

The following information resources have been selected by the National Health Library and Knowledge Service Evidence Virtual Team in response to your question. The resources are listed in our estimated order of relevance to practicing healthcare professionals confronted with this scenario in an Irish context. In respect of the evolving global situation and rapidly changing evidence base, it is advised to use hyperlinked sources in this document to ensure that the information you are disseminating to the public or applying in clinical practice is the most current, valid and accurate. For further information on the methodology used in the compilation of this document [] including a complete list of sources consulted [] please see our National Health Library and Knowledge Service Summary of Evidence Protocol.

YOUR QUESTION

What is the impact of COVID-19 on people with disability?

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IN A NUTSHELL

The WHO¹, UN⁵ and EU Disability Forum⁴ document the impact of COVID-19 on people with disability. Major considerations include:

- Difficulty with basic hygiene: eg hand washing.
- Limitations of the physical environment.
- Challenges in implementing physical distancing due to the need for personal care.
- Higher clinical risks due to co-existing health conditions.
- Disruption to supports and services due to health protection measures.
- Communication difficulties: eg lip-reading or use of sign language when wearing face masks.
- Access to information in a variety of formats.
- Financial difficulties.
- Social stigma and isolation.



HSE guidance on COVID-19 in Nurse Led Residential Care services for people with Disabilities² includes infection control practices, signs and symptoms, clinical investigations and information on the prevention of transmission. An NHS clinical guideline for staff supporting patients with a learning disability or autism³ includes statistics on increased morbidity and mortality and prevalence of co-existing conditions.

McCarron, reports on risks of COVID-19 for people with intellectual disability ^{50,51}. Inclusion Ireland⁷ describes impacts and reasons for increased risk, including co-morbidities, lower literacy levels, and high reliance on others for support and care. A BMJ letter⁵³ notes a rise in requests to psychiatrists for psychotropic medication.

In a blog post, Hatton⁵⁴ cites evidence that people with learning disability are more likely to have another health condition with a greater risk of a severe reaction to COVID-19. Sullivan⁶⁶ also reports that intellectual disability and other health conditions increase the risk of developing a more severe infection. The Centre for Research Excellence in Disability and Health Australia⁶ policy on COVID-19 includes concerns about accessibility of testing for people with intellectual disability and urges further support for clinicians to provide telehealth solutions.

The literature demonstrates widespread negative impacts of COVID-19 on communication for people with disability. Fei and Hu¹⁰ speak about the outbreak in China and note that the Law on Prevention and Treatment of Infectious Diseases did not include a section on disability. The authors include experiences of people with disability. People with Disability Australia¹¹, a group of ten disability organisations, published a joint response to the COVID-19 outbreak.

A number of writers speak about COVID-19 concerns in the D/deaf and hearing impaired community including:

- Use of sign language in official health communication.
- Availability of sign language interpreters at testing centres.
- Use of clear signs and pictures or images.
- PPE and face masks creating difficulties with lip-reading, acoustic transmission and the inability to see facial expressions when using sign language.



Use of transparent face masks has been widely discussed ^{8,9,15,57,73}. The Critical Disabilities Studies Network Sweden¹³ points to limited access to sign language interpreters during official government briefings, and the Swedish DeafBlind association notes a lack of guidelines for those who use tactile communication in light of policies on physical distancing.

Challenges in hospital setting are addressed under CLINICAL ISSUES below. Stroke, multiple sclerosis, and spinal cord injuries are highlighted. Under ENVIRONMENTAL ISSUES, difficulties encountered by people with sensory and mobility disabilities are of special concern. Lakhani⁶⁴ uses spatial analysis including key demographics to identify gaps in service for vulnerable groups, while Pineda⁷⁶ suggests that lessons learned from the pandemic should be used to develop a more universally user-friendly urban landscape.

Older people are particularly vulnerable, with the burden of disability highest in this specific demographic^{69,70}, as reflected also in McCarron's TCD/Tilda reports^{50,51}.

Charitable and voluntary organisations are a mainstay in delivering advocacy and supports for people with disabilities, with gaps being filled by freelance volunteers; however, their resources are coming under increasing pressure⁷⁷.

IRISH AND INTERNATIONAL GUIDANCE

What does the World Health Organization say?

World Health Organisation (March 2020) Disability considerations during the COVID-19 outbreak¹

People with disability may be at greater risk of contracting COVID-19 because of:



- barriers to implementing basic hygiene measures such as hand washing: eg hand basins, sinks or water pumps may be physically inaccessible, or a person may have physical difficulty rubbing their hands together thoroughly;
- difficulty in enacting social distancing because of additional support needs or because the person may be institutionalized;
- the need to touch things to obtain information from the environment or for physical support;
- barriers to accessing public health information.

Depending on underlying health conditions, people with disability may be at greater risk of developing more severe cases of COVID-19 if they become infected. This may be because of:

- COVID-19 exacerbating existing health conditions, particularly those related to respiratory function, immune system function, heart disease or diabetes;
- barriers to accessing health care

People with disability may also be disproportionately impacted by the outbreak because of serious disruptions to the services they rely on. The barriers experienced by people with disability can be reduced if key stakeholders take appropriate action:

- Work to ensure all clinics providing testing and services related to COVID-19 are completely accessible.
- Address physical barriers such as uneven pathways, stairs, hard-toreach spaces or hard-to-use equipment; attitudinal barriers such as social stigma against disability and the denial of essential services; and financial barriers such as high costs related to treatment or accessing the facility.
- Ensure that information about the accessibility of COVID-19 health services is disseminated to people with disability and their caregivers.
- Deliver information in understandable and diverse formats to suit different needs. Do not rely solely on either verbal or written information and adopt ways to communicate that are understandable to people with intellectual, cognitive and psychosocial impairments.



- Deliver home-based consultations for people with disability, including for their general health needs and, where appropriate, for COVID-19 related needs.
- Develop and disseminate information to health workers so that they are aware of the potential health and social consequences of COVID-19 for people with disability.
- Deliver sufficient support for people with disability with more complex needs, particularly if quarantined or isolated. When needed, coordinate care between health and social services, families and caregivers.
- Ensure that decisions on the allocation of scarce resources such as ventilators are not based on pre-existing impairments, high support needs, quality of life assessments, or medical bias against people with disability.
- Follow WHO guidance to prioritize those at high risk.

<u>Health Service Executive Disability Services (2020) Guidance for COVID-19</u> <u>in Nurse Led Residential Care Services for People with Disabilities.</u> <u>Version 1.1²</u>

Implementing infection prevention and control practice is extraordinarily difficult with service users who are unable to comply with requests from staff. In that setting the only practical approach is to apply the key principles of infection control as much as possible.

If an individual is unwilling/unable to comply with testing for COVID-19 and they are symptomatic, they should be managed as if they have confirmed case as described above.

A specific sub-group is being established to look at supports for those with behaviours that challenge and to make recommendations on how to ensure safety of the individual, staff and other service users.

NHS England (March 2020) Clinical guide for front line staff to support the management of patients with a learning disability, autism or both during the coronavirus pandemic³

People with a learning disability have higher rates of morbidity and mortality than the general population and die prematurely. At least 41% of them die from respiratory conditions. They have a higher prevalence of asthma and diabetes, and of being obese or underweight in people; all these factors make them more vulnerable to coronavirus. There is evidence that people with autism also have higher rates of health problems throughout childhood,



adolescence, and adulthood, and that this may result in elevated risk of early mortality.

European Disability Forum (19 March 2020) Updated statement: Open letter to leaders at the EU and in EU countries: COVID-19: Disability inclusive response⁴

As the situation continues to develop, we at EDF are adding more measures to our open letter to leaders of the EU and EU countries. The full letter was published on 13 March.

Added Measures

- Make public health communication accessible.
- Ensure all information is in plain language and easy to read.
- Accessible, inclusive, hygienic health services and other facilities.
- Sign language interpreters, personal assistants and all others that support persons with disabilities in emergency and health settings should be given the same health and safety protections as other health care workers dealing with COVID19.
- Instructions to health care personnel should highlight equal dignity for people with disabilities, that communication should be done directly with the person with disabilities whenever possible. They should include safeguards against disability-based discrimination. Rapid awareness-raising of key medical personnel is essential to ensure that persons with disabilities are not left behind or systematically deprioritized in the response to the crisis.
- EU should provide countries with deficits with personal protection kits to avoid infection. This equipment should be for frontline employees such as healthcare staff, social workers, law enforcement officers, etc.
- Quarantined persons with disabilities must have access to interpretation and support services, either through externally provided services or through their family and social network. Ideally there should be no disruption to ongoing support agreements (no change in personal assistant, sign interpreter, etc) upon both parties agreement and subject to adoption of all protective measures".

United Nations Human Rights Office of the High Commissioner (2020) COVID-19 and the Rights of Persons with Disabilities Guidance⁵

While the COVID-19 pandemic threatens all members of society, persons with disabilities are disproportionately impacted due to attitudinal,



environmental and institutional barriers that are reproduced in the COVID-19 response. Many persons with disabilities have pre-existing health conditions that make them more susceptible to contracting the virus, experiencing more severe symptoms of infection, leading to elevated levels of death. During the COVID-19 crisis, persons with disabilities who are dependent on support for their daily living may find themselves isolated and unable to survive during lockdown measures, while those living in institutions are particularly vulnerable, as evidenced by the overwhelming numbers of deaths in residential care homes and psychiatric facilities. Barriers for persons with disabilities in accessing health services and information are intensified. Persons with disabilities also continue to face discrimination and other barriers in accessing livelihood and income support, participating in online forms of education and seeking protection from violence. Particular groups of persons with disabilities such as prisoners and those who are homeless or without adequate housing face even greater risks. This guidance aims to:

- Bring awareness of the pandemic's impact on persons with disabilities and their rights.
- Draw attention to some promising practices already being undertaken around the world.
- Provide resources for further learning about ensuring rights based
 COVID-19 responses inclusive of persons with disabilities.

<u>Centre For Research Excellence in Disability and Health (2020) COVID-19:</u> <u>policy action to protect people with disability in Australia⁶</u>

There is an urgent need for the disability and health sectors to develop a coordinated response that protects the health of over 4 million Australians with disability.

On 15 March we made recommendations to government for significant measures to protect people with disability and the disability support workforce in the COVID-19 pandemic.

Our concerns are:

- the lack of accessible testing and health care services and no plan for people with intellectual and development disabilities
- the lack of support for clinicians providing services to people with disability to upscale their telehealth activities to enable high-level health care for people with disability



INTERNATIONAL LITERATURE

COMMUNICATION

Inclusion Ireland (2020) COVID-19 and Intellectual Disability: Supporting People with Intellectual Disabilities and Their Families⁷

COVID-19 and Intellectual Disability

People with intellectual disabilities and their families need to be supported to access the healthcare services and public health information that they need in relation to the ongoing COVID-19 outbreak. People with intellectual disabilities may be at greater risk of contracting COVID-19. Many are in a high-risk category as they may suffer from several health conditions, have low levels of literacy, and rely on others for support and care.

Other reasons people with intellectual disability are at higher risk include:

- They may have difficulty in taking part in social distancing due to additional support needs, or because of institutionalised settings and routines.
- There may be barriers to practising good hygiene measures due to inaccessible physical environments, or a lack of understanding of information related to hygiene.
- People with sensory issues may need to touch objects to get information or for physical support.
- Public health information may be inaccessible.

Armitage and Nellums LB (2020) [Correspondence] The COVID-19 response must be disability inclusive⁸

Equal access to public health messaging: all communication should be disseminated in plain language and across accessible formats through mass and digital media channels. Additionally, strategies for vital in-person communication must be safe and accessible such as sign language interpreters and wearing of transparent masks by health-care providers to allow lip reading. Second, measures such as physical distancing or selfisolation might disrupt service provision for people living with disability who often rely on assistance for delivery of food, medication, and personal care. Mitigation strategies should not lead to the segregation or institutionalisation of these individuals.



<u>Grote and Izagaran (2020) In the push for universal mask wearing, the</u> <u>communication needs of D/deaf healthcare workers and patients are</u> <u>being forgotten⁹</u>

This article was written by two D/deaf doctors who depend on lip reading for their everyday work.

"We, as a society and as a body of healthcare professionals, need to ensure that in our response to COVID-19, the rights of those with hearing loss are not forgotten.

"We would encourage all healthcare professionals to carefully consider the communication needs of their D/deaf patients. Apps, such as Google's Live Transcribe may help to decipher speech from behind a mask in quiet settings. Clear signs and pictures can also assist with communication; resources such as Cardmedic [] a digital package of communication flashcards [] can be helpful in some instances. However, written notes are not always an effective means of communication for those whose first language is British Sign Language, as the grammatical structure is entirely different.

"The lack of support in this area has been one of the hardest challenges we have faced at work during the coronavirus pandemic. It leaves us and our D/deaf patients feeling isolated and ignored. Reading articles and tweets about the importance of masks, with no consideration of the impact on the D/deaf, leads us to conclude that policymakers and academics have seemingly forgotten about the importance of equality impact assessments in this area."

The authors also mention the importance of transparent masks. With the outbreak of COVID-19, China had to declare a public health emergency within a short time. In order to control and prevent further spread of the disease, China activated the highest emergency response based on the Law on Prevention and Treatment of Infectious Diseases (LPTID). However, the LPTID lacks a disability perspective and to a large extent overlooks the needs of people with disabilities during emergencies.

People with Disability Australia (2020) Immediate Proactive Response To Coronavirus (COVID-19) For Australians With Disability¹¹ Immediate Welfare of People with Disability

— Ensure continuity of supports.



- Resource existing national information services to expand and be available to manage requests related to COVID-19 from people with disability, particularly those who may not have access to the Internet.
- Resource and establish a proactive, phone-based outreach program to existing National Disability Advocacy Program (NDAP) providers to enable advocates to connect and check in with people with disability. This program would also actively engage with any other person with disability in the region that the NDAP provider operates. The phone based outreach program would undertake the following tasks:
 - Simply asking how the person with disability is coping.
 - Do they require any equipment or supplies?
 - If so, investigate ways that these may be purchased online.
 - Schedule a follow up phone call.
- Establish a national prioritised delivery service for essential goods for people with disability such as sanitising equipment, continence aids and medical consumables: eg medical swabs, PEG feeding support, catheters, wound dressings.
- Active and ongoing liaison with states and territories to ensure full inclusion of people with disability in all plans to deal with COVID-19.
- Equal access to essential goods such as groceries and food.
- All information to be provided in plain English, Easy Read and Auslan, and departments to liaise with disability peak organisations about vital communications before the information is sent out or posted to ensure it is disability friendly and accessible.

<u>Centre for Research Excellence in Disability and Health (2020) COVID-19:</u> <u>policy action to protect people with disability in Australia¹²</u>

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On 15 March we made recommendations to government for significant measures to protect people with disability and the disability support workforce in the COVID-19 pandemic.

Our concerns are: the lack of accessible testing and health care services; and no plan for people with intellectual and development disabilities. The lack of support for clinicians providing services to people with disability to upscale their telehealth activities to enable high-level health care for people with disability.

Section: Recommendations for Healthcare and People with Disability



- That a new MBS [Medicare Benefits Schedule] item is introduced to develop COVID-19 health care plans with children and adults with complex disabilities so that they know how to implement social distancing and hygiene measures and how to access testing and treatment. Health practitioners should remain a single point of contact during the pandemic for COVID-19 and other health matters.
- That the recently introduced Medicare item for telehealth consultations with primary care and specialist providers be extended to children and adults with disability who are not included in the current definition of vulnerable populations. They do not qualify for access to these services unless they are in self-isolation or quarantine.
- A dedicated coronavirus health information hotline for children and adults with disability staffed by people with a deep understanding of disability issues and health co-morbidities. This hotline should operate alongside the existing hotline and share resources.

Section: Recommendations for the Disability Workforce

- Provide immediate access to personal protective equipment (PPE) to prevent transmission as a prevention strategy. There is a lack of recognition of the need for workers to access personal protective equipment to prevent transmission to the people they support.
 Because many of these workers see several disabled people in one day, it may be possible to acquire and transmit COVID-19. However, personal protective equipment is only available if they are supporting someone with COVID-19 or suspected COVID-19 infection.
- Safeguard the incomes of families and carers who need to take time off to provide care. In light of school and day service closures in some states and territories, many participants will rapidly need to have changes made to their plans including a large injection of funds so that essential supports can be provided. We previously recommended that family members should be paid for providing supports in the pandemic so that families are not placed under undue distress.
- That the NDIS rapidly reach out to self-managed participants particularly those using online platforms, unregistered providers or directly employing support staff to ensure they don't experience a disruption of supports and have access to PPE for staff when it becomes available.



 That disability support is considered and clearly defined as an essential service along with other services such as supermarkets and petrol stations.

<u>KritFunk Critical Disability Studies Network Sweden (2020)</u> <u>The impact of COVID-19 on disabled citizens in Sweden¹³</u>

Section: Communication

Many disabled citizens in Sweden face difficulties using the Internet due to the inaccessible design of devices, platforms and content. Social distancing practices have increased dependency on online communication, for important information, goods and services. Limited access to digital resources poses a major risk to the safety of many citizens with communication-related impairments.

The government and responsible agencies have held daily press conferences informing the public about current developments, but for 33 days there was no information in Swedish Sign Language (STS) available from the national authorities, something highlighted by the Swedish National Deaf Association (SDR). Information in easy-to-read Swedish was also missing. Furthermore, the Association of the Swedish DeafBlind (FSDB) pointed out a failure to develop guidelines for handling the demands of social distancing for people using tactile communication.

Castro et al (2020) [Correspondence] COVID-19: don't forget deaf people¹⁴

The authors found 15 or more different [sign language] signs are currently being used to describe the coronavirus in countries affected by the pandemic. Brazil alone uses at least 3. Some of these signs are based on unscientific variants that might for example evoke fear of an animal bite. Even providing written information is unreliable because of the different levels of understanding of Portuguese deaf citizens' second language among communities.

Lefrak (2020) [Blog] New Coronavirus Safety Measures Pose Challenges For The Deaf And Hard-Of-Hearing¹⁵

One of the most well-documented pandemic challenges is communicating through face-obscuring masks. The masks make it impossible for people who read lips to see people's mouths or follow facial expressions during essential trips to the grocery store or doctor's office. Facial expressions such as nose crinkles and mouth movements are also components of American Sign Language.



Cradden (2020) [Newspaper Article] Coronavirus highlights continuing marginalisation of deaf community¹⁶

Lianne Quigley, Chairperson of the Irish Deaf Society, says that for thousands of Irish Sign Language users, there is simply not enough key COVID-19 information being provided in their native language \Box now officially recognised as a language through the 2017 Irish Sign Act. The failure to do so is in clear breach of Article 9 of the UN Convention on the Rights of People with Disabilities, which says that member states must provide equal access to information to enable them to participate fully in all aspects of life. "Brendan Lennon, Head of Advocacy at CHIME, a national charity for deafness and hearing loss, says that TV ads are not even subtitled, further undermining the government's policy commitments in the National Disability Inclusion Strategy. "All of this has certainly resulted in some deaf and hard of hearing people not getting full information."

CLINICAL ISSUES

Disability Federation of Ireland (2020): Frequently Asked Questions¹⁷

DFI address a range of concerns in this document. They recognise the impact of closure of services on vulnerable populations. They also note that some people with disabilities may need to be accompanied if they require hospitalisation or a hospital visit, and recommend that they update and keep available their <u>health passport</u>.

HSE (2020) COVID-19 HSE Clinical Guidance and Evidence. Consensus Statement of Neurological Care during [the] COVID-19 Crisis¹⁸

This consensus statement by Irish neurologists provides guidance and recommendations in respect of the neurological care of patients including multiple sclerosis, epilepsy, muscular dystrophy, stroke and Parkinsons Disease. The statement emphasises the need to retain services for certain neurological conditions.

STROKE

Several papers report concerns about delays in seeking help when experiencing stroke symptoms.



<u>World Stroke Organisation (2020) The Global Impact of COVID-19 on</u> <u>Stroke: Survey Report from Prof. Marc Fischer, WSO President-Elect¹⁹</u>

In many countries, the volume of stroke/TIA admissions has decreased substantially. In a recent survey of large hospitals in China, stroke admissions declined by 40% in February 2020 during the height of the pandemic. Acute treatment was impacted as evidenced by an approximately 25% decline in the administration of IV thrombolysis and the performance of mechanical thrombectomy.

AHA/ASA Stroke Council (2020) Temporary Emergency Guidance to US Stroke Centers During the COVID-19 Pandemic On Behalf of the AHA/ASA Stroke Council Leadership²⁰

AHA/ASA Stroke Council ask that all participating stroke centers contribute their data to a central database vigilantly to document any decrement in stroke volume. The Council also encourages stroke leaders and advocates to work with local media and public marketing to encourage patients to continue seeking emergency care if experiencing acute stroke symptoms. This guidance notes that emergency response to Code Stroke may be affected by both lack of PPE equipment and of trained staff in Emergency Department and inpatient units. Full adherence may be challenging, but the Council recommended that required treatment should be offered to the greatest extent possible.

See also:

Markus, (2020) COVID-19 and Stroke: A Global World Stroke Organization Perspective²¹

Zhao, (2020) Challenges and Potential Solutions of Stroke Care During the Coronavirus Disease 2019 (COVID-19) Outbreak²² Derraz, (2020) Stroke Health Care Use and COVID-19²³

Meyer (2020) A Stroke Care Model at an Academic, Comprehensive Stroke Center During the 2020 COVID-19 Pandemic²⁴

In this new clinical pathway, recommendations include telestroke assessments as a specific option for all inpatient and outpatient encounters and accounts when telemedicine systems are not available or functional; and the complete conversion of daily inpatient stroke rounds on hospitalized stroke patients to virtual rounds. This adapted stroke code model maintains the rapid care required in acute stroke care to reduce treatment delays.



Royal College of Physicians (2020) Clinical guide for the management of stroke patients during the coronavirus pandemic²⁵

NHS guidelines for stroke care also recommends incorporating telehealth. Many stroke specialists will have dual or triple accreditation in general medicine and/or geriatrics and may be released to work on the frontline. An overview of rehabilitation pathways is also included.

Prvu Bettger (2020) COVID-19: maintaining essential rehabilitation services across the care continuum₂₆

The need for, and the effect on rehabilitation facilities are highlighted. They also advocate for the removal of any barriers to remote/telerehabilitation.

<u>Negrini (2020) Up to 2.2 Million People Experiencing Disability Suffer</u> <u>Collateral Damage Each Day of COVID-19 Lockdown in Europe⁸⁰</u>

35 countries responded to a 9-question survey on the impact of COVID-19 on people experiencing disability in Europe. Cessation of admissions to rehabilitation, early discharge and reduction of activities involved 194,800 inpatients in 10 countries. Outpatient activities stopped for 87%, involving 318,000 patients per day in Italy, Belgium and the UK, leading to an estimate range of 1.3 to 2.2 million people in Europe. 7 countries reported negative experiences on rehabilitation services for acute COVID-19 patients.

Baracchini (2020) Acute stroke management pathway during Coronavirus-19 pandemic²⁷

In addition to creating a dedicated hotspot as a pre-triage just outside the Emergency Department, together with the Neuroradiology Unit we obtained a mobile CT unit that could be used by COVID-positive or COVID-suspected patients. Throughout this suggested pathway, the stroke team is responsible for the stroke care of the patient.

See also:

Leira (2020) Preserving stroke care during the COVID-19 pandemic: potential issues and solutions²⁸



MULTIPLE SCLEROSIS

Bonavita (2020) Digital triage for people with multiple sclerosis in the age of COVID-19 pandemic²⁹

During the COVID-19 pandemic, neurologists involved in the care of people with multiple sclerosis [pwMS] face a particular challenge since many of these patients: 1. are on an immunotherapy; or 2. belong [] due to their disability and/or comorbidities [] to the vulnerable proportion of the population, or both. While careful surveillance is required of pwMS who belong to these categories, they should be kept away from the hospital or outpatient clinics to minimise their risk of COVID-19 infection. A digital triage tool is described.

<u>Willis (2020) Multiple sclerosis and the risk of infection: considerations in</u> <u>the threat of the novel coronavirus, COVID-19/SARS-CoV-2³⁰</u>

In this study, exposure to a second generation disease modifying therapy (DMT) was associated with an increase in the risk of infection, particularly with regard to natalizumab. First generation DMTs were not associated with an increased risk. Of note, IFN- β was associated with a lower risk of pneumonia which the authors speculate could be due to its anti-viral effect. The reason for the increased risk of upper respiratory tract infections with second generation DMTs and in particular natalizumab is unknown. It is acknowledged that the relatively small number of patients taking second generation DMTs may have limited the detection of differences.

Mansoor (2020) COVID-19 pandemic and the risk of infection in multiple sclerosis patients on disease modifying therapies: "what the bleep do we know?"³¹

Multiple sclerosis patients who are on disease modifying therapies (DMTs) might be at a higher risk of acquiring a poorer outcome due to their immune status. This review looks at the available evidence in managing this global crisis.

<u>Giovannoni (2020) The COVID-19 pandemic and the use of MS disease-</u> modifying therapies³²

Patients with confirmed COVID-19 infection: Withhold any first or secondline DMT until clinical resolution and/or approval to continue treatment by an infectious disease specialist. Note: given the potential antiviral activity of



beta-interferons, the decision to continue this treatment rests with the treating neurologist.

If the public health measures being taken flatten the peak of the epidemic, but extend its tail, the problem of community-acquired SARS-CoV-2 infection and COVID-19 may be with us for many months and potentially years. Are the SIN guidelines compatible with the best interests of our patients or a kneejerk response to an undefined problem that may not be a problem at all? The authors provide a table assessing the potential risks associated with different DMTs.

Brownlee (2020) Treating multiple sclerosis and neuromyelitis optica spectrum disorder during the COVID-19 pandemic³³

In this commentary we highlight the implications of COVID-19 for people with MS and related disorders, including the risk of respiratory infections, general health advice, and recommendations from consensus-based guidelines for immunotherapies, relapse management and service delivery during the COVID-19 pandemic.

Naser Moghadasi (2020) One Aspect of Coronavirus disease (COVID-19) Outbreak in Iran: High Anxiety among MS Patients³⁴

This paper highlights the potential for increased anxiety to exacerbate the severity of the disease in MS patients. It is well-acknowledged that anxiety is one of the leading causes of attacks among the MS patients and can also exacerbate this disease.

<u>Novi (2020) COVID-19 in a MS patient treated with ocrelizumab: does</u> <u>immunosuppression have a protective role?³⁵</u>

This single case report looks at the possible protective role of immunosuppression.

Sormani (2020) An Italian programme for COVID-19 infection in multiple sclerosis³⁶

In this pilot phase of an investigation of COVID-19 among people with multiple sclerosis, the authors investigate whether immunosuppressive therapies, the mainstay of treatment for multiple sclerosis, might confer additional risks or \Box on the contrary \Box protection.

Two clinical trials are currently underway investigating MS and COVID-19:



The United Kingdom Multiple Sclerosis Register COVID-19 Substudy (UKMSRCV19)³⁷

The aim of the study is to understand the impact of COVID-19 on people with Multiple Sclerosis in the United Kingdom.

Epidemiological Characteristics of COVID-19 in Patients With MS or NMO (COVISEP)³⁸

The purpose of this study is to collect French medical data for patients with Multiple Sclerosis or NeuroMyelitis Optica spectrum disorder who are diagnosed or strongly suspected of being infected with COVID-19.

Several papers consider a possible link between COVID-19 and Guillain-Barre Syndrome:

Scheidl (2020) Guillain-Barre syndrome during SARS-CoV-2 pandemic: a case report and review of recent literature³⁹

"Our case draws attention to the occurrence of GBS also in patients with COVID- 19 who did not experience respiratory or general symptoms. It emphasizes that SARS- CoV- 2 induces immunological processes, regardless [of] the lack of prodromic symptoms. However, it is possible that there is a connection between the severity of the respiratory syndrome and further neurological consequences."

See also:

Zhao, (2020) Guillain-Barré syndrome associated with SARS-CoV-2 infection: causality or coincidence?⁴⁰ Toscano (2020) Guillain-Barré Syndrome Associated with SARS-CoV-2⁴¹ Virani (2020) Guillain-Barré Syndrome associated with SARS-CoV-2 infection⁴² Coen (2020) Guillain-Barré Syndrome as a Complication of SARS-CoV-2 Infection⁴³ Marta-Enguita (2020) Fatal Guillain-Barre syndrome after infection with SARS-CoV-2⁴⁴



SPINAL INJURY

Palipana (2020) COVID-19 and spinal cord injuries: the viewpoint from an emergency department resident with quadriplegia⁴⁵

Spinal cord injuries (SCIs) present distinct physiological and social considerations for the emergency physician. During the COVID-19 pandemic, these considerations may generate unique challenges for emergency physicians managing patients with SCIs. Physiological disruptions may alter the way SCI patients present with COVID-19. The same disruptions can affect management of this vulnerable patient group, perhaps warranting early aggressive treatment.

<u>Gil-Agudo (2020) Clinical features of coronavirus disease 2019 (COVID-19)</u> <u>in a cohort of patients with disability due to spinal cord injury⁴⁶</u>

A cohort analysis of seven patients with SCI infected by COVID-19. (non peer-reviewed, Pre-Print).

Stillman (2020) COVID-19 and spinal cord injury and disease: results of an international survey⁴⁷

This survey of the international spinal cord medicine community showed substantial variability in COVID-19 screening practices and availability of screening kits. People living with SCI/D are expressing legitimate and real concerns about their vulnerability to COVID-19. Concerns included vulnerability to infection (76.9%) and fragility of caretaker supply (42%).

Spinal Injuries Ireland (2020) Important notice – coronavirus⁴⁸

SI Ireland cancelled all face-to-face meetings with patients: "This means that our outreach team will not meet service users in person, nor meet in their homes, hospital settings, at regional meetings [or] at training programmes."

MUSCULAR DYSTROPHIES

<u>Veerapandiyan (2020) The care of patients with Duchenne, Becker, and</u> <u>other muscular dystrophies in the COVID- 19 pandemic⁴⁹</u>

We address issues surrounding corticosteroid and exon skipping treatments, cardiac medications, hydroxychloroquine use, emergency/respiratory care, rehabilitation management and the conduct of clinical trials. We highlight the importance of collaborative treatment decisions between the patient,



family and health care provider, considering any geographic or institution specific policies and precautions for COVID-19. We advocate for continuing multidisciplinary care for these patients using telehealth.

INTELLECTUAL DISABILITY

Trinity College Dublin (2020) [News Article] People with an intellectual disability vulnerable to adverse outcomes of COVID-19 warns Trinity expert⁵⁰

Facts and Health risks for people with an intellectual disability:

- Extremely high prevalence of multimorbidity in adults with intellectual disabilities across the entire adult life course<u>.</u>
- IDS-TILDA identified multimorbidity for 71% of the older intellectual disability (ID) population in Ireland.
 - This is higher than rates reported in the general older population and it starts at an earlier age (59%).
- Mulitmorbidity starts earlier and increased with age:
 - 63% in those aged 40–49 years to
 - 72% in those aged 50–65 years and
 - 86% in those aged 65 years and older
- Prevalence of eye disease, mental health disease, endocrine disease, joint disease, hypertension, cancer and stroke increased with age for people with ID.
- Multimorbidity is highest among those with more severe levels of intellectual disability.
- Having >4 chronic conditions was associated with Down syndrome.
- Older people with Down syndrome are particularly at risk many having pre-existing cardiovascular and respiratory problems, confounded by a 55% risk of dementia in those age 55+ increasing to 88% in those age 65 years and older.
- Women with ID are at a higher risk of multimorbidity than men.
- The most prevalent multimorbidity pattern was mental health/neurological disease.

<u>Trinity College Dublin (2020) Timely and appropriate COVID-19 care</u> <u>urgent for people with an intellectual disability⁵¹</u>

Older people with ID have smaller social networks and fewer social supports than the general population. Disruption to their routines and contacts due to



COVID-19 places them at greater risk for social isolation and loneliness, potentially leading to poorer mental health outcomes. For those living at home with an ageing parent, themselves among the highest COVID-19 risk groups, Professor McCarron said: "There is a real worry about what might happen if someone in the house becomes ill. And that's why it is so important to put support in place so that health services can act quickly and appropriately to increase the chances of full recovery."

Courtenay (2020) COVID-19: challenges for people with intellectual disability⁵³

The letter discusses the fact that people with intellectual disability are vulnerable to COVID-19 as they depend on support in their everyday lives. He also mentions the challenge being faced by people with intellectual disability and their carers, including access to information, infection control, reduction of support due to physical distancing public health measures. Psychiatrists working with people with intellectual disability are seeing a rise in requests for psychotropic medication to support people and to assist families and carers manage behaviours that are challenging to them. Self-isolating or shielding a person with intellectual disability for 12 weeks is an immense challenge for families and services, especially when such support might contravene a person's human rights and liberty.

Hatton (2020) [Blog] Potential risk factors for the impact of COVID-19 on health: people with learning disabilities⁵⁴

In his blog, Chris Hatton highlights increased comorbidities especially in people with profound and multiple learning disabilities. Important concerns for these people include tube feeding and higher rates of epilepsy.

Reilly (2020) A complex challenge: Disability services respond to COVID-19⁵⁵

Citing Mark O'Connor, Community Engagement Officer at Inclusion Ireland, highlights the worry and disruption to routine involved when a person with intellectual disability has to go to hospital.



DOWN SYNDROME

Reilly (2020) A Complex Challenge: Disability Services Respond to COVID-19⁵⁶

It is not yet known if people with Down syndrome are significantly more vulnerable to contracting COVID-19. However, they are vulnerable to other respiratory viruses such as respiratory syncytial virus (RSV), according to Down Syndrome Ireland.

"We do know that they may be less able to tell us when they are sick, and that they may not show typical symptoms. People with Down syndrome may have abnormal temperature regulation and may also experience difficulty recognising and communicating that they are unwell."

SENSORY DISABILITIES

<u>Trecca (2020) [Letter] COVID-19 and hearing difficulties⁵⁷</u>

Key issues for people with hearing loss are postponement of treatment; communication difficulties associated with face masks; and discomfort in patients wearing hearing devices with face masks.

Pattisapu (2020) Defining Essential Services for Deaf and Hard of Hearing Children during the COVID-19 Pandemic⁵⁸

Health care providers must determine what procedures are considered elective, balancing risk of treatment delays with that of coronavirus exposure to the patient, family and providers. Cognizant of critical periods for language development and the long-term impact of auditory deprivation, some audiologic and otologic services should be considered essential.

<u>West (2020) Providing health care to patients with hearing loss during</u> <u>COVID-19 and physical distancing⁵⁹</u>

Provides recommendations on treating patients with hearing loss, including the use of technology such as speech-to-text software.

Armitage (2020) The COVID-19 response must be disability inclusive⁶⁰ The authors propose the use of transparent face masks to permit lipreading.



RESIDENTIAL CARE

<u>Health Service Executive Disability Services (2020) Guidance for COVID-19</u> <u>in Nurse Led Residential Care Services for People with Disabilities⁶¹</u>

This document provides in-depth guidance for nurses in a residential care setting, including recommendations on visitors. The document also states:

- 3.1 Appoint designated staff to care for COVID-19 residents for each shift. The service should maintain a log of all staff members caring for service users with COVID-19.
- 3.2Ideally care equipment should be dedicated for the use of an individual. If it must be shared, it must be cleaned and disinfected between use.

<u>Tseng (2020) The Impact of the COVID-19 Pandemic on Disabled and</u> <u>Hospice Home Care Patients⁶²</u>

When performing invasive treatments such as the replacement of tracheostomy or nasogastric tubes, we recommend wearing a face mask and a protective gown to avoid being splattered by secretions.

ENVIRONMENTAL ISSUES

Lakhani (2020) Which Melbourne Metropolitan Areas Are Vulnerable to COVID-19 Based on Age, Disability, and Access to Health Services? Using Spatial Analysis to Identify Service Gaps and Inform Delivery⁶⁴ Spatial analysis was used to identify and address gaps in service.

Health Protection Surveillance Centre (2020) Education programme: COVID-19 Infection Prevention and Control Guidance for Home visits⁶⁵ This document provides guidance for support staff and carers when visiting a client's home.

Sullivan (2020) COVID-19: Guidance for Prevention and Care, a guide for care providers of people with intellectual and developmental disabilities⁶⁶

Among other recommendations, the authors suggest that modifications may be needed for people with IDD for physical or social distancing, especially in residential settings.



Jalali (2020) COVID-19 and disabled people: perspectives from Iran⁶⁷

This report highlights the closure of services. Day care and nursing care centres administered by the Iranian government, NGOs and the private sector are crucial sources of care for people with disabilities after their families. Since the coronavirus pandemic, many of these facilities have reduced their activity in terms of personnel or working hours or even completely closed.

<u>Qi (2020) Including people with disability in the COVID-19 outbreak</u> emergency preparedness and response in China⁶⁸

Many service providers that were specifically targeted for people with disabilities have been closed. LPTID [Law on Prevention and Treatment of Infectious Diseases] lacks provision of alternatives for people with disabilities during such events. With limited accessible transportation, it is predictable that people with disabilities have a lower chance of obtaining assistance from their community or friends.

OLDER PEOPLE

UN Department of Economic and Social Affairs Disability (2016) Ageing and Disability⁶⁹

Currently, it is estimated that 15% of the population worldwide or some 1 billion individuals live with one or more disabling conditions. More than 46 per cent of older persons [] those aged 60 years and over [] have disabilities and more than 250 million older people experience moderate to severe disability.

National Disability Authority (2006) Ageing & Disability: A Discussion Paper⁷⁰

The 2002 Census in Ireland showed 136,000 people with disabilities over the age of 65. This represents 42% of the disabled population and more than one-third of people over 65. The population aged 65 and over in Ireland could increase from its present level of 436,000 to about 1 million in the next thirty years. The population aged eighty years and over is projected to increase three-fold in the same period, to over 300,000."



OTHER [NEWS ITEMS, MAINLY FROM PEOPLE WITH SENSORY DISABILITIES]

BBC News (2020) Coronavirus: Being blind during the pandemic⁷¹

"As someone who cannot see, I have to touch objects and surfaces much more than your average person."

"Added to these obvious hygiene problems, it's also harder to find a bathroom or alcohol gel point when you want to wash your hands."

"A trip to the supermarket is difficult: holding a week's shop in one hand and a white cane in the other makes navigating a challenge."

In store shopping is difficult as help is needed getting items: "I guess it was a contact thing, because of having to take someone's arm for guiding." Online shopping is also difficult: "Normally I get a delivery, but all the slots have been taken."

The Conversation (2020) What coronavirus crisis means for blind and partially sighted people⁷²

"Anna was struggling to get her usual supermarket delivery slot as blind and partially sighted people in the UK are not classified as <u>clinically extremely</u> <u>vulnerable</u> so are not automatically entitled to food parcels, priority supermarket deliveries or help with basic care needs."

<u>Murray (2020) Face masks and social distancing mean it's harder for deaf</u> <u>community to communicate during COVID-19 crisis⁷³</u>

"Grocery shopping, conversing with frontline workers and ringing a GP to make an appointment are all more difficult for members of this community right now, according to national charity CHIME.

Furthermore, the use of PPE such as face masks and plastic partitions coupled with two-metre social distancing are all making lip-reading and conversation more challenging, if not impossible.

CHIME is concerned that due to an apparent low number of sign language interpreters being booked for COVID-19 tests, the number of deaf people being tested is lower than that of the wider population."

Irish Deaf Society (2020) Coronavirus Irish Sign Language Support⁷⁴

The Irish Deaf Society have developed a series of videos summarising key restriction measures as well as signs for core COVID-19 terms.



Pulrang (2020) [Editorial] 5 Things To Know About Coronavirus And People With Disabilities⁷⁵

This article in Forbes highlights shopping, transport, hygiene issues and isolation issues "For one thing, some disabled people can't isolate themselves as thoroughly as other people because they need regular, hands-on help from other people to do everyday self-care tasks. Also, laying in supplies of groceries can be difficult for some disabled people to do, when shopping of any kind is always extra taxing, and they rely on others for transportation. For some of us, even cleaning our homes and washing our hands frequently can be extra difficult due to physical impairments, environmental barriers or interrupted services."

Pineda (2020) Disability, Urban Health Equity, and the Coronavirus Pandemic: Promoting Cities for All⁷⁶

"Persons with disabilities (PWDs) living in cities during the COVID-19 pandemic response may be four times more likely to be injured or die than non-disabled persons, not because of their 'vulnerable' position but because urban health policy, planning and practice has not considered their needs ... We suggest that the current pandemic be viewed as an opportunity for significant urban health reforms on the scale of the sanitary and governance reforms that followed ninetieth century urban epidemics. This perspective offers insights for ensuring the twenty-first century response to COVID-19 focuses on promoting more inclusive and healthy cities for all."

Brennan (2020) NHS faces 'major problems' as charities contemplate withdrawing support⁷⁷

"Community fundraising has literally gone off a cliff. This makes the work we as health and care charities do unsustainable, which will cause a major problem for the NHS, but more importantly for the people we support. Where are people going to go with their information and advice needs if charities need to reduce their service offer?"

<u>Association for Higher Education Access and Disability (AHEAD) (2020)</u> <u>Learning from Home Report⁷⁸</u>

This survey aims to shine a light on the reality for students with disabilities on the ground who are doing their best to continue learning 'as normal' in a situation that is far from it. The report hopes to authentically gather the experiences of learners with disabilities and bring their voice to the decision-



making process about our response as a sector and a nation. It seeks to use the use the voice of learners to highlight key challenges and issues which we can collectively address together: government bodies, institutions, ETBs, teaching staff and independent bodies all have a role to play in responding effectively.

Association for Higher Education Access and Disability (AHEAD) (2020) COVID-19 FET Practitioner Report⁷⁹

For learners with disabilities, many of whom are in the identified COVID-19 'at risk' categories, there are huge challenges in engaging in remote learning during this time and difficulties in how they access the support that is vital in their continuation and completion of FET programmes.

This survey report aims to shine a light on the difficulties that practitioners are experiencing in continuing to deliver those supports and their programmes more generally. It highlights key issues including a lack of engagement from a sizeable number of learners, a lack of continuity in the provision of disability support, difficulties for practitioners of juggling unfamiliar remote delivery with family responsibilities, a lack of practitioner experience with online delivery and the unsuitability of some programmes for online delivery.

Produced by the members of the National Health Library and Knowledge Service Evidence Team[†]. Current as at 15 MAY 2020. This evidence summary collates the best available evidence at the time of writing and **does not replace clinical judgement or guidance**. Emerging literature or subsequent developments in respect of COVID-19 may require amendment to the information or sources listed in the document. Although all reasonable care has been taken in the compilation of content, the National Health Library and Knowledge Service Evidence Team makes no representations or warranties expressed or implied as to the accuracy or suitability of the information or sources listed in the document. This evidence summary is the property of the National Health Library and Knowledge Service and subsequent re-use or distribution in whole or in part should include acknowledgement of the service.

The following PICO(T) was used as a basis for the evidence summary:

Population person person person condition/patient characteristic	PEOPLE WITH DISABILITY
Intervention length	CORONAVIRUS 2019 (COVID-19)
Comparison	
In a intervention	



The following search strategy was used:

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1

disability/ or adl disability/ or physical disability/ or attitude to disability/

2 (disab* or deaf* or multiple-sclerosis or muscular-dystrophy or autis* or parapleg* or quadripleg* or spinal-injur*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]

- 3 blindness/
- 4 cerebral palsy/
- 5 hearing impairment/
- б spine injury/
- 7 multiple sclerosis/
- 8 autism/
- 9 muscular dystrophy/
- 10 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9
- 11 coronavirus infection/
- 12 coronaviridae/

13 (covid-19 or (wuhan adj3 virus) or coronavirus or 2019-ncov).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating su! Bheading word, candidate term word]

14 ("2019" and (new or novel) and coronavirus).mp. [mp=title, abstract, heading word, DRUG TRADE NAME, ORIGINAL title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]

- 15 11 or 12 or 13 or 14
- 16 10 and 15

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National Health Library and Knowledge Service | Evidence Team





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