FAO: David at BBC

Access to life-saving treatment/prioritisation for health care/do not resuscitate

1. Inclusion Scotland survey

Respondents are very worried about the possibility that they will be denied treatment because of their impairment(s). Some respondents also had experience of being asked about DNR notices. This is having significant impacts on mental health.

- I am extremely anxious about the impact of C-19 and my greatest fear is that, if I were to experience complications from the virus and require admission to hospital, as a disabled person I would not receive the same care that I would as an able-bodied person. I am worried that my life is viewed as less valuable because I'm a wheelchair user and that if resources are scarce, I would be at the back of the queue.

- I fully expect to be left to die should I contract Covid19. I feel I would be also left without assistance should I have a severe asthma attack and be hospitalised for it even though it would not be Covid19

- I want to know if I will get a ventilator if required if I contract Corona19 I am extremely worried (outraged) that treatment may be denied people based on disability and age.

- I am very worried about reports of forced DNRs and the idea that because I am over 40 and have asthma I might be denied care. Concerned about DNR I have been told already that I would not be ventilated. I was in hospital last week with suspected covid19 and the doc stated I would not be treated. There is no dnr in file but this was put in my discharge letter. I feel written off before I start
  I hope I don't die.

- Although no one has contacted us with regards to her being extremely vulnerable. We already had been 'sheilding' weeks before it was suggested. I'd been hearing a out DNR being suggested for people deemed less likely to survive . And was horrified .

- I was contacted by my GP who was making sure I was aware thatI was at very high risk and following guidelines. I was also asked to give permission to DNR medical files. I agreed to this without realising it could mean that I wasn't offered treatment. This has impacted negatively on my mental health .

- No disabled people should be treated as collateral damage during this situation be that through lack of ventilators, lack of social care, lack of information or being ignored by any policy designed at this time. Orgs that speak for us shouldn't be scared to do that, we will thank you for it during and after this is all over!

- Constant worry about my son's worth - disabled and old people seem to be treated like second hand life worthless people. My friend had first hand experience of this last week when her disabled son died of covid. He was written off in the first few minutes by doctors - and he is a healthy disabled person like my son - both have cp

2. Lived experience and opinions from social media

DATE: 01/04/20
SOURCE: Twitter
ISSUE: Last week my brother was admitted to A&E with a severe chest infection. A bed in intensive care was requested. As someone who lives in a care home with limited mobility and slow cognitive response he didn't make the pandemic led prioritisation cut. He died at 6.10 this morning.

DATE: 02/04/20
SOURCE: Twitter
ISSUE: Thinking of a friend who lost her son today. A young adult with cerebral palsy, drs told her they wouldn't intubate him. The absolute horror you live with as a parent of a child with disability.

DATE: 02/04/20
SOURCE: Facebook
ISSUE: Hi, this is just a message in response to your post about do not resuscitate/ who has access to ventalators etc with coronavirus. I'm really concerned about this. Consultant for local hospital (also over all in charge of hospital) has been commenting on his twitter feed that he will use the frailty scale of if you need care etc to decide who gets help and expect to be asked this. Particularly concerning is he said that this shows how much value people have for the community. I feel this is a

concerning narrative for disabled people and assumes we have no value and can't be 'useful'- worrying if this is the idea not just with coronavirus but in general. Surely equipment if is between one person and another should be 'who is mostly likely to survive with this equipment' rather than out of date ableist views.

DATE: 02/04/20
SOURCE: Facebook
ISSUE: I've seen NICE guidelines [and the wishy washy update to these guidelines] and also someone with my condition got a letter about who is getting priority for ventilation based on current lung function. If I get Covid 19 and have serious symptoms I'm dead - the NHS isn't gonna save me.

DATE: 02/04/20
SOURCE: Facebook
ISSUE: I have chronic pain. I was once told by a Consultant to either find a way of living with or get a gun and 'you may as well shoot yourself.' Much as I support medics some drs and nurses can be right nasty. Takes all kinds I suppose.

DATE: 02/04/20
SOURCE: Facebook
ISSUE: I'm scared now 😔. I have a learning and physical disability along with other autoimmune health problems.

DATE: 02/04/20
SOURCE: Twitter
ISSUE: @nicolasturgeon Can you please answer whether Scotland has a policy of DNR for adults with learning disabilities when they are hospitalised with suspected or confirmed Covid 19. Thanks.

DATE: 03/04/20
SOURCE: Twitter
ISSUE: Devastated to hear that people with learning disabilities as well as elderly people are being included in DNR's....inhumane b*stards in UK gov still pushing their eugenics ideology...1 person with a learning disability is worth a billion of Tory eugenicists...FFS never vote Tory

DATE: 03/04/20
SOURCE: Twitter

ISSUE: I heard yesterday that this is being applied in a blanket way across care facilities in Scotlanf..certainly in case of one major provider.. i understand GPs are calling ppl to basically say that DNR is on your record...families not involved in any discussions,...worse if guardianship is in place. This cannot be allowed to continue....our families are not cannon fodder.

DATE: 03/04/20
SOURCE: Twitter
ISSUE: It's purely anexdotal but one major support provider was phoning families. GPs speaking to ppl..heard also it had happened at a care home in Fife. Another care home in West.but family fought back.

DATE: ?
SOURCE: Twitter
ISSUE: Carer in West of Scotland told me that GP called yesterday re DNR. TO fill in form over phone will ill hustabnd. She was devastated last night. He refused DNR…but I'd like to know if those wishes are followed.

DATE: 03/04/20
SOURCE: Twitter
ISSUE: This is a copy of a letter that every patient over the age of 40 received from our GO Practice, it's not just the elderly or vulnerable

Dear patient,

If you or a family member are anxious due to frailty / risk factors for severe COVID-19 disease, we ask you to please seriously consider the following information.

We know this is an uncomfortable topic, but it is also critical to ensuring that our patients are in control should the worst happen.

We are sharing these resources to empower you and your family, and ensure you are prepared for all eventualities which will be faced by many in our population in the forthcoming weeks and months.

Advance Directives (Health Improvement Scotland)	https://bit.ly/2QElh3h
Advance Directives (Age Scotland)	https://bit.ly/33J2edE
End of life care (Scot Gov)	https://bit.ly/33JXkNj
Do Not Attempt Resuscitation Orders (NHS)	https://bit.ly/3agv4o3

*(note: the signing of this document **does not** mean you will not be treated. It only means that you help make the decision relating to final intervention, rather than passing this on to your next of kin or welfare power of attorney to make)*

How to organise Power of Attorney (My Gov)	https://bit.ly/2JcKnSQ
How to organise a Will (Law Society Scotland)	https://bit.ly/39j5GwG

Ideally conversations would happen in person, in a relaxed manner by the doctor who knows you best. In these current times this is not necessarily possible. We want you to be prepared ahead of a scenario when you or someone you love already have symptoms of COVID-19 and are deteriorating.

Information gathered by us can be very useful to our doctor colleagues in hospitals. We share important 'Special Notes' electronically so that it is clear these conversations have happened already e.g. whether somebody would wish to be looked after at home or admitted to hospital, whether a DNAR form has been completed.

It's better to have these difficult discussions now with your family and doctor whilst you are in control.

We see countless cases where people have not settled their affairs or planned for the worst case scenario, and the outcome and aftermath can be traumatic for those left behind.

As challenging as this letter is, we hope it provides you with a starting point with which to act on soon.

Stay well and we hope to have you around for many years to come!

DATE: 06/04/20
SOURCE: Twitter
ISSUE: I'm in my 30s & have cerebral palsy. I'm deeply concerned about this. I also support a friend who has multiple health conditions. They've said they "don't fancy their chances of being given a ventilator if admitted 2 hospital. Scary!

DATE: 07/04/20
SOURCE: Anonymous care provider
ISSUE: Stirling - Young adult in 20s with learning disabilities and health conditions was admitted to hospital at the weekend. This is not unusual as the person is periodically admitted to hospital. The hospital doctor pursued conversation with the care provider manager about DNR order for the person. Manager was very surprised by the conversation as this had not happened before. The care provider (in light of current climate) is very concerned that this had happened.

Dundee – Care provider supports a number of people, including people with learning disabilities and mental health conditions who live in the same area. Some of these people are registered with the same GP practice. All patients (they understood it was a blanket letter) received a letter about DNR orders (not sure if they were asking people to sign a

DNR or just providing information). This was very distressing for many of the people the provider works with - many people didn't understand why they were receiving the letter - also caused distress to families. Care provider had to spend time explaining letters to people and giving reassurance.

DATE: 08/04/20
SOURCE: Twitter
ISSUE: I've just heard more reports of disabled people being asked to sign Do Not Resuscitate (DNACPR) forms by their GPs in Scotland. Unimaginably distressing.

DATE: 09/04/20
SOURCE: Twitter
ISSUE: @NicolaSturgeon today my Dr's secretary phoned with the checklist. She confirmed I can handwash and I'm a foster carer, then asked me to agree to a DNR and no hospital admissions if unwell. I refused. I'm a high risk lone parent. This call will increase disabled suicides.

After adamantly stating my wishes yesterday and refusing a GP discussion, I've just received a GP phone call asking the same questions. This could be perceived as bullying. This policy needs to stop now!

DATE: 09/04/20
SOURCE: Twitter (Mike Dailly – lawyer)
ISSUE: I'm seeing letters to frail folk in care homes telling them if they get ill there may be a Do Not Resuciatate. That's wrong. Please don't write people off. All life is equal. I will certainly be available to take up cases. You can't decide who lives and who dies.

DATE: 09/04/20
SOURCE: Twitter
ISSUE: Going through this now with Mum's carehome. Getting pressure but I refuse to sign anything that may take away care options. DNR is a Doctors's decision, determined by a patient's best interests/outcomes. As PoA for Mum I want to be fully involved in all decisions, as her voice.

DATE: 09/04/20
SOURCE: Twitter

ISSUE: I know a lady on her third lot of anti-biotics. All prescribed over the phone. Had her DNR letter sent to the pharmacy to be collected. I assume it was discussed but not sure. It seems so impersonal and 'convenient'. Chilling even.

DATE: 09/04/20
SOURCE: Twitter
ISSUE: We were asked to do the same for our 17yo son here in Scotland @joannaccherry as my MP please do not stand idly by! @JeaneF1MSP @OwenJones84 this must not be allowed! BBC News - Coronavirus: Autistic support group 'told it needed DNR orders'

DATE: 09/04/20
SOURCE: Twitter
ISSUE: My husband got a DNR phone call from the doctor's surgery yesterday but I can't get a slot at Tesco? Something stinks to high heaven in caring inclusive Scotland!

DATE: 09/04/20
SOURCE: Twitter
ISSUE: I refused a DNR when I was asked - twice. I get that there are insufficient respirators but that really is not the problem of the vulnerable, we should all be treated equally and favouritism to one social class must be avoided.

DATE: 10/04/20
SOURCE: Twitter
ISSUE: Spoke to a lady yesterday whose husband has cancer. His consultant told him he would not get any breathing support if he contracted covid. I worry about my son who should be on dialysis but they are delaying it. Worrying times.

DATE: 11/04/20
SOURCE: Twitter
ISSUE: My Care Agency are being forced to ask me every other day if I am ready for a DNR. the answer is still NO. it *is* bullying. My 16yo deals with his own medical stuff, and *HE* got asked by his GP if it would put ok To put a DNR on his records. He told them no in a not nice way...

DATE: ?
SOURCE: Inclusion Scotland correspondence
ISSUE: I'm a pysch researcher and psychotherapist. I'm also disabled. I had a phone call from my GPs secretary on 8/4 asking for my consent to a DNR. The next question was if I was happy for them to put on my file that I won't be admitted to hospital should I become unwell. I refused these measures adamantly, I also adamantly refused a discussion with the GP relating to these measures. I stated I will not waive my right to care. The following morning the GP phoned and asked these questions again along with asking why I will not agree to them. I've written an email to the clinical lead for the Aberdeenshire link practitioners proving feedback and requesting an apology. I have been tweeting Nicola Sturgeon, and anyone else my refusal. I've been contacted by a reporter and will be speaking to them tomorrow. I have also begun the process of finding legal support to put together an end of life plan to send to my Dr. I intend to put together a research project on this topic over the next week.

Other issues to consider

- People with learning disabilities may go to hospital without support (for example a family member or carer), discussions with medical professionals are likely to be inaccessible, and thus people are at further risk when 'acquiescent to suggestions put to them by health professionals in a position of authority at a time of great stress'.

  https://chrishatton.blogspot.com/2020/03/covid-19-people-with-learning.html

3. News coverage

- **DATE:** 26/03/20
  SOURCE: The Herald
  ISSUE: A piece in the Herald about NHS Fife noted that: 'Sources within wards had previously said that they had been told not to resuscitate patients as it could lead to the virus spreading.'

LINK: https://www.heraldscotland.com/news/18336097.coronavirus-scotland-health-board-denies-do-not-resuscitate-policy-covid-19-patients/

- **DATE**: 01/04/20
  SOURCE: BBC News
  ISSUE: A GP surgery has apologised after sending a letter asking patients with life-limiting illnesses to complete a "do not resuscitate" form.
  LINK: https://www.bbc.co.uk/news/uk-wales-52117814
  NOTE: this example is from a GP surgery in Wales.

- **DATE**: 01/04/20
  SOURCE: The Courier
  ISSUE: A Tayside family has hit out after an 86-year agreed to her GP surgery's "do not resuscitate" request despite suffering memory problems.
  LINK:https://www.thecourier.co.uk/fp/news/local/dundee/1235908/coronavirus-family-anger-after-dundee-doctor-asks-86-year-old-to-accept-do-not-resuscitate-request/

- **DATE:** 04/04/20
  SOURCE: Health Service Journal
  ISSUE: HSJ has seen one example of a letter which was sent to a Mencap care home in Cambridgeshire. The surgery has now accepted it should not have been sent to the families of the care home residents with learning disabilities – but there are concerns other similar letters have been sent out. Mencap, the learning disability charity, told HSJ GPs appeared to be "wrongly conflating" support needs with frailty. It said it would robustly "challenge this advice from GP surgeries", stating "people with a learning disability have a right to equal access to healthcare just like anyone else".
  NOTE: England example
  LINK: https://www.hsj.co.uk/coronavirus/learning-disabilities-patients-told-they-may-be-too-frail-for-mechanical-ventilation-if-they-get-covid-19/7027318.article

- **DATE:** 07/04/20
  SOURCE: Healthandcare.scot
  ISSUE: Government guidance on the treatment of care home residents with coronavirus is to be revised after cases where older people have been denied acute care - One care home manager in Moray told healthandcare.scot current guidance led her to believe

residents who contracted covid-19 would not be taken to hospital “under any circumstances”. They had to go through a "painful process" of trying to get treatment for three residents presenting with coughs who they thought had chest infections, not covid-19. She was informed by out of hours GP services they would receive no further treatment in line with government guidance. A local GP who was subsequently contacted agreed with care home staff and prescribed medication to the residents who are now on the road to recovery.
LINK: https://healthandcare.scot/default.asp?page=story&story=1571

- **DATE:** 09/04/20
  SOURCE: BBC News
  ISSUE: Coronavirus: Autistic support group 'told it needed DNR orders'
  NOTE: England example
  LINK: https://www.bbc.co.uk/news/uk-england-somerset-52217868

- **DATE:** 12/04/20
  SOURCE: Financial times
  ISSUE: NHS ‘score’ tool to decide which patients receive critical care – Covid-19 decision support tool
  LINK: https://www.ft.com/content/d738b2c6-000a-421b-9dbd-f85e6b333684