

UNDERSTANDING THE NICE COVID 19 GUIDANCE ON CRITICAL CARE. FOR FAMILIES WRITTEN BY FAMILIES

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There has been a lot of information about some NICE Guidance on Covid 19 and the use of the Clinical Frailty Score.

We want to try to reassure you just because your young person has a disability whether that be physical or cognitive, it does not mean they would not be treated.

We cannot cover every situation just the overarching principles:

A key principle in the guidance is shared decision making. NICE says that the 'risks, benefits and possible likely outcomes of the different treatment options' should be discussed with patients, families and carers 'so that they can make informed decisions about their treatment wherever possible.'

NICE also say that their guidance should not replace decision making appropriate to the circumstances of the individual, in consultation with them and their families and carers.

NICE refer to some tools to help inform shared decision making about the care of adults. One of these is the Clinical Frailty Score. There has been a clarification that this is not to be used for people under 65, those with a learning disability or those with a long term disability such as Cerebral Palsy.

The Critical care algorithm for Covid 19 is helpful though. The assessment is done on how was the person 2 weeks ago ie before they were unwell. This would be done in discussion with relatives/ carers. If our youngsters had capacity what would there wishes be? If they didn't have capacity best interest would apply. Although there wouldn't be a meeting as such you should be consulted, even by phone if necessary.

Like anyone else then these following key questions apply at every juncture of the decision tree.

Key questions to consider are:

- How will critical care treatments help the person in the short and long term?
- Could critical care treatments offer a quality of life that is acceptable to the person?
- Could critical care treatments help achieve a patient's goals for a good life?
- Are there non-critical-care treatments that may help the person and be more comfortable for them?

So even if your young person was on the left branch of the critical care pathways 'best interest' and that 'to do no harm' continues to apply.

We understand totally that there is a lot of new information to take in at what is already very stressful circumstances. We will be going into more detail once the new Guidelines come out as we know there will be a lot of questions you will want to ask.

Huge thanks to Janine and Helen who have given up their time to support us all by putting together this information.

