Child and Young Person's Advance Care Plan Collaborative

Sudden Unexpected Death in Infancy and Childhood (SUDIC) and the Medical Examiner Process in Advance Care Planning - Guideline

Who is this leaflet for:

This leaflet has been designed for professionals having Advance Care Planning discussions regarding (and with) Children (up to the age of 18 years) and their families. It is designed to be used to help these conversations, it is NOT designed to be given to patients /families without discussion. Although it is not unreasonable to subsequently pass this to the patient / family to help them remember / process the information.

Why this leaflet has been produced:

Advance Care Planning has various benefits for the patient, family and professionals. Helping to inform decision making at a future time by having detailed and sometimes difficult discussions. Good care planning also, prepares patients/families (and professionals) on what to expect (or at the very least on possible scenario's), potentially reducing stresses and uncertainty at the time.

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The Child and Young Person's Advance Care Plan (CYPACP) is a template to help guide some of these discussions. Within the document there are various prompts to help guide important areas to consider, and a place to document that these discussions have occurred (helping other professionals to know to either build on discussions or in some cases not to have to repeat things over and over again).

Whilst it is recognised that there are some very sensitive and potentially difficult topics to cover, families have informed us that they appreciate awareness of what to expect. It should be noted however, that many Advance Care Planning discussions take place over several conversations and it may not always be appropriate to cover each area.

Two particular processes / situations we wanted to highlight to professionals to help prepare families are the Sudden Unexpected Death in Infancy and Childhood (SUDIC) process and the Medical Examiner Process. This recognises that preparation and awareness of these two processes can hugely reduce (and potentially avoid) stresses to the family created by these statutory processes.

Within the CYPACP prompt of these discussions are found in the 'Wishes around End of Life' section and in the Sub section (Box) 'Preparation/communication of process for management after death'.

Sudden Unexpected Death in Infancy and Childhood (SUDIC)

SUDIC stands for **Sudden Unexpected Death in Childhood**. Defined as: The death of a child (less than 18 years old), or a collapse/ incident leading to death, that was not anticipated as a significant possibility 24 hours before the death'. Following the unexpected death of a child the SUDIC process is instigated by the SUDIC team. [1.]

What is the SUDIC process?

The SUDIC process, or Joint Agency Review (JAR), is the multi-agency response to unexpected child deaths and forms part of statutory Child Death Review Procedures. The SUDIC process aims to understand the reason(s) for the child's death, address the needs of other children and family members in the household and also consider any lessons to be learnt to safeguard and promote children's welfare in the future. The decision of whether a child's death meets the SUDIC criteria is made by the SUDIC Paediatrician and throughout the process the child remains under the jurisdiction of HM Coroner. [1.]

When a child dies unexpectedly the SUDIC team are informed, at which point the team obtain as much information as possible about the circumstances of the child's death from the informant. This includes visits, meetings and reports between various professionals representing health, police and social care and the HM Coroner. A post-mortem may also be required. [1.]

What about children with Life Limiting / Life Threatening Conditions?

Even when a child has been diagnosed / recognised to have a life limiting / life threatening Condition the SUDIC process must still be considered at the point of death.

Strictly speaking, the definition to carry out the SUDIC process, is if it was 'not anticipated as a significant possibility 24 hours before death'. However, it may be helpful to consider that some children with life limiting / life threatening conditions may have a 'sudden' but not necessarily 'unexpected' death and as such MAY not require escalation to the SUDIC process.

If there is any doubt then it would be sensible to discuss this with the SUDIC team at the time. (Please adhere to local policies for this).

What to mention in Advance Care Planning Discussions

It is important to prepare families of the existence of the SUDIC process and in particular to the fact that, if the child was to stop breathing and 999 (111) was called, it is likely that police will be called and may arrive at the call location. Likewise, that if a SUDIC process is carried out the child will be transferred to the hospital for appropriate investigations.

Depending upon the access to on-call services and palliative teams this may mean that in 'expected' deaths we advise families to ring those services /support / on-call numbers rather than 999. [Although it should be noted that it may still be appropriate for these services to instigate the SUDIC process, as each case needs to be considered recognising the circumstances at that time, for example if there are any abnormal (such as unexpected accident) or suspicious (safeguarding) circumstances.]

Advance Care Planning discussions are an opportunity to consider, plan and communicate appropriate action plans for these eventualities. This may include (depending on the local services available) that first responders (ambulance and police) may also be able to discuss and speak to palliative teams to discuss the situation and to come to joint decision making about the need to proceed with these legal processes.

A couple of examples:

A child with a life limiting condition that is actively dying at home.

Here, it would be appropriate to discuss and document in the Advance Care Plan (ACP) that this child is imminently expected to die due to their condition and would not warrant a SUDIC process (unless unexpected circumstances occur at the time).

It is most likely that it would be sensible to prepare family to call local and appropriate services (if available) in the event of deterioration rather than 999. If there are no local services available, then it may be the family require emergency services to help support them (where the ACP guidance would be particularly helpful for those services).

Example wording in the ACP:
… is a young boy, who has been transferred home for end of life care. Sadly, whilst we cannot state an exact time frame, we do expect him to die due to his condition in the near future. Parents have therefore been advised to call palliative services on …., for support should they need help or in the event of deterioration / death. Unless there are unexpected circumstances at the time of death / deterioration medical professionals who know him would not anticipate the SUDIC process to be required.

If the family do call emergency services please note that palliative services are available 24/7 on …… to discuss the situation to help joint decision making at this difficult time.

A child with a life limiting condition that is very frail, but NOT actively dying at home.
Here, it would be appropriate to discuss and document in the Advance Care Plan (ACP) that this child is expected to die due to their condition and MAY not warrant a SUDIC process but would need to be assessed at the time.

In this situation it may still be sensible to discuss and agree with the family who would be the best service to call in the event of deterioration, explaining the processes (and potential consequences) for each option. This may be local palliative services or may equally be emergency services (particularly where hospital treatment is still appropriate). If emergency services are called then it would be appropriate to ensure the ACP explains the situation helping guide the emergency teams on the appropriate management.

Example wording in the ACP:

… is known to have a life limiting condition and is known to have severe life-threatening apnoeic episodes. Usually for a child that dies in the community, national guidance indicates that 'Sudden Death' protocols may require a child to be taken to the hospital for investigations and that the police may be called by the ambulance service. A decision will need to be taken at the time as to whether a life-threatening event is 'unexpected' or 'sudden'. However, given that at the time of writing this care plan he is known to have these life-threatening episodes this MAY not be required. The palliative services can be contacted 24/7 on …. To help with this decision making if require, where staff are happy to discuss with any professionals (including ambulance services and / or the police).

Medical Examiner Process

What is the Medical Examiner and what do they do?

From 9 September 2024, all deaths in England and Wales will be independently reviewed, either by a coroner where they have a duty to investigate, or by a medical examiner.

Medical examiners address 3 key questions [2]:

- what did the person die from?
- does the death need to be reported to a coroner?
- are there any clinical governance concerns?

The purpose of the ME system is [3]:

- to provide greater safeguards for the public by ensuring independent scrutiny of all non-coronial deaths
- to ensure appropriate referral of deaths to the coroner
- to provide a better service for the bereaved with an opportunity for them to raise any concerns to a doctor independent of the case
- to improve the quality of death certification (Medical Certificate of Cause of Death (MCCD)) and the quality of mortality data.

Why is this important in Advance Care Planning?

It is important for patients / families to be aware that this process exists as:

- it is a legal requirement and cannot be avoided
  - (unless a coroner referral is being made directly)
- it may impact the immediate after death care of the child
  - In order for review and scrutiny to occur.

An example of this may be that families wishing a rapid burial (for religious reasons), should be informed that there may be an unavoidable delay in being able to bury their child. Particularly, if occurring during non-standard working hours.

Medical Examiners across the country do try and prioritise both children and cases where religious beliefs may be impacted. However, delays may still exist.

This highlights the importance of discussing spiritual beliefs / wishes around end-of-life care during advance care planning. As (although delays may still exist) we can notify Medical Examiners to prioritise these patients.

In some cases, it may even be possible to pre-emptively discuss a case where death is expected. Although this will depend upon local policies and it should be noted that whilst pre-emptive discussions may theoretically speed the process up, it does not replace post-death requirements.

Other Top Tips for Advance Care Planning

Implantable devices

Part of the Medical Examiner process helps guide the documentation of the Medical Certificate of Cause of Death (MCCD). It is important to note, that this now contains detail of any implantable device (previously recorded [in a cremation form] only if a cremation was required).

It is therefore good practice to include this information within the Advance Care Plan to help ensure timely and accurate completion of the MCCD. For the CYPACP this can be recorded in the ‘Wishes around End of Life’ section and in the sub section (Box) ‘Preparation/communication of process for management after death’.

There are also sections (such as ‘Management of Anticipated Complications/Deteriorating Health’ and ‘Management of an Acute Significant Deterioration/Emergency’ sections) where this information is also important to note, as it may impact management during life too.

Known situations where coroner referral will be required on death of a child

There are certain situations where a coroner referral is known in advance to be required following the death of a child. For example, where death was due (or contributed to by) by undergoing treatment or procedure of a medical nature.

An example of this is that any child having suffered from a significant injury such as a birthing injury like Hypoxic Ischaemic Encephalopathy (HIE) or previous Non-Accidental Injury (NAI) will need to be referred to the coroner on death, irrespective of the time passed since this injury. It is important to document this, to ensure:

- Professionals are aware of this requirement at time of death
- In preparing the families of this requirement, particularly where it could impact on their after death wishes

For the CYPACP this can be recorded in the 'Wishes around End of Life' section and in the Sub section (Box) 'Preparation/communication of process for management after death'.

Referral to the coroner does not necessarily mean a post-mortem will be required. This decision will depend upon the circumstances and will be decided by the coroner. It may, however, be helpful to record in the Advance Care Plan if the family have any preferences with this regard, and this information can be passed on to the coroner (although they may still have to override these wishes if they feel a post-mortem is necessary).

A more complete guidance for some of the issues covered above with regards to Medical Examiner and Coroner referrals can be found in the 'Guidance for registered medical practitioners on the Notification of Deaths Regulations (September 2024)' found here:

(https://assets.publishing.service.gov.uk/media/66d044a059b0ec2e151f847e/Guidance_for_registered_medical_practitioners_on_the_Notification_of_Deaths_Regulations__web_.pdf)

Resources:

1. One Minute Guide – SUDIC Sudden Unexpected Death in Childhood) April 2024, https://www.leeds.gov.uk/docs/One%20minute%20guides/One%20Minute%20Guide%20-%20SUDIC.pdf) [accessed 5.12.24]

2. National Medical Examiner's guidance for England and Wales, For use from 9 September 2024, NHS England. (https://www.england.nhs.uk/long-read/national-medical-examiners-guidance-for-england-and-wales/) [accessed 5.12.24]

3. Role of the medical examiner service in children and young people's deaths, Stephen Playfor (Role of the medical examiner service in children and young people's deaths | Archives of Disease in Childhood) [accessed 5.12.24]

Other useful documents:

Child Death Review, Statutory and Operational, Guidance (England) - https://assets.publishing.service.gov.uk/media/637f759bd3bf7f154876adbd/child-death-review-statutory-and-operational-guidance-england.pdf

We hope you find this information useful. If you have any feedback, we would be delighted to hear it admin@appm.org.uk