

10. Miscellaneous

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10. Miscellaneous

10.1 Preparation for surgery

It is important to ensure that BOTH the parents and child/young person have a clear understanding of what the surgery is for, and what the outcome of surgery will be. Consent will be obtained by the surgeon.

Pre-op nil by mouth -

6 hrs food and bottle milk

4 hrs breast milk

2 hrs water

General anaesthesia commonly leads to lung atelectasis (hence post-operative fever), even in healthy patients, a situation which is exacerbated in children with CF. We therefore routinely give peri-operative antibiotics to **all CF children** undergoing general anaesthesia, however good their lung function. This includes portacath insertion, gastrostomy insertion/changes, dental procedures, ENT surgery such as polypectomy, tonsillectomy and also gastrointestinal endoscopy. We do not do this for bronchoscopy however. Many of these procedures are carried out at Chelsea & Westminster Hospital but it is still important to ensure the surgeons and gastroenterologists are aware of this when arranging the procedure – always give antibiotic recommendations (IV vs oral, and choice of drug) in the referral letter.

- Minimal and moderate lung disease - (especially for minor surgery) can usually receive high dose oral antibiotics for 48 hours pre- and 48 hours post-op.
- Severe lung disease may need 7-14 days IV antibiotics pre-surgery and 7 days post-operatively, and these would usually be given at the Brompton. Choice of drug is determined by the latest sputum or cough swab culture. The on-call paediatric respiratory SpR at Royal Brompton Hospital will advise over the exact choice, which is usually ceftazidime and tobramycin. It is also important that chest physiotherapy is strictly adhered to during the admission.
- Children with severe lung disease ($FEV_1 < 40\%$, or oxygen-dependent) can be at high risk from anaesthesia and surgery, so the risk benefit of the procedure must be carefully considered, and pre-op assessment by the anaesthetist should be carried out. Their health status must be optimised prior to the operation.
- **Pre-op plan** for those with significant lung disease – IV antibiotic course (pre and post), IV fluids when NBM, see Pain Team for planning, organise postop on call physiotherapy, consider NIPPV post op, early mobilisation.
- Children with CFRD – Discuss management prior to admission with Dr Nicola Bridges or Dr Saji Alexander.
- Beware dehydration or opiates post-operatively leading to DIOS.

- In a non-sputum producing child see if a blind BAL can be performed by the anaesthetist if we are not bronchoscoping the child as well.

Bronchoscopy – no antibiotics beforehand but minimum 48 hours IVABs post-procedure if **significant** secretions are seen. In practice, bronchoscopy is often done at start of 14 day IVAB course when patient not doing well and no microbiology available or nothing ever grown.

10.2 Immunisation

We strongly recommend that all **routine childhood vaccinations** are given at the usual times and should be arranged by the general practitioner.

Influenza immunisation for children over 6 months of age is mandatory and is also arranged by GPs. However, families must be reminded, and it is also useful to put a reminder in to the clinic letters to GPs in early autumn. The vaccines are usually available in October each year. We follow the NHS policy –

Under 6 months	No vaccine	
6m – 2yrs	Inactivated injected vaccine	<ul style="list-style-type: none"> • Deep subcutaneous or intramuscular injection. • If never had before (and <9yrs old), they get 2 doses 4 weeks apart.
2 yrs and above	Live attenuated nasal spray vaccine - (Fluenz).	<ul style="list-style-type: none"> • If never had before (and <9yrs old), they get 2 doses 4 weeks apart. • Not to be given if large bilateral nasal polyps. • Contraindicated if severely asthmatic.

Egg hypersensitivity with evidence of **previous anaphylaxis** is a contraindication, although NHS guidance suggests children with milder egg allergy can receive the nasal vaccine. Parents should also receive the vaccine (but we do not routinely give to siblings).

Further information is available on:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/456568/29043_94_Green_Book_Chapter_19_v10_0.pdf

Pneumococcal vaccine - Prevenar is given as part of national immunisation policy, and Prevenar 13 covering 13 serotypes was introduced in April 2010. In older children who did not receive Prevenar, if the parents are keen, we would have no objection to them having the vaccination, although it is not routinely recommended, as Pneumococcus is not an organism particularly associated with CF. Pneumovax (a pneumococcal polysaccharide 23 valent vaccine) is used for children >5 years. It is of course mandatory for children who have had a splenectomy.

Palivizumab (Synagis) is a monoclonal antibody available as passive immunisation against respiratory syncytial virus (RSV). It is given as 5x monthly intramuscular injections. There is no good evidence for benefit in CF and we do not routinely recommend it.

10.3 Chicken pox

Although the literature is scarce, it has been documented that varicella-zoster infection can lead to infective pulmonary exacerbations and that early treatment with aciclovir may prevent pulmonary deterioration.

Children who are not on oral corticosteroids. If the diagnosis of chicken pox is confirmed and we are contacted early in the course of the illness, we suggest a one week course of oral aciclovir in those children who are unwell and particularly those who are known to have significant chest disease (see BNFC for dose).

If, however we are informed late in the course of the illness or the child really has mild chicken pox only with a few spots then aciclovir is not warranted. This is particularly the case in CF children who are well from the CF point of view.

If children are on oral corticosteroids or have recently been on them, then the Guidelines as outlined in the BNFC should be followed:

Chicken pox contacts should only receive **Varicella-Zoster Immunoglobulin (VZIG)** if:

- they have not had chicken pox previously.

and

- are currently taking oral steroids.

or

- within the last 3 months have been taking the equivalent of 2 mg/kg/day prednisolone (or >40mg/day) for 1 week *or*
- within the last 3 months have been taking the equivalent of 1 mg/kg/day prednisolone for 4 weeks.

VZIG is given by deep intramuscular injection at the following doses:

<6 years 250mg; 6-11 years 500mg; 11-15 years 750 mg; 15 years and over 1000mg.

VZIG is available directly through the Health Protection Agency, Colindale (tel. 0208 327 7471).

We would also recommend that we see those children and if a chicken pox rash still develops in these children who are at risk of serious disease, IV aciclovir is indicated for at least 7 days; total 10 days treatment.

At the 6th birthday annual review, we measure varicella antibodies, and if negative, we will offer **varicella immunisation** (even if there is a history of having had chicken pox). This is to ensure that we reduce the risk of a child contracting chicken pox while they are on a course of oral steroids for ABPA when older.

10.4 Travel abroad

Patients will need:

1. An information fact sheet which is available from the CF Trust (020 3795 1555).

2. Advice is also available in the BTS guidelines with an updated guideline published 2011.
3. Adequate travel insurance. They need to be advised to fill in the medical information in great detail so that there is no risk of the company not reimbursing a potential claim. They also need to check that the policy does not exclude pre-existing illness. CF Trust fact sheet has a list of suitable travel insurance companies. Everyone needs a European Health Insurance Card (EHIC) in order to receive free emergency care in EU countries.
4. All their medications (including for an extra week) plus suitable stand-by course of oral antibiotics. Remember to keep some medication in hand luggage in case of delays in airports. DNase will need to be carried in a cool bag.
5. Sunblock is needed if taking ciprofloxacin, doxycycline or voriconazole (and for 4 weeks after course has finished).
6. Adding extra salt to the food is usually sufficient. However, if going to a very hot & dry country, salt supplements may be necessary (Slow sodium (sodium chloride MR) 600mg (10mmol) tablets; 1 – 3 / day). This is also necessary in very hot weather in the UK.
7. In Europe (except for Cyprus, Gibraltar), the voltage for the nebuliser is not a problem (220v) and a standard travel plug adapter is all that is needed. If travelling to USA, South America, Caribbean, Cyprus, & Gibraltar, you will need a 110v nebuliser *e.g.* Port-a-Neb. A plug adapter is not enough. Discuss this with our Physiotherapy Department (extension 8088) well in advance of the holiday. A refundable deposit of £50 is required to borrow a nebuliser for a holiday.
8. Letter for customs explaining the need for all the drugs and equipment – available in clinic or from the CF secretary (appendix 13). There is a separate letter available for those with CF related diabetes.
9. Fitness to fly test needs to be considered. This consists of breathing 15% O₂ at sea level which is the equivalent O₂ concentration in the plane at altitude. It should be performed in patients with:
 - a history of oxygen requirement during chest exacerbations.
 - resting oxygen saturation < 94%.
 - FEV₁ < 50% predicted.
 - If on home oxygen, it will definitely be needed on the airplane, but a test can be used to determine flow rate necessary on the plane.

It is arranged with lung function laboratory (extension 88910). Patients who desaturate to less than 85% during the test (or who have baseline FEV₁ < 50% predicted) will need oxygen available during the flight. This is especially important during long haul flights when the children are likely to sleep. Patients whose SpO₂ is normally < 92% will definitely need oxygen, and those usually on home oxygen will need an increased flow rate. Oxygen is usually available at a flow rate 2 or 4 l/min and is not humidified, arrangements can be made through the travel agents, but adequate time is needed to do so. Costs vary between airlines (usually free of charge now). Signing the letter to say a patient is fit to travel must not be undertaken lightly – it is a disaster if a plane has to be diverted if the patient was not fit! If in doubt, check with a consultant.

Different airlines have different charges for providing on-board oxygen and these are available on the Pulmonary Hypertension Association website – <https://www.phauk.org/living-with-pulmonary-hypertension/travelling-with-ph/travelling-with-oxygen/airlines-rules-on-oxygen-use/>

Remember that oxygen for the airport itself is not part of the airline's responsibility.

10. Additional advice to drink plenty before & during flights. Chest physiotherapy should not be forgotten during long flights.
11. Check-up in clinic prior to departure may be necessary.

10.5 Palliative care

Death in childhood is a very unusual event amongst our CF population, and tends to happen in the hospital rather than at home. The overriding principal is that the child's comfort and wishes must come first followed closely by those of the immediate family. The management of a dying child needs to be flexible so as to cater for individual family needs. Regular daily (and if appropriate twice daily) reviews may be needed to accommodate changes in needs. We believe that communication amongst the CF team and ward staff is critical and must be consistent so as not to confuse the family (or the staff).

End of life care will be discussed with the parents by the child's consultant. These discussions, where possible and appropriate, should include the child. We would encourage an honest and open approach at all times, although we would also consider the wishes of the child and his or her family about sharing information. It is important that a child on the transplant waiting list receives appropriate end of life care and is not disadvantaged by false hopes of a last-minute donor organ becoming available.

Children and families should be given a choice as to where their child receives care. This can include staying at the tertiary centre, going to a hospital locally, a hospice or home. Informed discussions about the provisions available (including support and expertise) should be openly discussed with the family.

Specialist Paediatric Palliative care services are available to provide symptom management, support advance care planning and end of life care. All services offer a 24-hour telephone advice service for families and professionals:

1. The PATCH (Paediatric Palliative Care) service (based at Royal Marsden Hospital - RMH) Contact: 0208 661-3625 (Mon-Fri daytime) and out of RMH via Switch board (0208 642-6011) and ask operator for the PATCH service.

2. The GOSH palliative care team Contact: 020 7829 8678 (Mon- Fri daytime) and out of hours via Switchboard 0207 405 9200 and ask to be put through to the palliative care team

Additionally: The adult Palliative care team (Royal Marsden) provides a specialist adult service at the Brompton. Their service may be more appropriate in the older teenager and young adult population.

End of life care – the process

Please also refer to the Royal Brompton & Harefield NHS Foundation Trust policy document - "Guidelines for the management of patients and families during death and bereavement" available on the Trust Intranet; and NICE guidance for End of life care in children and young people.

- An advance care plan including symptom plan, preferred place of care and death, wishes, tissue donation, and emergency resuscitation plan should ideally be in place prior to, or at the start of, the end of life phase, (*e.g.* A commonly used Advance care plan document <http://cypacp.uk/>)
- Clear and open discussions about the appropriateness and need for specific observations, interventions and treatments should be discussed with the family and documented in the medical records for staff. This could include blood sampling and routine basic observations *e.g.* blood pressure monitoring. Intravenous access is usually unnecessary, since symptoms can often be managed via buccal, transdermal, enteral or subcutaneous routes.
- Regular review by the child's lead Consultant and Specialist nurses should continue and local services and involved professionals should be updated on any changes in the child's condition.
- Some of the medications should be continued, although only those offering symptomatic relief *e.g.* bronchodilators, enzymes supplements, humidified oxygen. Drugs such as antibiotics, vitamins, calorie supplements may offer no benefit at this stage.
- Gentle physiotherapy may be continued if it is giving symptomatic relief. It is such a way of life for most families that they may wish to continue it so that the child does not feel abandoned. The same may be true for some of the other therapies, so an individualised care plan should be agreed.
- Psychosocial support by the psychosocial team (including the CF clinical nurse specialists, family liaison team, psychology, play specialists and chaplaincy team) is offered to the patient with CF and their family. This is closely planned and offered to the family to prevent them feeling overwhelmed with support at such a difficult time.
- Each child and their family have specific cultural and religious needs, these should be sensitively explored. There is a hospital chaplain (020 73528121 Ext 4736), who leads a team of various faith representatives available both for consultation with staff members as well as to the child and their family. The child and family's local faith leader is welcomed if preferred by the family.
- Support for RBH staff both formal and informal is offered and all team members are encouraged to participate in treatment (or non-treatment) planning at all times.

Do-not-resuscitate (DNRCPR) and level of medical intervention recommendations must be discussed with the family (and when appropriate the child as well) by the consultant. Conclusions of the discussion must be documented clearly in the notes and on the trust DNRCPR forms.

Please refer to the Royal Brompton & Harefield NHS Trust policy document - "Do not attempt to resuscitation order in children and young people, the policy for the use of advanced statements and policy for the obtaining of consents" available on the Trust Intranet. Advance care plans and ReSPECT documents are replacing DNRCPR forms in many services. They provide a more comprehensive and detailed account of the levels of intervention offered to a child experiencing various clinical scenarios. The ReSPECT document is used to traverse all care and service settings.

Care at home

Should the family have decided to care for their child at home the local Paediatric & community teams will take the lead role in the child's care, with support from specialist palliative care services, and the CF community outreach team. The Specialist palliative care service will help facilitate the transfer of care and support the child and their family in all settings.

Medication for symptom relief

'APPM Formulary' provides up to date guidance on medication for children in the palliative care setting in the UK (it is also used throughout the world). This formulary is available free online via the APPM website and is regularly updated. The formulary is written from best evidence and expert advice (<https://www.appm.org.uk/>).

'Prescribing in palliative care' in British National Formulary for Children (BNFc) also provides advice around prescribing and drug doses.

1. Analgesia

- Paracetamol - oral.
- NSAIDs e.g. Ibuprofen- oral.
can be given with paracetamol.
- Short acting (immediate release) opiates:
 - Morphine: Oromorph (liquid) or Sevredol (tablet)
 - Oxycodone: Oxynorm (liquid or tablet)
 - Fentanyl: Fentanyl buccal or sublingual or intranasal spray (rapid release opiates)

Each drug has a different time to onset of action and clearance. The decision of which opiate to use should be based on the prescriber's experience with the opiate, the nature and onset of the pain and the child's route of administration preference.

In the opiate naïve child immediate release (IR) preparation should start on a standard starting dose. When a stable dose of opiate requirement is reached, this can be converted to a long acting opiate. The child may still experience breakthrough or incidental pain and require IR doses. The ongoing IR dose is 1/10th of the total 24hour background (long acting) opiate. Ensure constipation is avoided by a regular laxative when a child is commenced on an opiate. Nausea is a common side effect in the first few days of introduction to an opiate.

- Long acting (modified release) opiates:

Once the opiate requirement has been established the child could start a long acting opiate. The drug of choice will depend on the breakthrough opiate used *e.g.* Oromorph (breakthrough pain) and MST (long- acting agent) as well as the preferred route and preference of the child.

- Morphine: MST or Zomorph (oral)
 - Oxycodone: Oxycontin (oral)
 - Fentanyl: Fentanyl patches (transdermal)
 - Bupronorphine: BuTrans patches (transdermal)
- Opiate (IV/Subcut) infusions (*e.g.* Morphine, Diamorphine and Oxycodone) may be required especially if rapid pain controlled is required or gut absorption is poor. PCA (Patient controlled analgesia) may also be an effect means of pain control offering bolus sc/iv doses for breakthrough pain. PCA is offered in the community by both specialist palliative care services.

2. Anxiolytic

- Midazolam buccal or lorazepam sublingual for acute anxiety or longer-acting benzodiazepine *e.g.* Diazepam or Clonazepam may also be effective for frequent or persistent anxiety.
- Midazolam - (IV/Subcut)- Sedating and amnesic effect Nozinan (levopromazine) – (Oral /IV/Subcut)

3. Anti-emetic

- Cyclizine – (Oral /IV/Subcut)
May be 1st line if central element to nausea. It may also be given as a subcutaneous infusion using the total daily dose over 24 hours.
- Ondansetron – (Oral /IV/Subcut)
- Haloperidol - (Oral /IV/Subcut)
- Domperidone – (Oral)
- Lorazepam S/L for anticipatory nausea/vomiting.
- Levomepromazine – (Oral /IV/Subcut)
If no response to cyclizine, but useful as can be given subcutaneously, and has additional anxiolytic effect. May cause some sedation as well.
- Dexamethasone may help with nausea.

4. Cough

- Low dose (30-50% of pain dose) long-acting Opiates *e.g.* Morphine (MST/Zomorph) or Oxycodone (Oxycontin) may relieve intractable cough.

5. Dyspnoea

- Humidified oxygen may help.
- Opiates (Morphine/Diamorphine/Oxycodone) may also help with dyspnoea.
- Midazolam buccal for agitation or distress.
- Dexamethasone (Oral /IV/Subcut) may help bronchospasm / airway obstruction.

6. Restlessness / confusion / hallucinations

- Haloperidol – (Oral /IV/Subcut)
- Levomepromazine – (Oral /IV/Subcut)
- Midazolam (buccal) for acute agitation

7. Syringe driver mixing and compatibility

See APPM Formulary or BNFC for more details.

Once the child has died

More information is available on the Bereavement portal on the Trust's intranet

- The family should be given the opportunity to be alone with their child for as long as they want. Alternatively, they may require the presence of a member of the CF Team should they wish. It is worth gently encouraging the family to hold their child if they wish.
- The family should be offered the opportunity to take important and valuable memories of their child *e.g.* hand prints or casts, finger prints (silver casts), if they wish. There should be a memory box with equipment for the ward staff to use. Hospices are an excellent resource and guidance in this area. They have outreach hospice at home nurses who can support staff in this memory making.
- The on-call doctor will need to confirm death. This is done by looking for pupil reaction to light, feeling for a central pulse for 1 minute, listening for heart sounds for 1 minute, then listening to breath sounds for 1 minute.
- Inform the on-call consultant immediately unless they are already present.
- Inform the Bereavement team (ext. 82268) indicating that a child has died, giving their name, time of death and patient hospital number and ward.
- A bereavement pack must be given to the family (available on all wards and PALS office). They should also be given the Hospital Trust leaflet entitled 'When Your Child Dies'.
- The doctor will then need to write a medical certificate confirming the cause of death (MCCD) and this book is available on the PICU and Sydney Street reception, or in the PALS office. It is advisable for the doctor completing the MCCD to ensure they have seen the patient after death; this is because it is a compulsory requirement for completing a cremation form. If the death is 'Unexpected' (this is most unlikely with an expected death of a CF patient) then discuss with the on-call consultant. A discussion may be required with the coroner before the medical certificate is written. This discussion should take place in the presence of the bereavement officer.
- The family may wish to take the child home after death or transfer the child to a children's hospice local to their home. An advantage of the hospice is that the child can stay in a cooled bedroom or cooled bed for up to 5 days. Parents can visit freely or even stay in the hospice with their child. If going home, particularly during hot weather, it may be necessary for the family to use an air cooling units or mattress. A local funeral director will discuss this with the family or the team can contact the local hospice who may be able to provide this equipment. This cannot happen until the MCCD has been completed and handed to the family.

- The doctor or a member of the CF team must phone the GP and local paediatrician as soon as possible and record the time this is done in the notes.
- The CF nurse specialist is responsible for ensuring all members of the CF team at RBH and the local hospital are informed the child has died. The nurse will also ensure Out-patient Administrators are informed so that appointments are no longer sent to the family. Other health and allied services should also be informed.
- During normal working hours, either the paediatric family liaison team and/or the RBH Bereavement Officer (ext. 82268, or bleep 7701) will help provide information (including written literature) for the family. The CF CNS and/or family liaison team will be the main contact with the family once the child's body is no longer on the inpatient unit.
- Mandatory reporting. If a death is unexpected contact the local SUDI paediatricians - Dr Paul Hargreaves or Dr Kingi Aminu at Chelsea & Westminster Hospital. Far more likely is that deaths are anticipated, in which case no need to inform them. But we still fill in Initial Notification Forms A & B ensuring the box 'expected' is ticked and send to the single point of contact.
- Parents will need to make an appointment at Chelsea Old Town Hall (0207 351 3941) to register the death. They will need the death certificate in order to do this. The family will receive their child's 'Death certificate' from the Registrar at the Town Hall.
- They should be given the Hospital Trust leaflet entitled 'When Your Child Dies'.
- If a child has an expected death at home and the parents ring the ward, they must be told to phone their GP or community nurse when they feel able. If it is during the night they may want to wait until morning when the surgery opens. A death certificate will usually only be issued by their own GP or a doctor who has cared for the child during their last illness, the next working day. If they want a funeral director to move the child before a death certificate is issued, they need written confirmation of death from a doctor (usually the duty GP if out-of-hours) or a nurse (trained in confirmation of death). The on-call consultant must be informed immediately.

After care

1. Transport Home of a Child's Body from RBH

A child's body can be removed from the hospital at any time if it is an 'Expected' death and the MCCD has been completed by a doctor who has cared for the patient. The family may wish for the child to go home, to a relative's house or to a hospice. The documentation of death by a doctor is called the 'Medical certificate of Cause of Death (MCCD)'. The 'Death certificate' is the document issued by the Local Registry Office. According to the Child Death Review process all 'Unexpected deaths' should be discussed with the Coroner prior to any discussion or consideration about transfer of the body out of the hospital.

A parent can take a child's body home.
A hospital MCCD must be given to the family before they leave.
A covering letter from a doctor or another medical member of staff is required
The exception to this is if the child is travelling outside England or Wales where the Coroner must provide an Out of England Certificate prior to travel.

The family may wish to move the child themselves. If so:

1. Ensure they are given the MCCD.
2. Give them a letter (written by a doctor or nurse) stating
 - a. Date
 - b. Child's name, date of birth and that the child has died
 - c. Address they are travelling from
 - d. Address they are travelling to
 - e. Contact details of the doctor or nurse in the case the family are stopped on route by police.
3. Legally, a body must be transported "in a suitable container". We interpret this as meaning that children must be safely secured in a car seat, as they would be if alive (to prevent injury to other passengers in a collision)

If parents want the child to go home or to a hospice, but are unable to transport the child themselves, there are several options:

1. Contact a funeral director (either local to the family or local to the hospital). They will be able to arrange transfer of the child and can usually act fairly quickly. Normally parents bear the cost of transport of their child's body as part of the bill for the funeral if a Funeral Director is used.
2. The hospice may be able to advise on a local funeral director
3. The family may have a friend/relative who can help
4. See if hospital transport can assist
5. NB. London Ambulance Service DOES NOT perform this service

2. Bereavement support

- Parents will be invited (by letter) to come back to discuss any issues with a consultant, 4-6 weeks after the child's death.
- Bereavement counselling is available to families at the Brompton or we can help the family to try to access support in the community. There are various on line and telephone support forums/sites including:
 - Child death helpline (0800 282 986 | 0808 800 6019)- run by bereaved parents for bereaved parents
 - www.childbereavementuk.org
 - www.togetherforshortlives.org.uk/families/familys_journey/bereavement_support
 - www.cruse.org.uk
- The CF team should signpost the family to local bereavement services. This can be supported by the specialist palliative care team or the local hospice.
- Another invitation given routinely is to the hospital commemorative ceremony for children who have died. This is an annual event (late Oct/early Nov), comprised of words and music, open to those of any or no religion. Although the hospital chaplaincy and other religious leaders attend, there is no overt religious content. Parents chose music their child loved, or a reading, or ask for a poem they have themselves written. The

reading may be given by the parents themselves, by a sibling or a friend or staff member. A brief talk is given by a senior member of staff, and a brief closing ceremony such as the release of balloons ends the occasion. Refreshments are served.

- Staff 'debrief' meetings, facilitated by representatives from the paediatric clinical psychology team, are offered to all involved. Additional support is offered to staff as requested.

3. Child death review process

It is a statutory requirement to notify the Child death overview panel (CDOP) of all child deaths from birth up to their 18th birthday. After the child dies a child death notification form should be completed by the team looking after the child when they died. A Child death reporting form may be completed by other professionals involved in the child's care. The purpose of this form is to gather a wide range of information about a child's death and his/her illness. Its primary purpose is to enable CDOP to review all children's deaths in their area in order to understand patterns and factors contributing to children's deaths. This information contributes to the national child mortality database. A child death analysis form should be completed after a child death analysis meeting (similar to mortality meeting) which reviews the child's care and death and also reviews any questions raised by parents/carers. This should be completed within 3 months of the child's death.

<https://www.gov.uk/government/publications/child-death-reviews-forms-for-reporting-child-deaths>)