

Parkinson's and ethical decisions on access to treatment during the pandemic

Background

The coronavirus pandemic has sparked concern over equality of access to medical treatment if people become unwell, and in what circumstances decisions may be taken not to provide the highest levels of care to individuals.

The UK Government has said that people with Parkinson's are at higher risk of complications if they catch coronavirus.

Media stories have reported:

- There are resource shortages, including not enough beds, critical care equipment or trained staff to meet the demand created by the coronavirus.
- Some NHS bodies have made blanket decisions to exclude groups of people from certain types of treatment. These include cardiopulmonary resuscitation (CPR), hospital-based coronavirus care and the most invasive forms of support, such as mechanical ventilation.
- Some NHS institutions have been encouraging vulnerable groups of people such as care home residents or older people to sign "do not attempt cardiopulmonary resuscitation" (DNACPR) orders¹. In some cases, letters have been sent to request this.

People with Parkinson's have also raised concerns relating to DNACPR decisions following media reports of these orders being applied "en masse" or letters being sent recommending seriously ill patients have a DNACPR in place. These concerns have included not being able to receive lifesaving treatment if they have a DNACPR in place or being pressured into agreeing to having a DNACPR put in place.

We recognise that in the early stages of the pandemic these processes may have been rushed and incorrectly followed in some areas. This has led to anxiety among people with Parkinson's and their families.

What we think

When making decisions about whether to offer a treatment, doctors have a moral and ethical duty² to make decisions in the best interest of the person that they are treating, which includes assessing the

¹ <https://www.theguardian.com/world/2020/apr/01/uk-healthcare-regulator-brands-resuscitation-strategy-unacceptable>

² <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/good-medical-practice/duties-of-a-doctor>

risks of the treatment, whether or not the person is likely to survive, and the extent of any likely recovery.

Cardiopulmonary resuscitation (CPR) and a “do not attempt CPR” (DNACPR) decision

It is important to outline what is meant by cardiopulmonary resuscitation (CPR) and a “do not to attempt CPR” (DNACPR) decision.

CPR is a life-saving treatment to restart a person’s heart and breathing when they have entered cardiac arrest. This can be done through chest compressions (pressing up and down on the person’s chest), rescue breaths (inflating the lungs), defibrillation (electric shocks to the heart) or a combination of these measures.³

DNACPR is “a decision not to attempt CPR, made and recorded in advance, to guide those present if a person subsequently suffers sudden cardiac arrest or dies”.

A DNACPR decision may be made and recorded:

- at the request of the person themselves
- as a shared decision (made by the person themselves and their doctor and/or other healthcare team members) that the likelihood of CPR being beneficial in their current situation would not outweigh the potential burdens and risks of receiving attempted CPR
- by the healthcare team, because CPR should not be offered to a person who is dying from an advanced and irreversible condition and therefore CPR will not prevent their death
- by the healthcare team because the person themselves is not able to contribute to a shared decision and a decision has to be made in their best interests.”⁴

This does not mean other life-saving treatments such as oxygen or treatment in an intensive care unit are not attempted.⁵ It does mean cardiopulmonary resuscitation techniques such as chest compressions or defibrillation will not be attempted.

CPR may not always be considered in the best interests of people with more advanced Parkinson’s or those with other serious health conditions, either by the person themselves or their family or their medical practitioner. This could be because it is very unlikely that the person would survive, or the process of undergoing CPR is considered too traumatic and painful.

Having a diagnosis of Parkinson’s is not in itself grounds to make a DNACPR decision.

We believe that people with Parkinson’s and their carers should be supported to consider whether CPR is the right choice for them as part of their advance care planning, and in light of their personal health circumstances. This must be approached sensitively, and on an individual basis. Nobody should feel uninformed or excluded from discussions and decision-making about whether resuscitation is appropriate for them and they should not be issued a blanket policy.

³ <https://compassionindying.org.uk/making-decisions-and-planning-your-care/planning-ahead/dnar-forms/about-cpr/>

⁴ <https://www.resus.org.uk/faqs/faqs-dnacpr/>

⁵ <https://www.theguardian.com/commentisfree/2020/apr/08/do-not-resuscitate-orders-caused-panic-uk-truth>

PARKINSON'S^{UK}

CHANGE ATTITUDES.

FIND A CURE.

JOIN US.

This is in line with joint guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing, which must be followed. This states:

“There should be clear, accurate, honest and timely communication with the patient and (unless the patient has requested confidentiality) those close to the patient, including provision of information and checking their understanding of what has been explained to them.”⁶

Access to treatment in critical care settings

We recognise that, currently, critical care is operating under capacity following the impact of the public adopting social distancing measures and the increased critical care capacity the NHS has put into place. While this remains the case, decisions on access to critical care remain a clinical decision, and we have not seen evidence of care being “rationed”. However, we will continue to monitor this situation closely to see if this is no longer the case.

If this situation does change and critical care units are overwhelmed, decisions will need to be made about admission to hospital and treatment given.

We believe that a diagnosis of Parkinson’s in and of itself should not be a reason to deny someone admission to hospital and to receive treatment such as oxygen or ventilation in a critical care setting such as an intensive care unit.

Why we think this

Coronavirus is a new illness, and evidence is limited, but it’s currently estimated that almost one in three⁷ who are hospitalised with the virus will require intensive care treatment, which might include mechanical ventilation.

Intensive care treatment is increasingly recognised as being frightening, with some survivors experiencing post traumatic stress disorder as a result of their experiences.

Receiving hospital care for coronavirus may be even more frightening because staff’s protective equipment makes it impossible to recognise individuals, and the experience is very isolating because visiting is not permitted. If the treatment is ultimately successful, it is very likely to have been a terrifying experience for the person.

This position is in complete alignment with NICE guideline [NG159] COVID-19 rapid guideline: critical care in adults⁸ in relation to hospital admission which states that the Clinical Frailty Scale (CFS)

⁶ Guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing '[Decisions relating to cardiopulmonary resuscitation](#)' 3rd edition (1st revision) 2016

⁷ <https://www.telegraph.co.uk/global-health/science-and-disease/coronavirus-hospitalisation-rates-revealed-80-per-cent-infected/>

⁸ <https://www.nice.org.uk/guidance/ng159/chapter/1-Admission-to-hospital>

PARKINSON'S^{UK}

CHANGE ATTITUDES. FIND A CURE. JOIN US.

should not be used for “people with stable long-term disabilities” and that consideration should be given to “comorbidities and underlying health conditions in all cases.”

And on receiving treatment in a critical care setting, our position is aligned to the British Medical Association’s (BMA) statement on “Covid-19: ethical issues”⁹ which states:

“Under our guidance, the fact that someone is above a particular age, or that they have an existing medical condition is not, in itself, a factor that should be used to determine access to intensive treatment. Similarly, someone with a disability should not have that disability used by itself as a reason to withhold treatments, unless it is associated with worse outcomes and a lower chance of survival. A decision to exclude from treatment everyone above a particular age, or with a disability, would be both unacceptable and illegal.”

What we are doing

When it started to become clear that the pandemic was going to have a significant impact on our community, we focussed on delivering critical support including the following:

- producing [regularly updated information on coronavirus and Parkinson’s](#)
- managing a [Facebook group](#) so members of the community can provide mutual support to each other
- listening to our community
- raising concerns with the Department of Health and Social Care, NHS England and Improvement and National Voices, and governments and the NHS in Northern Ireland, Scotland and Wales, as well as with service providers
- strengthening capacity on our helpline and local advisers to meet demand for information, emotional support, and signposting
- providing updates to our community on our website and through social media and other communications.

We plan to continue our work in this area to ensure the needs of our community are met by:

- communicating our activity with our community and how they should prepare if they go into hospital
- gathering experiences and insights from our community to enable us to raise concerns and influence changes.

Acknowledgement

We are grateful for the advice and guidance of the Clinical Leads of the UK Parkinson’s Excellence Network in shaping this position paper on government definitions of vulnerability.

⁹ <https://www.bma.org.uk/media/2283/bma-ethics-guidance-and-age-and-disability-statement-april-2020.pdf>

PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

Further information

Please contact the Policy and Campaigns team. Tel: 020 7963 9349 or email:
campaigns@parkinsons.org.uk

May 2020