

People with intellectual disabilities, Covid-19, and end-of-life care



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People with intellectual disabilities and death



The Learning Disabilities Mortality Review
(LeDeR) Programme

Median age at death: 59

Most common cause of death:

Pneumonia 25%

Aspiration pneumonia 16%

Our advice for clinicians on the coronavirus is [here](#).
 If you are a member of the public looking for health advice, go to the [NHS website](#). And if you are looking for the latest travel information, and advice about the government response to the outbreak, go to the [gov.uk website](#).

Covid-19 deaths of patients with a learning disability notified to LeDeR

| Week of death | All deaths in period | Number of Covid-19 related deaths in period |
|--|----------------------|---|
| Up to 20-Mar ¹ | 240 | 10 |
| Week ending 27-Mar | 105 | 40 |
| Week ending 03-Apr | 160 | 85 |
| Week ending 10-Apr | 170 | 110 |
| Week ending 17-Apr | 185 | 120 |
| Week ending 24-Apr | 115 | 75 |
| Week ending 01-May | 105 | 50 |
| Week ending 08-May | 70 | 25 |
| Week ending 15-May | 60 | 25 |
| Week ending 22-May | 65 | 20 |
| Week ending 29-May | 50 | 15 |
| Week ending 5-Jun | 45 | 15 |
| Week ending 12-Jun | 25 | 10 |
| Total | 1395 | 590 |
| Date of death not yet known ² | 30 | 15 |
| Total | 1425 | 605 |

Breakdown of deaths by pre existing conditions:

| Date introduced | Condition | Count of condition | Count of unknown or not reported for condition | Count of all deaths since condition introduced | % of deaths since introduced with condition | % of deaths (excluding unknown or not reported) with condition |
|-----------------|--|--------------------|--|--|---|--|
| 24-Mar | Received treatment for a Mental Health condition | 1,163 | 8,371 | 28,137 | 4% | 6% |
| 24-Mar | Learning Disability and or Autism | 506 | 6,899 | 28,137 | 2% | 2% |

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Statistics

Statistical work areas

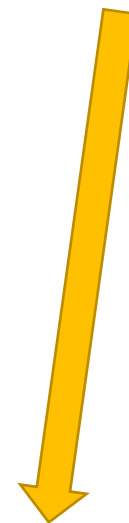
COVID-19 Daily Deaths

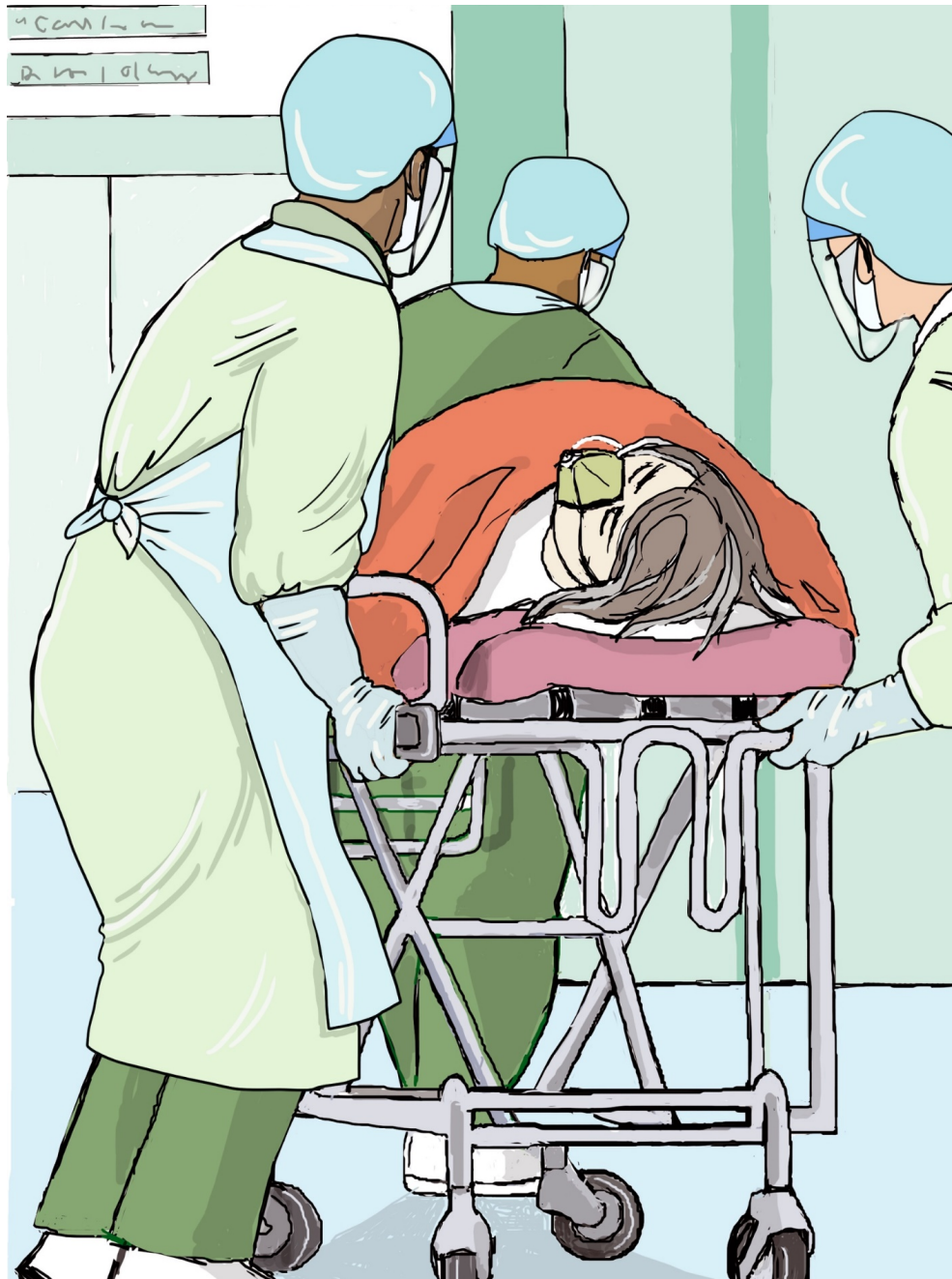
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COVID-19 Daily Deaths

This section contains information on deaths of patients who have died in hospitals in England and had tested positive for COVID-19 or where COVID-19 was mentioned on the death certificate. All deaths are recorded against the date of death rather than the date the deaths were announced.

The Daily file contains only deaths from the latest reporting period, 5pm 2 days prior to publication until 5pm the day before publication. The Total file contains all reported deaths.





Clinical Frailty Scale



1 Very Fit – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.



2 Well – People who have no active disease symptoms but are less fit than category 1. Often, they exercise or are very active occasionally, e.g. seasonally.



3 Managing Well – People whose medical problems are well controlled, but are not regularly active beyond routine walking.



4 Vulnerable – While not dependent on others for daily help, often symptoms limit activities. A common complaint is being “slowed up”; and/or being tired during the day.



5 Mildly Frail – These people often have more evident slowing, and need help in high order IADLs (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.



6 Moderately Frail – People need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing.



7 Severely Frail – Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).



8 Very Severely Frail – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.



9 Terminally Ill – Approaching the end of life. This category applies to people with a life expectancy <6 months, who are not otherwise evidently frail.

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

Learning Disability England

Stronger, Louder, Together!

Search ...

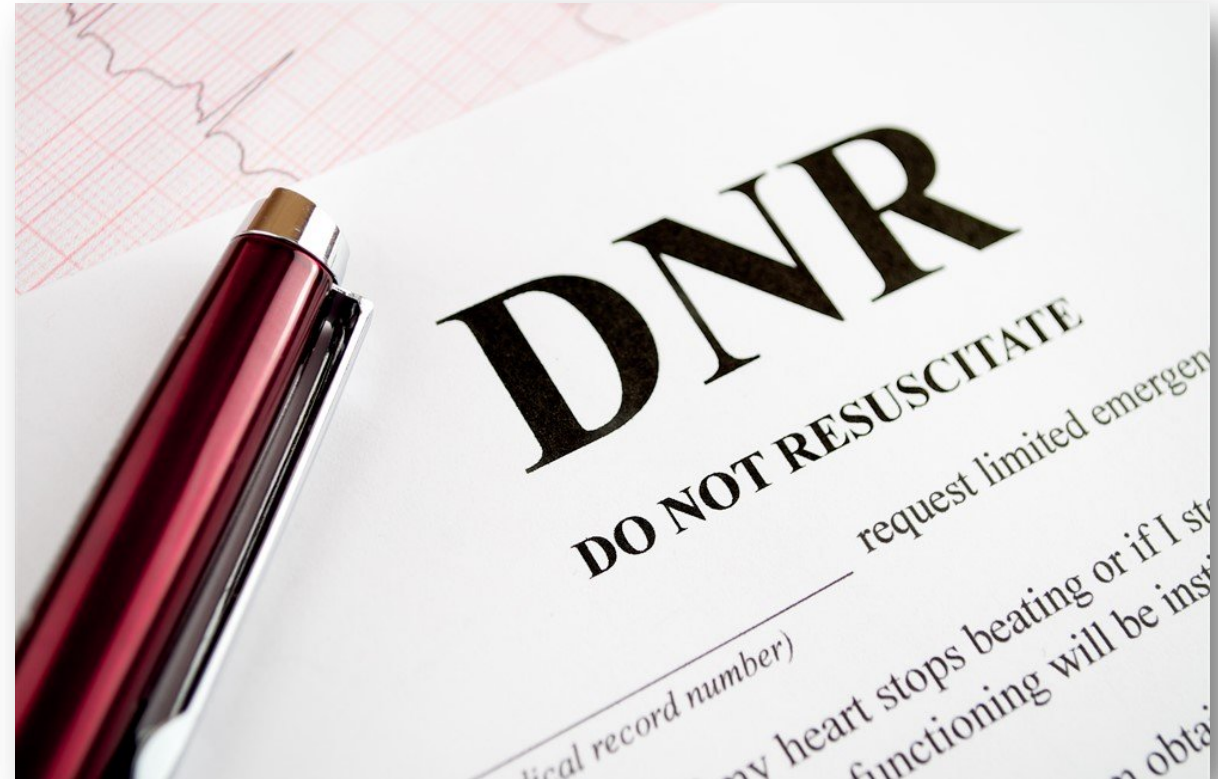
Disabled People's Rights, DNAR and Covid19



[Return to Resources That Can Help](#)

Learning Disability England has joined voices with Over 70 other disabled people's organisations and allies in an Open Letter supporting a [Statement about the rights of disabled people during Covid 19](#).

We are all concerned about recent media coverage and letters from GPs about DNAR.





Equal treatment
does not mean
the same treatment!



Provide
reasonable adjustments...



...or remove the barriers
(the source
of the inequity)



PCPLD Network

Palliative Care for People with Learning Disabilities

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WELCOME

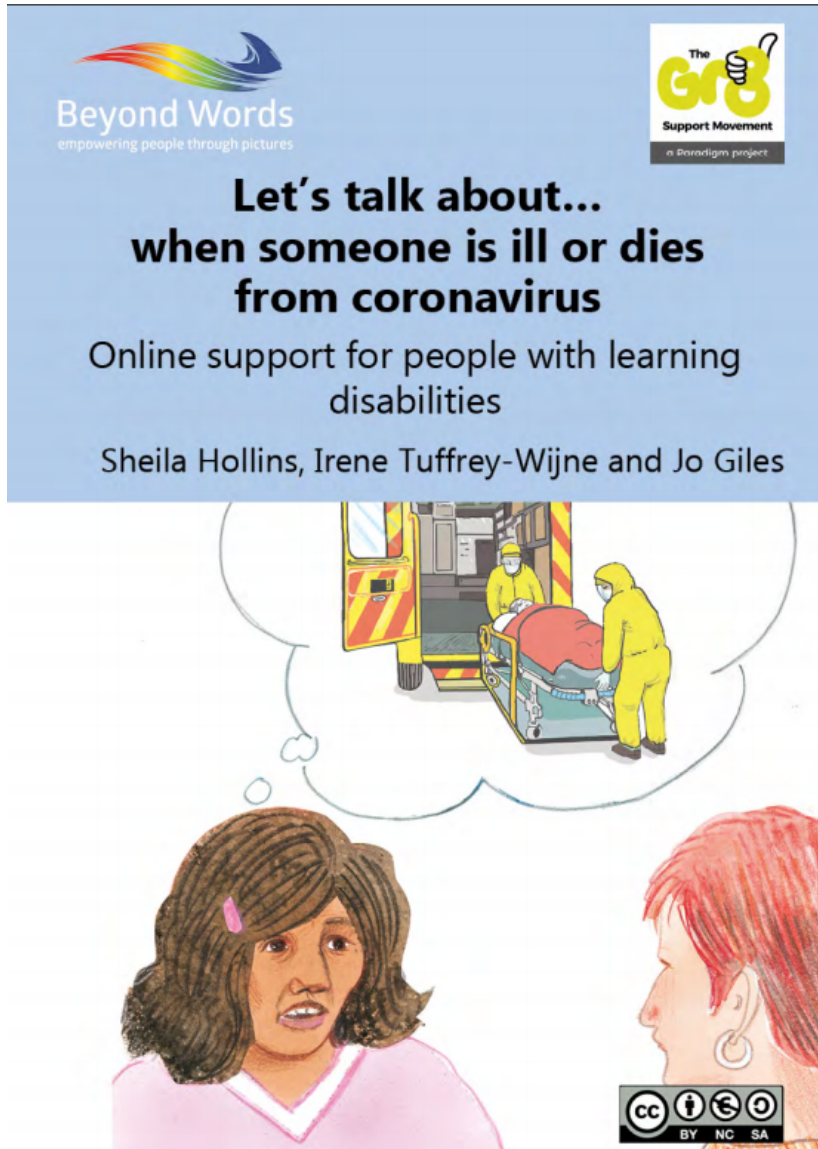
to the PCPLD Network

[Become a member](#)

We aim to raise awareness of the palliative care needs of people with learning disabilities, to share and promote 'best practice' and to enhance collaboration between all services providers, carers and people with a learning disability.

Coronavirus (COVID-19)

We have added [useful information and resources](#) in relation to supporting people with learning disabilities around coronavirus. Coping with death, dying and bereavement at a time of social isolation, and making decisions around care and treatment, is especially



www.tuffrey-wijne.com

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