**Advance Care Planning – Learning Disability**

You may be aware that messages have gone out locally and nationally that decision making in advance care planning must not be on the basis of someone having a learning disability ([link](https://content.govdelivery.com/accounts/UKCQC/bulletins/283e565)). The message concludes:

‘*It is unacceptable for advance care plans, with or without DNAR form completion to be applied to groups of people of any description. These decisions must continue to be made on an individual basis according to need*’.

ReSPECT forms and DNACPRs are only completed by those specifically trained to do so. DNACPRs are completed by medics and ReSPECT forms by senior nurses and medics.

These forms are best supported by Advance Care Plans (ACP). The purpose of the ACP is to ensure good decision making going forward by people who do not know the individual.

**Advance Care Plans and Covid-19:**

If someone you care for has had repeated admissions to hospital (particularly due to chest infections), has a respiratory condition or does not tolerate hospital well consider completing an ACP. If there is a specialist team involved contact them to discuss whether an ACP would inform decision making if they become unwell.

ACP’s help medics know the persons wishes and guides the healthcare team to make decisions on the person’s behalf of the best care pathway.

ACP’s are ordinarily initiated by a member of the **person’s care team** and completed in consultation with the person, wherever possible, their family and by a multi-disciplinary team where this exists.

Locally it has been identified that there is a lack of advanced care planning for people who are having repeat hospital admissions. The Community Learning Disability Team are well placed to support these discussions as well as the person’s GP in Primary Care ([link](https://www.sussexcommunity.nhs.uk/downloads/services/endoflife_care/advance-care-plan.pdf)).

[e-learning for health](https://www.e-lfh.org.uk/) has an advance care panning module and the [ReSPECT site](https://www.resus.org.uk/respect/) has some good films although not learning disability specific.

They also have a suite of easy read resources:



A Mental Capacity Act assessment will be needed where someone is not able to participate in their ACP and this is being done in their best interests. If a person who lacks capacity has no close family or friends, then an Independent Mental Capacity Advocate (IMCA) should be instructed and consulted regarding decision making about serious medical treatment.

**In the event of admission to hospital:**

Please see briefing from NHS England ([link](https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0031_Specialty-guide_LD-and-coronavirus-v1_-24-March.pdf)).

This states the importance of an up-to-date hospital passport to include information about how the person would cope with PPE.



Contacting the Learning Disabilities Acute Liaison nurses **- Conquest Hospital, Hastings & Eastbourne District General Hospital.   – 07876578366** - is advised as they can provide phone support for the admission. *COVID specific hospital passports are not considered helpful in that hospital staff were unfamiliar with them and multiple documents poses a risk.*

For people with behaviour that challenges or autism, specialist advice is available from the CLDTs.

**Other resources:**

* Legal guidance for mental health, learning disability and autism, and specialised commissioning services supporting people of all ages during the coronavirus pandemic.



* Nice guidance 159 regarding critical care admission ([link](https://www.nice.org.uk/guidance/ng159/resources/critical-care-admission-algorithm-pdf-8708948893)). Under the MCA consideration should be given to instructing an IMCA for decisions around serious medical treatment.
* Palliative care and learning disability webpage has a range of resources to share best practice ([link](https://www.pcpld.org/)).
* [Webinar](http://www.professionalpalliativehub.com/covid-19/project-echo-aiihpc-webinars-intellectual-disability-services) recording from Project Echo AIIHPC on ‘How to support people with intellectual/learning disabilities with a diagnosis of COVID-19’