

Document prepared in consultation with WVT, CCG, STP End of Life Group

**Withholding or Withdrawing Life Support for Children**

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**Withholding or Withdrawing Life Support for Children**

**1.** **Introduction**

This document is a protocol which is adopted by Herefordshire Council.

The aim of this protocol is to provide practical guidance to social work practitioners when a child who is the subject of a statutory order made under section 31 [**Care Order**](http://trixresources.proceduresonline.com/nat_key/keywords/care_order.html), section 38 [**Interim Care Order**](http://trixresources.proceduresonline.com/nat_key/keywords/interim_care_order.html) or section 44 [**Emergency Protection Order**](http://trixresources.proceduresonline.com/nat_key/keywords/emerge_prot_order.html) of the Children Act 1989 becomes the subject of a “Do Not Resuscitate (DNR)” status or if consideration is being given to withholding or withdrawing life sustaining medical treatment.

This protocol also provides guidance in situations where a child is [**accommodated**](http://trixresources.proceduresonline.com/nat_key/keywords/accommodated.html) for the purposes of section 20 of the Children Act 1989 or abandoned. A distinction must be made between children subject to an order and those who are not, as in the case of the latter, Herefordshire Council’s Children’s Services do not share/hold [**Parental Responsibility**](http://trixresources.proceduresonline.com/nat_key/keywords/parental_respons.html) (unless PR has been delegated by agreement) and therefore our powers and duties are limited.

This protocol should be read in conjunction with the guiding principles set out in up to date relevant clinical guidance relied upon by health professionals. Please note that this guidance can be made the subject of future amendment and it should be ensured that the most up to date version is consulted.

The key current guidance is contained in the following documents:

* By the General Medical Council *“Withholding and withdrawing life-prolonging treatments: Good Practice in decision making” (2010[[1]](#footnote-1)*; and
* By Royal College of Paediatrics and Child Health *“Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice” (23 March 2015)[[2]](#footnote-2)*.

 **2.** **The reasons why a protocol is needed**

The Local Authority, in its role as a statutory parent, is involved in the decision making process when a child, who is the subject of an order (s31, s38 or s44 CA1989 Act) requires medical treatment.

Social work practitioners are sometimes faced with dilemmas as to whether it is in the best interest of the child/patient to start or continue treatment. These dilemmas can arise in cases concerning the possible application of advanced techniques of life support. The application of such techniques can have the potential in some cases to be able to sustain life artificially, where there exists little or no hope of recovery. In other cases their application may have the effect of simply prolonging the process of dying and of causing unnecessary distress to the patient.

This protocol sets out the Local Authority’s decision-making process and establishes clear guidelines for social workers to follow when faced with such difficult decisions.

This protocol is intended to assist all social work teams, where required across Children’s Services.

 **3.** **When does the issue arise?**

Once a patient is admitted to hospital, the medical staff are under a positive duty at common law to care for the patient. A fundamental aspect of this positive duty of care is a duty to take such steps as are reasonable to keep the patient alive.

However, the clinical team in charge of the patient’s care has an ethical obligation to ensure that the benefits of a particular treatment outweigh any burdens or risks associated with the treatment. Therefore, there are certain circumstances that may absolve a doctors’ positive duty to keep the patient alive.

The current guidance and case law suggest that, where it has been decided that a treatment is not in the best interests of the patient, there is no ethical or legal obligation for the treating clinicians to provide it. In such situations, there are two distinct treatment options that the hospital may need to consider:

1. **Withholding or the withdrawal of life sustaining medical treatment** - this is where the hospital is proposing to transfer life-sustaining care to palliative care.

1. **Do Not Resuscitate** - Cardiopulmonary resuscitation (CPR) is a process of restarting the heart and lungs of a patient. If a patient is the subject of a DNR status, the hospital will not attempt CPR and therefore there will be no further treatment.

**3.1** **Withholding or the withdrawal of life sustaining medical treatment**

In 1997 the Royal College of Paediatrics and Child Health (RCPCH) produced a framework for practice in relation to withholding or withdrawing life-saving treatment in children. This was subsequently updated in May 2004 and it has again been updated more recently on 23 March 2015. The framework reports that there are three sets of circumstances when treatment limitation can be considered because it is no longer in the child’s best interests to continue, because treatments cannot provide overall benefit:

1. **When life is limited in quantity**

If treatment is unable or unlikely to prolong life significantly it may not be in the child’s best interests to provide it.

These comprise:

A. Brain stem death (1), as determined by agreed professional criteria appropriately applied

B. Imminent death, where physiological deterioration is occurring irrespective of treatment

C. Inevitable death, where death is not immediately imminent but will follow and where prolongation of life by LST confers no overall benefit.

**2. When life is limited in quality**

This includes situations where treatment may be able to prolong life significantly but will not alleviate the burdens associated with illness or treatment itself.

These comprise:

A. Burdens of treatments, where the treatments themselves produce sufficient pain and suffering so as to outweigh any potential or actual benefits

B. Burdens of the child’s underlying condition. Here the severity and impact of the child’s underlying condition is in itself sufficient to produce such pain and distress as to overcome any potential or actual benefits in sustaining life

C. Lack of ability to benefit; the severity of the child’s condition is such that it is difficult or impossible for them to derive benefit from continued life.

**3. Informed competent refusal of treatment**

Adults, who have the capacity to make their own decisions, have the right to refuse LST and to have that refusal respected. So an older child with extensive experience of illness may repeatedly and competently consent to the withdrawal or withholding of LST. In these circumstances and where the child is supported by his or her parents and by the clinical team there is no ethical obligation to provide LST.

In situations other than those described, or where there is uncertainty about the nature of the child’s condition or its likely outcome, treatment should be continued until greater certainty is possible. The degree of certainty should be proportionate to the gravity of the decision to be taken. Adequate time must be allowed to collect evidence and this may entail obtaining second opinions from clinicians with appropriate skills, knowledge and expertise of the child’s condition.

Decisions to limit treatments—or what treatments should be given—should be made by clinical teams in partnership with, and with the agreement of, the parents and child (if appropriate).

They should be based on shared knowledge and mutual respect. Where possible they should be made in advance of acute events in the form of care plans and be available for all relevant parties.

A wide range of treatments may be withheld or withdrawn if it is in the child’s best interests to do so. They include cardiopulmonary resuscitation, clinically assisted nutrition and hydration as well as mechanical ventilation. Limitation of treatment agreements are increasingly used because of the greater range of options in decision making they offer.

**3.2** **Do Not Resuscitate (DNR) /** Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

Where a patient is already seriously ill with a foreseeable risk of cardiopulmonary arrest, or a patient is in poor health and nearing the end of their life, a decision about whether to attempt CPR could arise.

When considering the withholding or withdrawing of life support, the issue facing Children’s Services is whether to endorse the change in the treatment plan from actual treatment towards palliative or terminal care needs. In circumstances where DNR/DNACPR arises, there will be no life-saving treatment plan. As such Children’s Services have an involvement in whether or not to endorse the hospital recommendations not to treat the patient.

Children and Young People with chronic life threatening/life limiting conditions may have a Child and Young Person’s Advance Care Plan (CYPACP). The CYPACP is a document that records the advance wishes of an infant, child or young person and/or those with parental responsibility for them. A CYPACP will include whether the cardiopulmonary resuscitation status has been discussed, and the outcome of that discussion should a cardiorespiratory arrest occur. A child with a valid DNACPR decision in place should not have any attempt made to resuscitate them in the event of a cardiorespiratory arrest (excluding cardiorespiratory arrest due to rapidly reversible causes such as choking or anaphylaxis, or causes specific to the individual child as specified in the CYPACP). A DNACPR decision does NOT mean a withdrawal of care. Every attempt should always be made to make the child as comfortable as possible, and to fulfil the child’s and the family’s wishes. All children must be assumed to be for attempted resuscitation unless there is a valid, documented DNACPR decision in place. If there is any doubt about the validity or applicability of a DNACPR decision, then resuscitation should usually be initiated.

The ReSPECT process creates personalised recommendations for a person’s clinical care and treatment in a future emergency in which they are unable to make or express choices. These recommendations are published in a ReSPECT plan that is endorsed by the child (if they have capacity) and their parent. The CPR/DNACPR section is validated by the signature of a senior clinician and can be found in the ReSPECT form section 4 or on the final page of the CYPACP. Unlike for adults, where the option is for CPR to be attempted or not to be attempted, for anyone under 18yrs of age, there is also the choice of ‘modified’ CPR –The Child’s CYPACP/ReSPECT must be consulted and wishes considered.

 **4.** **Is consent required?**

The courts have accepted that where the withdrawal of life-sustaining treatment was in accordance with good medical practice and was appropriate in the clinical judgement of the doctors responsible for the patient’s care and best interests, it would be lawful to discontinue such treatment even though it would bring about the death of a patient[[3]](#footnote-3) . This is the minimum legal requirement.

When withdrawal or DNR is an option that has been raised by the clinical team, the hospital must then consider whether “consent” is sought to authorise the proposed action.

The guidance suggests that it is best practice to seek patient and/or parental consent in respect of a proposed treatment plan or non-treatment plan, and in the case of DNR, if the option is available[[4]](#footnote-4).

Usually in cases of doubt, the clinical team would seek the consent of the patient or those who have authority to consent on behalf of the patient.

**4.1** **Who Can Provide Consent?**

Once a child reaches the age of 16, they are presumed in law[[5]](#footnote-5) to be competent to give consent for themselves for their own surgical, medical or dental treatment, and any associated procedures, such as investigations, anaesthesia or nursing[[6]](#footnote-6)). Therefore the child should be treated as an adult.

Children under the age of 16 can be considered competent to give valid consent to a particular intervention if they have “*sufficient understanding and intelligence to enable him or her to understand fully what is proposed*”, otherwise known as Gillick competence[[7]](#footnote-7). Subsequent court rulings have retreated from the original Gillick level of respect for the competent child’s views and have reaffirmed parents’ rights of consent as a necessary legal protection when doctors care for minors[[8]](#footnote-8)

If a child is aged 16/17 or under 16 and is not competent to consent for themselves; consent must be sought from a person/body with [**Parental Responsibility**](http://trixresources.proceduresonline.com/nat_key/keywords/parental_respons.html).

Wherever possible consensus between the medical professionals, families and Local Authority should be achieved. In circumstances of dispute between medical professionals or any holder of PR, it is clear from the guidance[[9]](#footnote-9) that it is essential to safeguard the child’s life in the interim.

The local authority must make an application to the High Court in the following circumstances:-

1. Where there is no consensus between those who hold PR (including disagreement between holder of PR and the local authority) in relation to medical advice and proposed care plan in respect of treatment or otherwise
2. Where there are doubts as to the ability of anyone with PR to give valid consent
3. Where someone with PR cannot be located

**5.** **Legal responsibilities of the local authority parent**

**General**

The Children Act 1989 provides an overall statutory framework for the provision of children’s welfare and services but makes no specific provision concerning withholding or withdrawing treatment. The bundle of parental rights and duties which is comprised in “parental responsibility” under the Act includes the right to consent to the giving or withholding of medical treatment (subject to the consent of other holders of PR). The Act does specifically provide that:

* The child’s welfare is paramount[[10]](#footnote-10);
* Particular regard should be paid to the ascertainable wishes and feelings of the child[[11]](#footnote-11);
* Children of sufficient maturity and understanding may be allowed to refuse medical or psychiatric examination or other assessment (but only for the purpose of a Child Assessment Order (section 43 (8)) or an Emergency Protection Order (section 44 (7).)

Social workers must bear in the mind the above principles at all times when considering the issue of DNR or the withdrawal / withholding of life support.

A social worker (and other local authority officers – please see the scheme of delegation) will only become involved in decisions of a child/young person’s medical treatment if the child / young person is subject to the following:

* An interim / full care order (section 31 and 38 of the Children Act 1989);
* An emergency protection order (section 44 of the Children Act 1989).

**5.1** **Full Care Orders[[12]](#footnote-12)**

If the local authority obtains a full care order, it gains Parental Responsibility and by virtue of the order, it is empowered to give consent to certain medical treatment matters on behalf of a child.

Whilst the local authority is given the power to consent to medical treatment, the local authority must also obtain consent from all other holders of PR to any medical treatment/intervention on behalf of the child. Due to the significance of withholding end of life treatment and the difficulty of assuring itself that any consent is fully informed consent, consideration must be given by the local authority to making an application to the High Court.

If the child is the subject of a full care order there should be an application to the High Court where:-

* + 1. There is any conflicting medical advice as to what is in the best interests of the child;
		2. There is any disagreement between any person holding parental responsibility and the medical advisors. The local authority must not rely on its PR to override the consent of any other parental responsibility holder unless there is in place a High Court order authorising the local authority to do so in the circumstances with which it is faced.
		3. There is any doubt as to the ability of any person holding Parental Responsibility to give a fully informed valid consent
		4. There is information to suggest that the child concerned had expressed a view regarding treatment which differed to that of those with parental responsibility
		5. The local authority believes based on the history and current circumstances that the people holding parental responsibility should not be informed or consulted about the issue
		6. Where there is an inability for any reason to consult with those holding parental responsibility.
		7. Where the day to day care of the child has been undertaken for an extended period of time by carers who do not hold PR for the child but who have expressed a different view on the proposed treatment to the local authority and other PR holders

If there is any doubt as to whether or not the matter should be referred to the court for the court to make the ultimate best interests decision then the best course of action would be to bring the matter before the Court.

**5.2 Where court proceedings are ongoing**

Where a child is already the subject of court proceedings pursuant to the Children Act 1989, and the local authority is considering a High Court application, the Court must as a minimum be informed of the evolving circumstances at the earliest possible opportunity.

**5.3 Interim Care Order[[13]](#footnote-13)**

The local authority should make an application to the High Court

This approach was endorsed in in the matter of Re K (A Minor)[[14]](#footnote-14), where it was held that in the case of a seriously ill child who was the subject of an ICO, the parents were not legally able, without the agreement of the local authority, to make a decision to consent to the withdrawal of the treatment. In this case a declaration was sought and obtained from the High Court that the treatment should be withheld.

**5.4 EPO[[15]](#footnote-15)**

The local authority should make an application to the High Court

**5.5 Ward of Court**

An application must be made to the High Court.

 **6.** **Hospital’s Responsibilities**

If a child or young person who is subject to an ICO or Final Care Order is admitted into hospital with a life threatening condition, this protocol should be observed.

In the cases of a planned withdrawal of CPR or withholding life supporting treatments or withdrawing artificial nutrition and hydration the hospital will ensure:

* That an appropriate and clear plan is identified for the child;
* This must be recorded in the hospital notes and consistent with the CYPACP+ ReSPECT plan
* That this is communicated to the social workers at the first available opportunity to  enable them to determine the Children’s Services formal position with the benefit of its own advice as necessary;
* That every possible option has been considered with a view to sustaining life;
* That there exists good co-operation and communication between children’s services, hospitals, children and their families to facilitate collaborative decision making at a difficult and sensitive time;
* That it will improve and develop an appropriate support service to children and their families.

 **7.** **The Procedure**

**7.1** **The Hospital’s Role**

**Stage 1: Relevant Persons to be notified**

Once the clinical team/leading doctor has formed a view that a child who is in statutory care should be the subject of a DNR status and/or the issue of withholding or withdrawing life support has arisen, written notification of this must be circulated to the Children’s Services relevant Team Manager. The notification must set out the following:

* The clinical recommendations of the leading clinician and or team in respect of the child;
* Whether parental consent to the action is perceived to be required or not, and if not the clinical guidance which is relied upon to justify that conclusion.

**Stage 2: The Planning Meeting**

A Planning meeting must called by the hospital to discuss the hospital’s view as soon as possible after the notification has been given.

Present at the meeting should be the Children’s Services Team Manager and social worker, any parent or guardian (any holder of PR) and the relevant treating clinicians.

At the Planning Meeting, the leading treating Consultant must circulate a written report clearly setting out their recommendations and the proposed care plan. The care plan must set out the proposed timescale and process for any change in the health care plan. Under no circumstances must the process / timescale be rushed and it should take into account sufficient time to enable Children’s Services and/or parents/those with parental responsibility to reflect on the recommendations and to communicate any relevant views to the hospital with the benefit, where necessary, of professional advice.

**7.2** **Children’s Services Role**

Once the social worker is informed by the hospital staff that DNR / Withholding / Withdrawing Life Support is being considered, the following procedure is to be applied:

1. The following people are to be notified immediately:
	* Director of Children’s Services – (Social Care lead);
	* Assistant Director of Children’s Services
	* The identified legal advisor from Legal Services and Head of Childcare legal team;
	* The social worker’s team manager.
2. Social workers should ensure that written notification is obtained from the leading clinician and they should forward this to the relevant people identified above;
3. Contact should be made with the parents and any other individuals who hold parental responsibility in order to ensure that they attend the Planning Meeting (as discussed at 6) in order to ensure that they are fully aware of the proposed decision of the hospital and in order to obtain their consent. It should be established whether there is a need for interpreting services, communicators/advocates or signers at the Planning Meeting;
4. At the Planning Meeting, any consent that is given should be recorded in writing. Even in cases where the local authority holds PR, all other PR holders and medical advisors agree with the proposed course of treatment, there should be discussion as to whether or not it would be appropriate to take the matter to court. There should be a clearly noted discussion of the fact that a referral to the High Court was an option which the local authority would undertake if any person holding parental responsibility wished for that route to be taken and that any person holding parental responsibility is made aware of this option. Whilst consensus has benefits, attempts to achieve it should not result in any person with parental responsibility feeling under pressure to agree or feeling that they have no other course of action available to them.
5. Medical professionals may have previously discussed the recommendations, and social workers need to be clear about the nature of any meetings and ensure all the relevant medical professionals will attend;
6. Both the social worker and team manager must attend the Planning Meeting arranged by the hospital;
7. All holders of PR should be invited to the Planning Meeting to ensure they fully understand the hospital’s treatment plan;
8. Following the Planning Meeting, it is the social worker’s responsibility to update the identified legal adviser of the outcome of the meeting and any other subsequent meeting and arrange a Legal Planning Meeting should be made as soon as possible thereafter, as necessary;
9. If consent remains an issue of dispute following the Planning Meeting, the following persons are to be notified as necessary:
	* Director of Children’s Services;
	* Cabinet Member for Children’s Services (to be notified by the Director);
	* Chief Executive (to be notified by the Director).
	* The legal department
10. Social workers should ensure that case recordings are updated as soon as possible and accurately reflect any discussions held with parents, carers, children and the medical professionals.

**7.4** **Disputes**

**7.4. Disputes between the medical practitioners and Children’s Services**

When withdrawal of medical treatment or DNR is an option that has been raised by the medical team and consent to carry out such treatment is required, section 7 and 8 of the protocol will apply.

In accordance with paragraph 76 of the GMC guidance, if any holder of parental responsibility is not willing to authorise treatment, the medical practitioner is bound by the refusal unless his responsible hospital trust obtains a ruling from the court.

In respect of children who are the subject of an interim or final care order, the hospital trust should only accept a decision whether to administer the withdrawal or withholding of life sustaining treatment or endorse a DNR status from a non-statutory or statutory Chief Officer on behalf of Children’s Services, being:

* The Director of Children’s Services;
* The Chief Executive.

It is the responsibility of the Local Authority to obtain consent from all those with PR, if a consensus cannot be reached then the local authority is required to seek a declaration from the High Court in respect of the decision.

Even when those with PR appear to be consenting to the decision, a record should be made by the local authority that they offered the Holders of PR the opportunity to take the matter to court, and such an offer should be recorded in writing. If there is any query whatsoever about whether they have given fully informed consent, the local authority is required to seek a declaration from the High Court in respect of the decision.

**7.4.2 Disputes between Children’s Services and parent /guardian**

This situation arises when parental consent is required but the local authority and those with PR fail to achieve a consensus.

If such consensus cannot be achieved, the legal team must be informed and an application must be made to the High Court for a declaration in respect of this decision.

Once practitioners have complied with section 7.1 - 7.2 of this protocol, the following procedure should be applied;

1. The team manager must forward the written report / recommendation of the treating / leading clinician to the Lead Consultant Paediatrician for the relevant treating hospital;
2. The Lead Consultant Paediatrician to consider the report and provide her recommendation in respect of the proposed treatment. This report is to be forwarded to the social worker and team manager:
3. Once the social worker and team manager are in receipt of the report from the Lead Consultant Paediatrician they must forward this to the following persons:
	* Director of Children’s Services
	* The identified legal advisor and Head of the Childcare legal team;

In matters where parental consent is sought and the child is under an interim or final care order, the hospital trust should only accept a decision whether to administer the withdrawal or withholding of life sustaining treatment or endorse a DNR status from:

* The Director of Children’s Services;
* The Chief Executive.

Before communicating this decision, the local authority in these circumstances should have reached a consensus in respect of the decision with the holders of PR (if there is any doubt as to whether full informed consent has been given then an application should be made to the High Court for a declaration), and if no consensus has been achieved, an application for a declaration from the High Court regarding this decision needs to be obtained prior to this decision being communicated to the hospital trust.

The hospital must act in accordance with the written notification of Children’s Services.

**7.4.3 Dispute between the local authority and the parents in respect of a child subject to an Emergency Protection Order**

If the child is subject to an EPO as with ICOs and Final Care Orders, declaration from the court under section 100 of the Children Act 1989 is required.  Again, the onus is on the local authority to make the application.

**7.4.4 Dispute between the local authority and children aged 16 - 17 or “Gillick” competent**

The wishes of a child, who has the capacity to decide whether to consent or refuse a proposed treatment should normally be respected, however if Children’s Services in its statutory care authority role disagrees with the child, legal advice should be sought immediately.

**9.** **Section 20 / Abandoned Children**

This protocol focuses upon children who are the subject of a care order. However social workers may find themselves in situations where abandoned child/ren are admitted into hospital with life threatening conditions. For example, when a child is born with multiple disabilities and is left in the hospital with staff.

Children’s Services responsibility for abandoned children is limited to section 17[[16]](#footnote-16)) and 20[[17]](#footnote-17) of the Children Act 1989 and therefore it does not acquire parental responsibility without obtaining a care order or emergency protection order. Therefore, if the hospital is considering the possibility of administering the withdrawal or withholding of life sustaining treatment or DNR, it is vital that Children’s Services uses its best endeavours to contact the parents.

Until a parent is contacted to discuss their consent, a medical practitioner should continue to treat the child provided it is limited to that treatment which is reasonably required either to save the child’s life, or to prevent deterioration in the child’s health.  However, for any child/young person with an agreed CYPACP+ ReSPECT in place this should be followed even when the parent or legal guardian is NOT present at the time of the child’s acute deterioration or collapse (CYPACP Policy 11.4)

If a parent does not provide consent, it will be the hospital in this instance who make the application for a declaration from the High Court as the local authority would not share PR in these circumstances. The local authority would need to ensure that it is made clear to the hospital that it does not share PR and therefore it is not able to provide consent.

 **10.** **Removal, Storage and Use of Human Organs**

The issues of transplant and / or organ donation is addressed in the Human Tissue Act 2004. Under section 1 of the Act, it is lawful to store, use and remove human organs of a deceased person and use it for a purpose specified within the Act provided “appropriate consent” is obtained. The schedule of the Act is annexed to this protocol for ease of reference. Within the CYPACP the child or young person and their carer/parent have the opportunity to express their wishes in regards to organ and tissue donation.

Under section 2 of the 2004 Act, “appropriate consent” under section 1 of the Act in relation to the body of a person who is a child or has died as a child is defined as:

1. Where the child is alive, “appropriate consent” means the consent of the child (section 2 (2)); OR
2. Where the child is alive, but does not have the capacity to consent (either by virtue of being a minor or otherwise) or fails to consider the issue, if s/he are competent, “appropriate consent” means the consent of a person who has parental responsibility for him (section 2 (3)).

If a child has died and the issue of organ removal arises, then section 7 of the 2004 Act will apply:

1. “Appropriate consent” means the consent of the child, if it was in force immediately before he died (section 7 (a)); OR
2. If no consent is in force, the consent of a person who had parental responsibility for him immediately before her died section 7 (b) (i)”.

Therefore, if the child is subject to a care order, Children’s Services must provide the consent on behalf of the child. Consent should however be obtained from the other holders of PR. If no consensus is reached then the Children’s Services department can make this decision as it is not possible to seek a declaration from the High Court in respect of a child who has deceased. Social workers must ensure that the consent forms, if agreed, are signed by a Chief Officer on behalf of Children’s Services, being one of:

* The Director of Children’s Services;
* The Chief Executive.

 **11.** **Procedures Following the Death of a Child Subject to a Care Order**

It has been held that the effect of a care order (and thus parental responsibility held by a local authority) ceases on the death of a child[[18]](#footnote-18). Nevertheless the social worker must complete the following before proceeding to close the relevant files:

* Complete an OFSTED Serious Incident Form and send a copy to The Director of Children’s Services and the Head of Commissioning Services and OFSTED;
* Notify the Secretary of State and the Commission for Social Care Inspection[[19]](#footnote-19)
* Inform the Safeguarding Children Partnership;
* Notify the corporate parenting team;
* Notify the local PCT;
* Complete an Event Form;
* Notify care agencies if support services have been in place;
* Notify the Herefordshire Council Business and Finance Manager;
* Notify benefits agency when appropriate if a child is in receipt of benefits e.g. Disability Living Allowance;
* Notify the Child Health Department;
* Ensure that the date of death is recorded on computer system and case file.

Workers **must** obtain a copy of the Death Certificate.  It is usual for the parents to register the death.

**Funeral Arrangements**

The right to arrange the disposal of the remains of a child vests exclusively in the parents.

Funeral arrangements for a Looked After Child is dealt with in paragraph 20 of Schedule 2 to the Children Act 1989 as follows:-

* The local authority may, **with the consent** (so far as it is reasonably practicable to obtain it) of every person who has parental responsibility for the child, arrange for the child’s body to be buried or cremated. In relation to a child who was under the age of 16 when he died, the local authority may recover from the parent of the child any expense incurred by them;
* The local authority may make payments to any person who has parental responsibility for the child, or any relative, friend or other person connected with the child, in respect of travelling, subsistence or other expenses incurred by the person in attending the child’s funeral, subject to (a) it appears to the authority that the person concerned could not otherwise attend the child’s funeral without financial hardship and (b) the circumstances warrant the making of the payments.

Following the death of a child, the social worker should discuss the funeral arrangements with the parents/guardians and establish whether they wish to organise the funeral. Social worker should also establish whether the child has an estate.

If the parent is unwilling or unable to arrange the funeral and has no other financial means, and the child has no estate, the local authority can apply for funding to support the funeral arrangements.  The social worker must ensure that they contact legal services for advice. Under **no circumstances** do social workers arrange a funeral without seeking advice and guidance.

If a child does have an estate this goes directly to the parent who can use this finance to pay for the child’s funeral as the family will not be eligible to apply for a death grant.

The allocated social worker will remain in contact with the family until the funeral has taken place.

The allocated social worker will ensure that appropriate counselling and support services are offered, to the family should they require post funeral support.

If CYPACP in place, consideration should be given to any wishes re place of rest/funeral preferences/possessions agreed prior to C/YP death

1. ***The General Medical Council****. Treatment and care towards the end of life: good practice in decision making. GMC, London; 2010. http://www.gmc-uk.org/guidance/ethical\_guidance/6858.asp Accessed May 2020* [↑](#footnote-ref-1)
2. *Larcher V Craig, Craig F, Bhogal K, et al. Arch Dis Child 2015 :100 (suppl 2) s1-s23* [↑](#footnote-ref-2)
3. Airedale National Health Service Trust v Bland (1993) Re J (1991) Fam 33 AND Re c (1998) 384 [↑](#footnote-ref-3)
4. GMC Gudiance - August 2002 [↑](#footnote-ref-4)
5. Family Law Reform Act 1969 [↑](#footnote-ref-5)
6. Section 8 of the Family Law Reform Act 1969 as amended. [↑](#footnote-ref-6)
7. Gillick v West Norfolk & Wisbech HA in 1986 [↑](#footnote-ref-7)
8. Re R (1991) 4 All ER 177, 185 Re W (1992) 4 All ER, 633 [↑](#footnote-ref-8)
9. ***The General Medical Council****. Treatment and care towards the end of life: good practice in decision making. GMC, London; 2010. http://www.gmc-uk.org/guidance/ethical\_guidance/6858.asp Accessed May 2020 and* Royal College of Paediatrics and Child Health *“Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice”Larcher V Craig, Craig F, Bhogal K, et al. Arch Dis Child 2015 :100 (suppl 2) s1-s23* [↑](#footnote-ref-9)
10. Children Act 1989 section 1 [↑](#footnote-ref-10)
11. Children Act s 1 (3)(a) [↑](#footnote-ref-11)
12. section 31 of the Children Act 1989 [↑](#footnote-ref-12)
13. Section 38 of the Children Act 1989 [↑](#footnote-ref-13)
14. (2006) EWHC 1007 (Fam) [↑](#footnote-ref-14)
15. Section 44 of the Children Act 1989 [↑](#footnote-ref-15)
16. It shall be the responsibility of the local authority to safeguard and promote the welfare of the child within their area who is in need. [↑](#footnote-ref-16)
17. The duty to provide accommodation. [↑](#footnote-ref-17)
18. R v Gwynedd County Council ex parte B (1992) 3 All ER 317, (1991) 2FLR [↑](#footnote-ref-18)
19. Children Act 1989, Schedule 2, para 20. [↑](#footnote-ref-19)