



TIPS

Useful expressions, wording and advice

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1 Introducing Advance Care Plans.

- “When you are ready, we would like to talk about the future care for your child”.
- “These are difficult decisions to make, they may take time”.
- “Some parents find this easier to talk through when they not on a crisis/emergency situation”.
- “It can be tiring repeating your story time and time again and the advance care plan helps record your wishes in writing and can be shared with others”.

2 What does the Advance Care Plan involve.

- “An opportunity to discuss your values, beliefs, hopes and goals”.
- Not just about resuscitation or emergency planning.
- It should consider social, education and spiritual dimensions of care.
- Helps discuss options and an opportunity for joint decision making between professionals and families.

Example(s) for written documentation:

- Avoid the expression ‘CPR’.
- If you mean chest compressions then write this, some interpret CPR as chest compressions whilst others may take this to mean any form of ‘cardiopulmonary resuscitation’.

3 The form is for the families benefit not ours (although it is extremely helpful for professionals too).

- “You don’t have to complete one, it is an opportunity not a requirement”.
- “The document is like having the clinician who knows your child best at the side of the bed wherever you are”.

4 ‘Care plans are individualised’.

- “Not just based on a diagnosis, but what is right for your child”.
- “Helps us work out together what would or would not be helpful”.

5 Helps professionals know how best to look after your child, when well but also in emergencies.

- Helps ensure holistic care – including likes and dislikes.
- Helps us share expertise.
- Vital in parallel planning.
 - Plan for all eventualities.
 - Hope for the best but plan for the worst.
- Good Advance Care Plans consider benefits and harms of all treatment and consider and respect views of families.
 - Beware of using the term ‘best interests’ as this can be inflammatory, all families will argue that what they want is in the young person’s best interest.
 - Remember ‘best interests’ includes consulting with close relatives, friends or others who take an interest in the person's welfare.

6 Empowering others who either do not have seniority to make decisions and / or who do not know child.

- This gives paramedics, nurses, junior doctors permission to not start (or to stop) resuscitation efforts if the family say to do so and professionals agree. However, please ensure all professionals agree with this before adding.

Example(s) for written documentation:

- ‘If at the time of arrest the family feel they want professionals to stop (or not start) resuscitation efforts, professionals would support this and mum should be allowed to comfort’



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7

Recognise that Advance Care Plans help future decision making.

- This highlights an acceptance of the need (and an invitation) for future discussions and decision making. Highlighting that often families cannot make decisions in advance.

Example(s) for written documentation:

- Please be open and honest about the likelihood of recovery of any event such that appropriate decisions can be made.
 - The family do not wish for repeated or prolonged intensive care admissions for, particularly where he/she may not be able to return to his/her previous quality of life and level of function.
 - The family would wish for discussions about appropriate further treatment, as they would not want to suffer unnecessarily to no benefit.
- Helps to recognise a decision balancing benefits, burdens and likelihood of reversibility will need to be made at the time.

Example(s) for written documentation:

- has a good quality of life and the family would want any reversible conditions treated should the burden of treatment not be too great.
- Helps professionals be honest with families and highlight them to the possibility of end of life ensuring appropriate decisions and management occur.

Example(s) for written documentation:

- If it is recognised that is reaching end of life, please be aware that the family would wish for him to be at and as such this should be arranged as soon as possible.

8

Be careful about saying for 'full resus' – this can be difficult for professionals to stop.

Example(s) for written documentation:

- There are no limitations in place so resuscitation should be commenced and delivered as with any other child.
- As with ANY child or adult, resuscitation can still be withheld or stopped by clinical staff, due to specific clinical events at the time such as a failed period of resuscitation or an arrest when the patient is already on maximal intensive care treatment.

9

If parents and professionals disagree.

- Whilst not always able to resolve conflict, it is helpful to highlight to others that it exists and may therefore help appropriate and careful communication, together with appropriate escalation and or contacting those who are aware of the situation.
- Parents opinions must always be considered and respected where possible, however professionals must ensure they do not act in ways which they feel are unethical or inappropriate. In the past, second opinions and ethics committee opinions have been sought and if needed they should be again.

Example(s) for written documentation:

- Parents feel x, y, z and would wish for resuscitation or, However, professionals / consultants question / do not feel resuscitation or would be beneficial because of x, y and z.
- Remember the power of agreement. It is particularly helpful for those who do not know the child or who may not have the seniority for decision making around these complex / difficult decisions.

Example(s) for written documentation:

- This is fully supported by the medical professionals who know
- Both parents and professionals agree



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- Parental disagreement - if professionals and one parent agree – legally this is enough. However, please respect that this can be very difficult.
- It is our responsibility (even if it is not easy) to ensure both parents with responsibility are aware / have had an opportunity to express their views.

Example(s) for written documentation:

- Whilst Dad does not fully agree with all elements of this care plan, he understands that clinicians must act in the best interest of the child at all times. He would however, appreciate the opportunity to discuss the options available to at the time of any deterioration.
- Whilst’s father is not involved in the day to day care of, he should be contacted if is very unwell, in particular if is felt to be at the end of his life.’s father is a Christian and he wants to be able to pray for him and hopefully get to his son’s side if he can.

10

Wording to help management of acute sudden death

- For children with life limiting conditions, it is often still appropriate (and necessary) to undertake the full SUDIC (Sudden Unexpected Death in Childhood) protocol.
- It is often better to state contact number to discuss at the time and state ‘**may** not need SUDIC’.
- The discussions surrounding this wording are often helpful to families. Informing them of required procedures, and knowing who to call in such circumstances for support etc.
- Discussion with all professionals is essential to ensure they are in agreement.

Example(s) for written documentation:

- In the event of sudden death / acute deterioration, there may be no need for the police to be called, unless there are concerns about aspects other than the already diagnosed illness, such as safeguarding concerns.