presented at hospital thinking they may have COVID / presented as suspicious – and then are at risk of catching COVID from the hospital d. Risk of getting problems with UTIs because not being treated in community properly in the first place – lacked hydration, hygiene not maintained, antibiotics not given early enough to control the UTI at an early enough stage

E. Existing good practice tools - for working with and supporting people with disabilities

Resources	Main lessons to take away
People with challenging behaviours / people with learning disabilities / people living with dementia	
<p>Top tips for tricky times</p> <p>A group of care home researchers from two NIHR Applied Research Collaborations (ARC)</p> <p>Claire Goodman (Centre for Research in Public health and Community Care (CRIPACC) University of Hertfordshire)</p> <p>2020</p> <p>https://ltccovid.org/2020/07/01/new-resource-top-tips-for-tricky-times-evidence-and-guidance-grounded-in-good-practice-and-experience-to-support-care-homes/</p>	<p><u>Excellent Top Tips documents</u> around 8 topics that had been raised by care homes related to dementia, where guidance was grounded in good practice and experience, learning from a WhatsApp group of care home managers and academics, clinicians and a commissioner:</p> <ol style="list-style-type: none"> 1. When residents do not understand social distancing or self-isolation 2. Supporting residents at the end of life when there is uncertainty 3. Providing physical comfort and reassurance to care home residents during Covid-19 4. Hydration and Covid-19 5. Using music to provide comfort and reassurance for care home residents living with dementia 6. Supporting staff following multiple deaths in care home environments 7. Supporting families at a distance 8. Helping care home residents with dementia to use video to communicate with their families
<p>Challenging behaviour</p> <p>Challenging Behaviour Foundation</p> <p>Various documents - downloaded - 17/10/20</p> <p>https://www.challengingbehaviour.org.uk/information/covid19information.html</p> <p>https://www.challengingbehaviour.org.uk/learning-disability-assets/quickreadchallengingbehaviourguidev6.pdf</p>	<p><u>Various documents about:</u></p> <ul style="list-style-type: none"> • Challenging behaviour • Video and tip sheets related to challenging behaviour • Also has some Covid guidance <p><u>Examples:</u></p> <ul style="list-style-type: none"> • Beyond Words – picture book with no words – for explaining about Covid-19 – “Beating the Virus”: https://booksbeyondwords.co.uk/downloads-shop/beating-the-virus • Pre-written cards that can be given to members of the public who question why someone with a learning disability is not following social distancing/mask guidance: https://www.challengingbehaviour.org.uk/learning-disability-assets/goingoutcardupdates17thjuly.pdf • Provides links to a range of useful info from other resources related to Covid: https://www.challengingbehaviour.org.uk/cbf-articles/latest-news/otherorganisations.html

	<ul style="list-style-type: none"> • Tips on how to manage a person who is spitting: https://www.challengingbehaviour.org.uk/learning-disability-assets/spitting.pdf • Hand-washing tips – with links to videos and activities: https://www.challengingbehaviour.org.uk/learning-disability-assets/handwashinginformationsheet.pdf <p>Other links:</p> <ul style="list-style-type: none"> • Going into hospital with Covid19 • Temperature taking • Routine Health Care During Covid19 • Activity ideas Covid19 part 1 • Activity ideas Covid19 part 2 • What happens when you are tested for Covid 19 - easy read • Coronavirus resources for children and families • Now, Next Later Chart and Visual Timetable • MCA Swab Testing Template Letter • Template letter when you have restricted access to visit your relative • Covid-19 Grab and Go NHS Form - I have a learning disability, or I am autistic • Local Lockdown Easy Read Guide - from Surrey & Borders Partnership NHS Foundation Trust • Also a video explaining local lockdown.
<p>Tips on how to sensitise people with learning disabilities in using / accepting PPEs / masks</p> <p>Challenging Behaviour Foundation</p> <p>Down-loaded - 17/10/20</p> <p>https://www.challengingbehaviour.org.uk/learning-disability-assets/sldandppeupdated30thjuly1.pdf</p>	<p><i>Desensitisation is a method to teach a person to associate feelings of relaxation with something they previously felt anxious about. Starting from an enjoyable and familiar social situation, the thing the person is scared of can be slowly introduced in a series of easy steps, for example:</i></p> <ul style="list-style-type: none"> • <i>Start by looking at a picture or video of a mask and people wearing masks</i> • <i>Use the word mask to get your relative used to it</i> • <i>Show an actual protective mask</i> • <i>Play with the mask, add it to fun interactions: do this for very short periods</i> • <i>Next, they could be shown different types of mask e.g. scarves/bandanas; funny face masks and a protective mask (or use the funny animal/people masks to make a game of it!)</i> • <i>Look at videos of preferred people wearing masks in different situations (firemen, superheroes, fancy dress parties, nurses)</i>

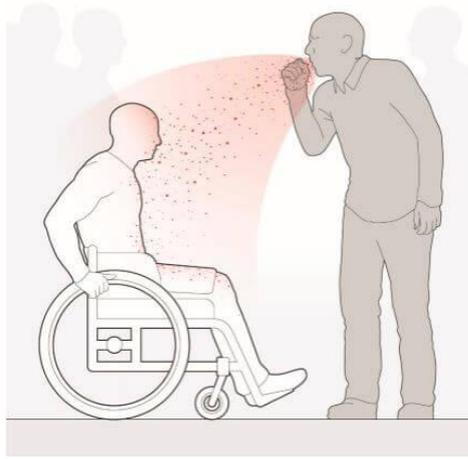
	<ul style="list-style-type: none"> • <i>Encourage the person to touch a mask</i> • <i>The person supporting them could put the mask in front of their own face</i> • <i>Encourage the person to put the mask up to their staff's face and take it down</i> • <i>Hold a mask each and encourage your relative to put the mask up to their own face, while you do the same</i> • <i>It might be useful to use a mirror or photograph so the person can see themselves</i> • <i>Follow similar steps with the goal of working towards the person being able to tolerate wearing a face covering or mask</i> <p><i>Don't rush each step. Over time the person learns not to react with anxiety. You will have to be guided by your relative/the person to ensure that anxiety is kept to a minimum. Rushing the steps may cause greater fear. The key to success is to take small steps and work at a pace your relative is comfortable with. Have fun.</i></p> <p><i>We can learn to cope with difficult things if we are relaxed and supported by people who we know and trust, and if we're not rushed. It often helps to 'embed' a hard activity in a fun or relaxing one.</i></p>
<p>Easy read information about Coronavirus – simple guides with pictures and images</p> <p>MenCap + Easy read online</p> <p><i>Note – there is no date on these documents and they do not include the use of face masks – so they are likely to be a bit out of date – but are useful examples</i></p>	<p><u>Mencap – No date:</u></p> <ul style="list-style-type: none"> • https://www.mencap.org.uk/sites/default/files/2020-03/Information%20about%20Coronavirus%20SrS1.pdf <p><u>Easy read – online:</u></p> <ul style="list-style-type: none"> • https://www.easy-read-online.co.uk/media/53192/advice-on-the-coronavirus-v1.pdf
<p>Handwashing rap by people with disabilities</p> <p>Hertfordshire County Council</p> <p>6 March 2020</p> <p>https://www.youtube.com/watch?v=4eY59qr2FTo&feature=youtu.be</p>	<p>Positive hand-washing rap video featuring youth with disabilities.</p>
<p>People with Down Syndrome</p>	
<p>Useful resources for working with people with Downs Syndrome re Covid</p>	<p>Simple visual guidance on how to stay safe:</p> <p>https://www.downs-syndrome.org.uk/download-package/coronavirus-what-is-it-how-to-stay-safe-easy-read/</p>

<p>From Down syndrome Oxford with inputs from:</p> <ul style="list-style-type: none"> Down's Syndrome Association (DSA) Down's Syndrome Medical Interest Group (DSMIG) <p>10 May 2020</p> <p>https://www.dsoxford.org.uk/useful-resources</p> <p>https://www.dsoxford.org.uk/essential-information</p>	<p>Simple visual guidance on social distancing:</p> <p>https://www.downs-syndrome.org.uk/download-package/social-distancing-easy-read/</p> <p>Handwashing songs for children (you Tube):</p> <ul style="list-style-type: none"> Frère Jacques Faster Baby Shark The Wiggles Mr Tumble
<p>People living with autism</p>	
<p>COVID-19: Guidance for care staff supporting adults with learning disabilities and autistic adults</p> <p>UK Guidance</p> <p>24 April 2020</p> <p>https://www.gov.uk/government/publications/covid-19-supporting-adults-with-learning-disabilities-and-autistic-adults</p> <p>https://www.gov.uk/government/publications/covid-19-supporting-adults-with-learning-disabilities-and-autistic-adults/coronavirus-covid-19-guidance-for-care-staff-supporting-adults-with-learning-disabilities-and-autistic-adults</p>	<p><u>Introduction:</u></p> <ul style="list-style-type: none"> <i>This guidance is for care workers and personal assistants who provide support to adults with learning disabilities and autistic adults.</i> <i>This guidance aims to help care staff keep people with learning disabilities and autistic people safe, to support them to understand the changes they need to make during the COVID-19 outbreak, and to protect their own wellbeing.</i> <i>It builds on the COVID-19 adult social care action plan and more detailed guidance published by the Social Care Institute for Excellence which will continue to be updated with resources to support those who care for people with learning disabilities and autistic people. The advice and resources may also be helpful for those supporting people with other needs relating to a cognitive impairment, such as dementia or mental health conditions.</i> <i>When following this guidance, it is important to note that people with learning disabilities and autistic people will have unique needs and preferences. They are more likely to need support to understand the current measures, such as the stay at home guidance, and any changes to their care and support provision. All care and support should continue to be given in the least restrictive way possible and continue to maximise independence wherever possible. More guidance is in the supporting the person through change section.</i>
<p>People with disabilities – in low- and middle-income countries</p>	
<p>Considering disability and ageing in COVID-19 hygiene promotion programmes</p> <p>Jane Wilbur</p>	<p>Has a wide range of useful sections and associated links covering:</p> <ul style="list-style-type: none"> Why should we include people with disabilities and older adults in the Covid-19 response?

<p>Updated: mid Oct 2020</p> <p>https://resources.hygienehub.info/en/articles/4097594-summary-report-on-considering-disability-in-covid-19-hygiene-programmes</p>	<ul style="list-style-type: none"> • Are people with disabilities and older adults at a higher risk during the Covid-19 pandemic? • What do we know in general about disability, ageing and WASH access? • What specific barriers might people with disabilities, older adults and older adults with disabilities face in relation to handwashing with soap? • How can we ensure people with disabilities, older adults, older adults with disabilities and their caregivers are included in all COVID-19 hygiene promotion programmes?
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People with physical disabilities / people who use assistive aids for mobility

<p>Covid-19 Tips for Wheelchair Users</p> <p>Sunrise Medical and Beneficial Designs – by Peter Axelson</p> <p>https://www.sunrisemedical.co.uk/blog/wheelchair-precautions-for-covid-19</p>	<p>Beneficial Designs. My name is Peter Axelson. I am a wheelchair user, designer, and engineer, and I am reaching out today with important information regarding COVID-19 precautions to be taken by wheelchair users.</p> <p>Key points:</p> <ol style="list-style-type: none"> 1. <i>Wash your hands often and wipe them with anti-bacterial wipes just before and after you eat.</i> 2. <i>Wipe down your wheelchair (especially push rims, tires, and joysticks) or other AT with a sanitized cloth or anti-bacterial wipe.</i> 3. <i>Observe a minimum of 6 ft. of distance from others in social interactions, and consider the benefits of wearing a face mask, medical or otherwise.</i> <p>Provides more detailed tips and guidance, such as:</p> <ul style="list-style-type: none"> • <i>Importance of disinfecting hands – particularly as they can be rough from years of pushing a wheelchair</i> • <i>How to clean your wheelchair – which parts and how</i> • <i>The extra importance of social distancing – because someone in a wheelchair sits lower and are more vulnerable to infected saliva droplets and aerosols</i> • <i>Also wearing a mask – can also help protect yourself from people spraying droplets on you</i>
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Protocol for cleaning wheelchairs

Tennessee Department of Intellectual and Development Disabilities

Accessed: 17 Oct 2020

<https://www.tn.gov/didd/for-consumers/seating-and-positioning/seating---positioning-maintenance.html>

Daily wheelchair cleaning:

- Use warm soapy water and a rag
- Small toothbrush can help clean the tilt mechanism
- Pay special attention to the wheelchair frame
- Wipe seat and back surfaces completely
- If meals are taken in the chair, immediately clean any spills
- Clean shoulder harness
- Let everything air dry before the person transfers back to the chair

General maintenance of wheelchairs:

This link provides other links to videos showing how to clean the different parts of a wheelchair: <https://www.tn.gov/didd/for-consumers/seating-and-positioning/seating---positioning-maintenance.html>

F. Good practice – keeping in touch and visiting people in care homes

Resources	Main lessons to take away
<p>Gov.UK – Guidance on visiting care homes during the pandemic</p> <p>15 Oct 2020</p> <p>https://www.gov.uk/government/publications/visiting-care-homes-during-coronavirus/update-on-policies-for-visiting-arrangements-in-care-homes</p>	<p><u>Extracts – see the full version for all components:</u></p> <ul style="list-style-type: none"> • <i>First priority is for preventing infections in care homes</i> • <i>As the rate of community transmission reduces then limited visits can be permitted</i> • <i>This should be on the basis of a dynamic risk assessment which takes into account the significant vulnerability of residents in most care homes, as well as in compliance with obligations under the Equality Act 2010 and the Human Rights Act 1998, as applicable.</i> • <i>This approach is based on the circumstances and needs of the individual care setting including both residents and staff and the external COVID environment. The external COVID environment includes the prevalence and incidence of infection in the local community and/or outbreaks or hotspots which may increase risk of infection in visitors to care homes in the area.</i> • <i>The care home’s visiting policy should be made available and/or communicated to residents and families, together with any necessary variations to arrangements due to external events.</i> <p><u>The assessment should consider relevant factors including:</u></p> <ul style="list-style-type: none"> • <i>The level and type of care provided by external visitors and the ability of care home staff to replicate this care</i> • <i>A balance of the benefits to the residents, against the risk of visitors introducing infection into the care home, or spreading infection from the care home to the community</i> • <i>Limit visitors to a single constant visitor wherever possible, with an absolute maximum of 2 constant visitors per resident. This, for example, means the same family member visiting each time to limit the number of different individuals coming into contact. This is in order to limit the overall number of visitors to the care home and/or to the individual, and the consequent risk of disease transmission</i> • <i>The ability of a particular setting to put in place practical measures to mitigate any risks arising from visits. Wherever possible, visits should take place outside or in a well-ventilated room, for example, with the windows and doors open where safe to do so. The Care Provider Alliance protocol for the sector has more advice on different types of visits</i> • <i>The health and wellbeing risks arising from the needs of the cohort of residents in that setting. This should include both whether their residents’ needs make them particularly clinically vulnerable to COVID-19 and whether their residents’ needs make visits particularly important (for example, people with dementia, a learning disability</i>

or autistic people may be permitted visitors when restricting visitors could cause some of the residents to be distressed). Social workers can assist with individual risk assessments, for visits, and can advise on decision-making where the person in question lacks capacity to make the decision themselves. This should include an individualised risk assessment to assess the rights and needs of individual residents as well as any specific vulnerabilities outlined in their care plan and the role that visiting can play in this. In making these decisions, the care provider should actively involve the resident, their relatives or friends, any advocates, commissioners and appropriate members of the multi-disciplinary team and where appropriate volunteers

- Advice from the PHE local HPT (in the event of an outbreak) and the local DPH and Infection Prevention and Control Lead from the responsible CCG. For local areas with a high local COVID alert level (high risk and very high risk), visiting should be limited to exceptional circumstances such as end of life
- The precautions that will be taken to prevent infection during visits and ensure these are communicated in a clear and accessible way, including through discussions with staff to address any anxieties and provide appropriate support, policies and procedures to enable staff to facilitate visits safely and in line with all the relevant guidance
- The likely practical effectiveness of social distancing measures between the visitor and the residents, having regard to the cognitive status of the resident and their communication needs
- Where the healthcare needs of the individual cannot be met by socially distant visits, whether there are sufficient infection-control measures in place to protect the residents, staff and visitors, to allow the visit to take place (see the [‘Infection-control precautions’](#) section).
- Ensuring that the appropriate PPE is always worn and used correctly – which in this situation is an appropriate form of protective face covering (this may include a surgical face mask where specific care needs align to close contact care) and good hand hygiene for all visitors
- Supervision of visitors at all times to ensure that social distancing and infection prevention and control measures are adhered to

Infection control measures for visits:

The CQC will include adherence to infection control measures for visitors as part of their infection prevention control inspections. It is vital that providers are meeting required standards.

The following considerations and precautions should be taken into account:

- *Visitors should be limited to a single constant visitor per resident, wherever possible, with an absolute maximum of 2 constant visitors per resident to limit risk of disease transmission*
- *It is recommended that the home has an arrangement to enable booking/appointments for visitors – ad hoc visits cannot be enabled*
- *In line with test and trace guidance, providers should maintain a record of any visitors to a care home as well as the person and/or people they interact with, for example if a person visits their loved one who is also visited by a chaplain in the course of the visit*
- *Visitors should have no contact with other residents and minimal contact with care home staff (less than 15 minutes / 2 metres). Where needed, conversations with staff can be arranged over the phone following an in-person visit*
- *Visitors should be reminded and provided facilities to wash their hands for 20 seconds or use hand sanitiser on entering and leaving the home, and to catch coughs and sneezes in tissues and clean their hands after disposal of the tissues*
- *Consideration should be given to the availability of additional protective clothing (for example, apron and gloves) if a resident has COVID-19 and social distancing is difficult to maintain*
- *In exceptional circumstances, a very small number of people may have great difficulty in accepting staff or visitors wearing masks or face coverings. The severity, intensity and/or frequency of the behaviours of concern may place them, visitors or the supporting staff at risk of harm. A comprehensive risk assessment for each of these people identifying the specific risks for them and others should be undertaken for the person's care, and this same risk assessment should be applied for people visiting the person. If visors or clear face coverings are available, they can be considered as part of the risk assessment. Under no circumstances should this assessment be applied to a whole care setting*
- *All visitors should be screened for symptoms of acute respiratory infection before entering: no one who is currently experiencing, or first experienced, coronavirus symptoms in the last 10 days, should be allowed to enter the premises,³ nor anyone who is a household contact of a case or who has been advised to self-isolate by NHS Test and Trace. Screening questions that care homes may wish to ask visitors on arrival are:*
 1. *Have you been feeling unwell recently?*
 2. *Have you had recent onset of a new continuous cough?*
 3. *Do you have a high temperature? A care home may consider providing a temperature check for all visitors to provide confidence to visitors and to staff.*
 4. *Have you noticed a loss of, or change in, normal sense of taste or smell?*

5. *Have you had recent contact (in the last 14 days) with anyone with COVID-19 symptoms or someone with confirmed COVID-19 – if yes, should you be self-isolating as a family member or as a contact advised to do so by NHS Test and Trace?*

- *Visitors must follow any guidance, procedures or protocols put in place by the care provider to ensure compliance with infection prevention control. Therefore, copies of the guidance, procedures and protocols should at least be available to be read by visitors on arrival*
- *Wherever possible, visits should take place either outside or in a well-ventilated room, for example with windows and doors open where it is safe to do so*
- *Providers should supervise visitors at all times to ensure that social distancing and infection prevention and control measures are adhered to*
- *Consider the use of plastic or glass barriers between residents and visitors*
- *Consider the possible use of designated visiting rooms, which are only used by one resident and their visitor at a time and are subject to regular enhanced cleaning*
- *Ensure areas used by visitors are decontaminated several times throughout the day and avoid clutter to aid cleaning*
- *Visitors should be encouraged to walk or cycle if they can. Where this is not possible, they should use public transport or drive. It might be that some assistance is required to enable visitors who are especially vulnerable to get to the care home. Care homes may consider giving visitors telephone numbers or website information of organisations which can offer advice on safe travel arrangements if required*
- *Visitors should be encouraged to keep personal interaction with the resident to a minimum, for example avoid skin-to-skin contact (handshake, hug) and follow the latest social-distancing advice for as much of the visit as possible*
- *Discuss with visitors any items they wish to bring with them on their visit, such as a gift. It will need to be something that can be easily cleaned by the care home to prevent cross contamination. For example, it is unlikely that they will be able to bring flowers but a box of chocolates that could be sanitised with wipes would be allowed*

Visiting people in care homes

Alzheimer's Society UK

24 July 2020

<https://www.alzheimers.org.uk/get-support/coronavirus/care-home-visits#content-start>

Keeping in touch with a person with dementia in a care home through the pandemic

Alzheimer's Society UK

3 Aug 2020

<https://www.alzheimers.org.uk/get-support/coronavirus/dementia-care-home-support#content-start>

Over the past few months, most care homes have worked out safer ways for you to speak with the person you care about. Depending on the home, its layout and the weather, you might be asked to:

- *Meet in a garden or outdoor space – where you can safely sit or walk two metres (three steps) apart*
- *Catch up in a special visiting room – which is cleaned thoroughly between visits*
- *Speak to the person from behind a see-through plastic screen – like those seen in supermarkets now*
- *Meet in the person's room – but go directly there and meet no other residents*
- *Chat through an open ground-floor window or patio door*
- *Have a 'drive-through' visit – where you talk through your open car window to the person sitting two metres away.*

*Your reunion may well be emotional. If it's been a long time since they saw you – and if the person has memory problems, you may need to gently remind them who you are. **Clothes, a hair style and perfume/aftershave that are more familiar to the person may help them remember you.***

You may need to mention the virus to explain why you couldn't visit before. Talking about earlier times you've enjoyed together may be a way of keeping the conversation more cheerful.

Don't be surprised if the person's dementia has got worse since you last saw them or if they seem low. They may improve with ongoing support, and their feelings for you remain, even if they seem hidden.

It's natural to want to hold hands or have a hug or cuddle. Staff will advise but it will come down to the individual. This type of close personal interaction will sadly need to be kept brief, if at all.

Try to be flexible and work with everyone as best you can. Before you leave, arrange the next visit. This will give you and the person something to focus on and look forward to.

<p>Detrimental effects of confinement and isolation on the cognitive and psychological health of people living with dementia during COVID-19: emerging evidence.</p> <p>Aida Suárez-González - LtcCovid</p> <p>1 July 20</p> <p>https://ltccovid.org/2020/07/01/detrimental-effects-of-confinement-and-isolation-on-the-cognitive-and-psychological-health-of-people-living-with-dementia-during-covid-19-emerging-evidence/</p>	<p>Practical examples of how care homes around the world have tried to enabled visits in their facilities that, yet still very restrictive, may allow better direct interaction than video calls for many people - include:</p> <ul style="list-style-type: none"> • “window visits” • “car visits” <p>Examples of strategies enabling more meaningful, private and direct interaction between residents and their partners in care:</p> <ul style="list-style-type: none"> ○ Hug curtains ○ Glass booths ○ Glass-pod ○ Visits in care home open spaces (e.g. gardens, terraces, purpose-built tents...) ○ Designated spaces within the care home
<p>Covid-19: Visitors’ protocol</p> <p>CPA Briefing for care providers</p> <p>19 June 2020</p> <p>https://careprovideralliance.org.uk/coronavirus-visitors-protocol</p> <p>https://careprovideralliance.org.uk/assets/pdfs/cpa-visitors-protocol.pdf</p>	<p>Practical suggestions for visits:</p> <ul style="list-style-type: none"> • Window visits: <i>This will need safe ground floor window access for both residents and their visitors and the relevant social distancing and PPE measures will need to be observed.</i> • Garden visits: <i>Relevant PPE measures and social distancing will apply. Independent access to the garden will be needed to avoid visitors moving through the care setting to the garden. Providers will need to consider how to facilitate garden visits in different weather conditions, how to ensure cleaning of areas and any items used between visits and keep everyone safe, whatever the weather.</i> • Drive through visits: <i>These are facilitated visits in the car parks of homes. Again, any relevant PPE measures and social distancing will apply.</i> • Designated areas within a care setting where settings allow for this: <i>depending on the physical layout of the care setting, it may be possible to enable visits to an identified location inside the care home reserved for this purpose, that facilitates good ventilation, social distancing, ease of access by residents, and limits visitor journeys through the residential areas. An example might include the use of a conservatory as a designated visiting area.</i> • In-room visits: <i>These visits may continue to be facilitated as appropriate, in line with national guidance in relation to essential / end of life visits to ensure the person can die with dignity and comfort, taking into account their physical, emotional, social and spiritual support needs.</i>

G. Legal guidance - for families of people with disabilities

Resources	Main lessons to take away
<p>Legal facts for people with learning disabilities</p> <p>Challenging Behaviour Foundation</p> <p>Updated - 21 Sept 2020</p> <p>https://www.challengingbehaviour.org.uk/learning-disability-assets/faq1legalpanelupdated21stseptember.pdf</p> <p>https://www.challengingbehaviour.org.uk/learning-disability-assets/faq2updated15thoctober.pdf</p>	<p>Covers a range of legal advice for families related to their relatives with learning disabilities – is in two parts and includes:</p> <p><u>Information sheet 1 (40 pages):</u></p> <ul style="list-style-type: none"> • Right to activities and routine for well-being • Visiting your relative or friend • Support around behaviour that challenges • Meeting health needs • Mental Capacity Act • Access to advocacy • DNAR notices • Personal health budgets and direct payments • Children accommodated under Section 20 in residential schools • Education • Personal Welfare Deputy • Complaints – Local Authority and NHS Complaints <p><u>Information sheet 2:</u></p> <ul style="list-style-type: none"> • Homes schooling a child with an EHCP • Visiting rights for families • Right to appropriate management of behaviours that challenge • Going to hospital during Covid-19 • Employment issues • Care Act Easements

H. Government legislation

Resources	Main lessons to take away
<p>Guidance on looking after people who lack mental capacity</p> <p>Gov.uk</p> <p>15 Oct 2020</p> <p>https://www.gov.uk/government/publications/coronavirus-covid-19-looking-after-people-who-lack-mental-capacity?utm_source=a4a3d322-fbe7-424e-bc47-ed85741782a8&utm_medium=email&utm_campaign=govuk-notifications&utm_content=immediate</p>	<ul style="list-style-type: none"> • <i>This emergency guidance is for health and social care staff in England and Wales who are caring for, or treating, a person who lacks the relevant mental capacity during the coronavirus outbreak.</i> • <i>The guidance ensures that decision makers are clear about the steps they need to take during this period. It focuses on new scenarios and potential ‘deprivations of liberty’ created by the outbreak.</i> • <i>During the outbreak, the principles of the Mental Capacity Act 2005 (MCA) and the safeguards provided by the deprivation of liberty safeguards (DoLS) still apply.</i> • <i>The MCA provides protection for people who lack or may lack the relevant mental capacity to make decisions about different aspects of their life.</i> • <i>The DoLS are an important part of this act and provide further safeguards for those who need to be deprived of their liberty in order to receive care or treatment in a care home or hospital, but do not have the capacity to consent to those arrangements.</i>
<p>The Mental Capacity Act (2005) (MCA) and Deprivation of Liberty Safeguards During the COVID-19 Pandemic</p> <p>UK Govt</p> <p>9 April 2020</p> <p>https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/878910/Emergency_MCA_DoLS_Guidance_COVID19.pdf</p> <p>Easy read version:</p> <p>Mental Capacity Act and the Deprivation of Liberty Safeguards in relation to caring for people during the Coronavirus pandemic</p> <p>https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/888422/emergency-mca-guidance-covid-19-easy-read.pdf</p>	<p>The Easy Read version of this act – is very nice and simple and provides guidance on:</p> <ul style="list-style-type: none"> • Introduction • The Covid-19 pandemic • Caring for people during the pandemic • The Mental Capacity Act (2005) • The Mental Capacity Act (2005) and the best thing for you during the pandemic • Giving you the same treatment as everyone else • Rules that order people to be looked after safely when people cannot make decisions for themselves • Staying indoors