Updated Solent advice on supporting people with a learning disability around COVID-19

Introduction

As we gain further information and experience of COVID-19 we have changed our understanding of the needs of people with a learning disability and how best to support them. The following guidance is intended to support the key issues being experienced currently.

Context

Most people with a learning disability live with their families. If they move from home, they are likely to live in a "supported living" service. This is very different to a residential care home even though they may receive 24-hour staff support. The reason for noting this is because access to testing had not been available in supported living services in the same way it was in care homes. As of 23rd November 2020 the situation has changed and weekly testing is now available to carers working in other people's homes (A testing service for homecare workers in England - GOV.UK (www.gov.uk)

Unfortunately, we are aware that people with a learning disability also have poorer health, in general, compared to the general population. Early national reports have been released that raise a number of issues that need to be considered for patients with a learning disability.

The initial report, based upon 50 deaths, published in July 2020, drew a number of conclusions:

I. *Mobility impairments and/or mental health needs may be proxy indicators of people at risk of catching the virus, or may underpin prejudicial attitudes towards care, treatment and judgements about ceilings of care.*
II. *It would seem appropriate to consider people with learning disabilities and epilepsy as being at increased risk of death from the virus and pay attention to protecting them.*
III. *The key symptoms of COVID19 in the general population (fever, new continuous cough, loss of sense of smell or taste) may not be as apparent in people with learning disabilities.*
IV. *The use of DNACPR decisions and the initiation of palliative/end of life care should be monitored to ensure that this population is not being disadvantaged.*
V. *Close attention needs to be paid to safe and appropriate hospital discharge planning. One in five of the completed reviews indicated that the person had previously been discharged from hospital, only to be readmitted again soon afterwards.*

A wider study, of 206 deaths, has been recently published and the summary of the key findings are:

1. *People with a learning disability are likely to be younger when they die from COVID-19 than the general population. In the general population of England and Wales, 47% of deaths from COVID-19 were in people aged 85 years and over. Of all deaths of people with learning disabilities from COVID-19 notified to the LeDeR programme, just 4% were aged 85 years and over. As such age cannot be seen as an indicator of risk for people with a learning disability.*
2. *A third (35%) of those who died from COVID-19 lived in residential care homes, rising to almost half of those with Down's syndrome. A quarter (25%) lived in supported living*

settings. Priority must be given to supporting measures to prevent the spread of COVID-19 in these settings.

3. *People who died from COVID-19 were more frequently reported to have respiratory conditions (72%), compared to those who died from other conditions (60%).*
4. *The majority of those who died were not seen as being particularly vulnerable a significant number of people are thought to have been infected due to contact with others they lived with or staff. It is therefore critical that infection control measures are clearly understood, and followed, within all services for people with a learning disability.*
5. *Self-reporting common symptoms (e.g. loss of taste) of COVID-19 may be problematic for these patients and other indicators, lethargy and tiredness, may be more reliable. This will require asking carer's to be more vigilant in monitoring people's health status.*
6. *Access to healthcare that was problematic for some people who died from COVID-19 included: the responsiveness of NHS111; access to COVID-19 tests; and access to specialist learning disability nurses.*
7. *Reviewers noted in 21% of cases that the need for reasonable adjustments was indicated but such adjustments to service provision had not been made.*
8. *Some concerns were raised about the absence of tools (and the specific equipment required for these, such as oxygen saturation monitors) that can be used to detect acute deterioration in a person's health, particularly in primary care and community settings.*
9. *A wide variety of recommendations was made by reviewers in relation to preventing deaths from COVID-19. Some focused on the identification of illness and recognition of deterioration, including the use of specific deterioration tools such as the National Early Warning Score (NEWS2); paying particular attention to the concerns of families and paid carers about subtle signs that a person may be unwell; and the use of pulse oximeters in community settings*

A copy of the full report is available (http://www.bristol.ac.uk/media-library/sites/sps/leder/Deaths%20of%20people%20with%20learning%20disabilities%20from%20COVID-19.pdf) as is access to mortality data (https://www.england.nhs.uk/publication/covid-19-deaths-of-patients-with-a-learning-disability-notified-to-leder/).

Public Health England have separately reviewed this data (https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/933612/COVID-19__learning_disabilities_mortality_report.pdf) and concluded that:

- *People with a learning disability are 6 times more likely to die from COVID-19 compared to the general population.*
- *Those aged 18-30 were 30 times more likely to die*.

A summary leaflet is being developed to ensure all health professionals aware of these risks.

The following guidance is a local response to these findings as well as reflecting NHSE advise. (https://www.england.nhs.uk/wp-content/uploads/2020/11/C0843-Covid-LeDeR-report-131120.pdf)

Understanding vulnerabilities

People with a learning disability are more vulnerable to COVID-19 than the general public. When looking at the risk profiles for individuals please consider:

- Age, although people may become frailer in their health earlier. Public Health England recommend that we be extra vigilant of people over 55.
- Ethnicity.
- Whether they are classified as Clinically Extremely Vulnerable. This now includes people with Downs Syndrome. If you support someone with Downs Syndrome, they should have received a letter from their GP advising them that they are Clinically Extremely Vulnerable. Unfortunately, not everyone has received such a letter, if this is the case please contact the GP.
- Epilepsy
- Obesity
- Other long-term health conditions.
- Peoples ability to comply with the rules around "hands, face, space".

Understanding Symptoms

As well as looking for the core COVID-19 symptoms of

● *High temperature or fever (anything over 37.8ºC or above)*

● *New or continuous cough, this means coughing a lot for more an hour at a time or 3 or more episodes of coughing in 24 hours*

● *change to persons normal sense of smell or taste*

carers supporting people with a learning disability should also look for other signs of the person being unwell, especially tiredness and lethargy. It is better to be cautious so any early signs of a deterioration in the persons health, that cannot be explained by other long-standing health concerns, should be thought of as possible COVID-19 and testing sought.

Access to testing

Testing can be accessed by the national helpline (119), in order to get the most helpful response possible, the reporter should refer to the person as a "patient" rather than client (or similar), should be as clear as possible with regards to the symptoms being observed or reported (exact temperatures should be given and symptoms should not be minimised), explain that they live in a "care setting" with other vulnerable adults, and, that you are concerned about their health. By providing such information it is more likely that a positive response will be received.

Should there still be difficulties in accessing a test, or for those who cannot travel, then contact should be made with the regional Public Health Team (Hiow@phe.gov.uk) or the Community Testing Team (community.testing@nhs.net).

Immediate actions

Isolate symptomatic client away from others.

Once a test has been requested then steps should be taken for the person, and those they live with, to self-isolate.

If the test is positive the symptomatic individual isolates for 10 days from the start of symptoms. They should also be free from a temperature for 48 hours although other symptoms may persist. All contacts must isolate for 14 days from their last contact with infected person.

If the test is negative contacts no-longer need to isolate.

Carers may need to review the environment to reduce the risk of cross infection by restricting access to communal areas (e.g. kitchens).

Monitor the persons health status and contact emergency services should there be concerns.

If the person is defined as Clinically Extremely Vulnerable (e.g. people with Down's Syndrome) please inform their GP.

Cancel attendance at day services or similar explaining why.

Explain what you are doing, and why, to the people with learning disabilities who are affected.

Inform the persons family/support network. If they have visited family at any time within 48 hours before the symptoms developed, they must also commence 14 days isolation from date of their last contact with positive person.

Inform the person's GP.

Inform any other services the person uses.

Should contacts develop symptoms they must arrange a COVID-19 test themselves.

Consider preparing for a possible admission to hospital by reviewing the national resources, "COVID-19 grab and go", available at https://www.mencap.org.uk/advice-and-support/coronavirus-covid-19/coronavirus-information-about-going-hospital.

Access to test results

Any difficulties in accessing test results within a reasonable time (24 hours) should be highlighted to Solent's Infection Control Team (ipc@solent.nhs.uk) or 0300 123 6636 who may be able to access those for you.

Defining an outbreak

Outbreak definitions can be found here - https://www.gov.uk/government/publications/covid-19-epidemiological-definitions-of-outbreaks-and-clusters/covid-19-epidemiological-definitions-of-outbreaks-and-clusters-in-particular-settings . Essentially 2 or more cases in a setting where transmission has occurred within the setting is considered an outbreak. 14 days is the amount of time any close contact of a case need to self-isolate for.

Preventative measures

The best way to manage COVID-19 is to try and stop the infection before an incident. In order to promote this all services are required to observe the following measures:

- Ensure all carers observe the "hands, face, space" protocol. People with learning disabilities should be supported to understand and observe this also.
- Hand washing is crucial to reduce the risk of transmission. Regular use of alcohol hand rub or soap and water is effective against Covid19.
- Staff must observe national PPE guidance. This now requires them to wear Type IIR fluid resistant surgical masks whenever at work. Face coverings are no longer appropriate. Staff should wear masks even when not directly engaged in care tasks.
- Staff need to observe social distancing at all times including during breaks and/or travelling to and from work.
- It is important that we actively encourage service users to also wear masks to protect themselves, co-tenants, and carers. Information to support this is provided. The first link is information about how to support individuals with autism about becoming more comfortable with wearing masks and some tips to help – the second link is for a silicone guard that you can place inside the mask to stop it touching their face as much which can help.

https://www.autism.org.uk/advice-and-guidance/topics/coronavirus/going-out-and-shielding/face-coverings

https://www.amazon.co.uk/Silicone-Homemade-Comfortable-Breathing-Washable/dp/B08931ZQZC

- When staff are within 2m of a patient / service user who is not wearing a mask, they must be wearing full PPE including a surgical mask, visor, apron and gloves. If not and a patient becomes positive this will be viewed as a PPE breach and if the staff member was within 2m, for a cumulative time of 15 mins, they would be required to self-isolate for 14 days.
- Staff should change/wash clothes at 60 degrees or above when they arrive home from work.
- Staff must observe the "bare below the elbow" principle of infection prevention. This will enable effective hand hygiene practices.
- Staff who themselves experience COVID-19 symptoms must self-isolate and seek testing.
- The general environment including frequent touch points (door handles, light switches), shared pens, mobile phones, etc) must be frequently cleaned with a detergent and disinfectant that is effective against enveloped virus such as influenza virus H1N1 i.e. Clinell disinfectant wipes.
- People using services and staff should have their temperatures checked regularly.

- Please ensure people's health documents are up to date.
- Support influenza vaccination for all clients and staff
- Where possible, larger services should try and develop smaller social bubbles within services. For example, in houses for 6 or more people would it be possible to make 2 social bubbles of 3 people each. Could access to communal areas be staggered?

Reference documents

https://www.gov.uk/government/publications/supported-living-services-during-coronavirus-covid-19/covid-19-guidance-for-supported-living

https://www.gov.uk/government/publications/covid-19-supporting-adults-with-learning-disabilities-and-autistic-adults#history

https://www.gov.uk/government/publications/supported-living-services-during-coronavirus-covid-19

https://www.scie.org.uk/care-providers/coronavirus-covid-19/day-care

https://www.gov.uk/government/publications/personal-protective-equipment-ppe-illustrated-guide-for-community-and-social-care-settings

https://www.gov.uk/government/publications/covid-19-how-to-work-safely-in-domiciliary-care

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24.11.2020