



Child and Young Person's Advance Care Plan Collaborative

Child and Young Person's Advance Care Plan (CYPACP) Collaborative: Our position on the 'Universal Principles for Advance Care Planning (ACP) – Published in March 2022'

The publication of the Universal Principles for Advance Care Planning for people in England was published in March 2022. These principles were published in response to decisions about living and dying for adults and the necessity to ensure people are empowered to participate in planning for their future.

We commend this guidance and the commitment from all involved with endeavours to implement a supportive and personalised approach to ACP for everyone.

However, the principles use wording throughout and a definition of Advance Care Planning that implies an individual must have capacity. As such we, as a collaborative, were concerned that this excludes many of the patients that utilise the CYPACP.

We expressed our concerns and met with the group who wrote these principles to discuss this.

The group listened to our concerns and confirmed, what they have stated in their principles, namely that the principles 'may need to be adjusted to meet the different needs of people, due to their age, condition or circumstance.'

They also confirmed that 'Advance Care Planning is appropriate in children and those without capacity' if done carefully and correctly. Even if this is not explicitly stated in their principles.

We had asked for an addendum or revision to their principles. Sadly this is not going to occur. However, they were happy for us to confirm the above.

It is beyond the scope of this statement to detail how to undertake advance care planning 'appropriately'. However, we highlight that many resources exist to help support this. Including (but not exclusively): NICE Guidance (NG61), NICE Quality Standard (QS160), the Association of Paediatric Palliative Medicine, Together for Short Lives, the CYPACP website and GMC Guidance 'Guidance for 0–18-year olds'.

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