Brian House Children's Hospice
Position statements on common ethical dilemmas

Information governance and confidentiality of personal data

Brian House Children's Hospice keeps the minimum identifiable personal information on the children/young people and families it cares for so a safe, effective and high standard of care can be provided. We hold personal information on the child/young person and their family, both electronically and on paper. To provide effective care we need to share information with other professionals but, wherever possible, we will tell you who we are sharing the information with and why. We will ask you as soon as your child is referred to our service whether you are happy for us to do this and explain how it can be helpful in caring for your child. The main exception to this is when there may be a safeguarding concern about a child and then, because it is in the best interests of that child, we may not seek consent from parents to share information with the appropriate authorities.

All personal information about your child and family will be checked regularly with you to make sure it is correct and we will always keep it safe. We have clear guidelines around which staff and volunteers can access your child and family's information and this includes maintaining your confidentiality. Any breach of a child and family's confidentiality by a staff member or volunteer is treated as a serious offence. Brian House is compliant with the Data Protection Act 1998 and the Caldicott Guardian for our organisation, who is responsible for making sure all information we hold is kept safely, is our Medical Director.

Once a young person cared for in Brian House reaches the age of eighteen then the statement on this subject written for Trinity Hospice will apply. This states that no identifiable, personal information will be shared with anyone else, including family members, except with the expressed permission of the person concerned. However many of the young people reaching the age of eighteen in Brian House have some learning difficulties and are unable to consent themselves. Professionals leading their care will then act in that young person's best interest, following the procedures laid down in the Mental Capacity Act. Brian House recognises that many parents of children we care for have always had to take decisions surrounding their child's care so will continue to be consulted and involved.

It should also be noted that Brian House is a charity and must raise funds to run the service. Any clinical information will be kept separate from information of those who donate to us, but this may sometimes mean that information about one person may be held on two databases at the same time.

Susan Salt Medical Director
January 2018

Position statement on the doctrine of double effect

The doctrine of double effect states that the risk of a potential known, unintended consequence or side effect of treatment is justified only if all the following criteria are met:

- The intended effect is good in itself
- The clinician's intention is solely to produce the good effect
- The intervention is proportionate to the situation
- The good effect is not achieved through the bad effect

We do not believe that the doctrine of double effect is relevant to the care of children / young adults in a paediatric palliative care setting because:

- Brian House Children's Hospice does **not** accept that morphine or similar strong painkillers or sedative drugs, when used appropriately to manage symptoms as a child/ young adult approaches the end of their life hastens death.
- We believe that the correct use of drugs routinely used in paediatric palliative care to treat symptoms and have no impact on length of life.
- We believe that there is currently no credible research evidence that suggests a child's life is shortened either by strong painkillers such as morphine or sedatives when used within accepted palliative care practice.

Medication which is sedating in its effect will only be used within Brian House Children's Hospice to treat symptoms of agitation, restlessness and distress. If sedating medication is used, it will be given at an appropriate dose tailored to the child's needs and in relation to the severity of their symptoms. We believe that sedating medication used in this limited and controlled way does not shorten life.

Rarely, children may experience distress when symptoms cannot be controlled even after many attempts with specific interventions. In these circumstances, some patients may require sedating medication to diminish awareness of their suffering. All medication used for symptom control, including the use of sedative medication, is aimed at the relief of specific symptoms. Sedation used in this way is sedation while the child dies and not sedating the child to death.

Morphine and related painkilling drugs are wholly unsuitable for use as sedation and will not be used for this purpose within Brian House.

Susan Salt Medical Director
January 2018

Position statement on advanced care planning

Brian House supports the use of advanced care plans as a way of planning for an uncertain future.

Advance care planning allows individuals and those important to them, where appropriate, to think about and express their wishes and preferences about the kind of care they would like to receive at the end of life. This may include issues such as the location of end of life care, withholding or withdrawing certain treatments and who should be involved in decision making.

We will encourage and support the child or young person to be involved as much as they wish to be involved and as far as they are able. We will support and encourage the production of advance statements about wishes and, where appropriate, advance statements to refuse certain types of treatment or intervention.

We recognise that writing an advance care plan is complex and challenging and needs to take into account wishes and needs alongside their understanding of their condition and local resources.

Advanced care planning will be undertaken in a sensitive, timely manner after honest conversations with the child/young person, their parents and those they choose to be part of such discussions.

Writing an advanced care plan will recognise what may happen to a child as part of their journey, and will be re-discussed and amended if wishes change. The writing of an advance care plan is voluntary and can be changed at any time.

We see advance care planning as a process, not a single discussion and will support and provide parents with the information they need, and ensure they have the time required, to make such a plan if that's what they wish to do for their child.

With the consent of the individual, advance care plans will be shared with other organisations involved in that person's care. Once a young person cared for in Brian House reaches the age of eighteen the statement on this subject written for Trinity Hospice will apply.

Susan Salt Medical Director
January 2018

Position statement on Cardio-Pulmonary Resuscitation (CPR)

Most children cared for in Brian House, although having a diagnosis of a life threatening or shortening condition and unlikely to reach adulthood, are stable within their condition whilst staying at the hospice for respite care.

Clinical staff will discuss the issue of cardio-pulmonary resuscitation with parents when a child is accepted for care at Brian House and explain the limitations of resuscitation that we are able to provide. Whether a child is for resuscitation, and subsequent transfer to Blackpool Teaching Hospital, will be recorded on the child's consent form.

Brian House w**ill** ensure that all clinical staff are trained to provide **basic** cardio-pulmonary resuscitation for both adults and children. Brian House **will not** perform **advanced** cardio-pulmonary resuscitation (including defibrillation and the administration of medication to restart the heart) on anyone cared for within the hospice or anyone visiting the hospice.

Some children have an advanced care plan in place and this may state within it the limit of resuscitation measures a child will receive. This information will be cascaded to all services involved with the child - including the ambulance service - so if appropriate, resuscitation will not be started.

Declining cardio-pulmonary resuscitation is a very specific decision and will not affect any other decisions about care. Hospice staff are willing to discuss decisions around cardio-pulmonary resuscitation with children, young people and their families and will support them in any decision made. Such a decision will be reviewed on a regular basis.

Once a young person cared for in Brian House reaches the age of eighteen the statement on this subject written for Trinity Hospice will apply.

Susan Salt Medical Director
January 2018

Position statement on the use of an individualised care plan in the last few days and hours of life

Brian House supports the widespread use of prompts and frameworks to empower good care and open communication with the child/young person who is dying (if able) and their family, to ensure there is two-way conversation in determining the care a child/young person will receive at the end of their life. This will be individualised to the child/young person and their family and is dependent on excellent, honest and open communication.

The goal of an individualised care plan at the last few days or hours of life is to ensure that a death is as dignified as it can be.

No matter how ill a child, play is an important part of a child's life and should not be forgotten, telling stories, music and blowing bubbles for example can be enjoyed by the most poorly of children and in addition can have a beneficial effect on parents caring for their child at this time.

An individualised care plan for the last days or hours of life should only be started if professional, child (where able) and family agree that the person may be approaching the end of life.

The plan asks staff, along with the child and family, to review the care of the child on a regular basis. If the situation changes and new information comes to light or the child appears to improve the plan should be revised. The plan MUST be based on the unique needs of the child approaching the end of their life and those close to them. It does not tell a child, or professional or a family member what should be done; rather it encourages discussion about what seems to be the right thing to do for this child, at this moment.

Such a discussion will involve the review of how useful certain interventions are at this stage in a child's illness, including:

- Prescribed medications
- Tests and observations
- The most appropriate way to keep the child physically as comfortable as possible. This might include some or all of the following:
    - Providing regular mouth care
    - Offering small sips of fluid, tastes of soft food such as ice cream or sorbet
    - Using a subcutaneous syringe driver to make sure key medicines to control symptoms are administered even when the child is too tired or unable to take them by mouth
    - Using an appropriate bed and pressure relieving mattress
    - Whether fluids should be given artificially when a patient is unable to eat or drink
- The spiritual or religious needs of the child and those closest to them
- Clear agreement around which members of staff are responsible for reviewing the child with the family. This should include general agreements around mutually convenient meeting times, frequency and length.

Susan Salt Medical Director
January 2018

Position statement on the use of drugs beyond licence in palliative care

Brian House recognises that the use of drugs beyond licence is both necessary and common in paediatric palliative care and should be seen as a legitimate aspect of clinical practice.

Prescribing unlicensed may be necessary where:

- There is no suitably licensed medicine to meet the child's need
- A medicine is licensed for use in one group and is used in another group
- Dosage specified for a licensed medicine would not meet the need of the child
- The child needs a medicine in a formulation that is not specified in an applicable licence
- A suitably licensed medicine that would meet the child's need is not available e.g. a temporary shortage
- As part of a properly approved research project

It is expected that parents will be made aware that they are taking a medication beyond its UK licence and the reasons for this.

All medication available from legitimate sources, whether licensed or unlicensed, and prescribed by an authorised practitioner must comply with strict manufacturing, safety and reliability tests. The term unlicensed is used to describe medicines that are used outside the terms of their UK licence or which have no licence for use in UK. This does not mean the medicine is ineffective but more likely that that no pharmaceutical company has submitted a request to the licensing authority to license its use.

Healthcare professionals involved in prescribing, dispensing and administering drugs beyond licence should select drugs that offer the best balance of benefit against harm for any given patient. Only therapeutic practices that are underpinned by evidence and advocated by a responsible body of professional opinion will be used within Brian House.

When an unlicensed medicine is prescribed the clinician must:

- Be satisfied that there is sufficient evidence or experience using the medicine to demonstrate safety and efficacy
- Take responsibility for prescribing the medicine and for overseeing the child's care, monitoring and follow up or ensure arrangements for another suitable doctor to do so
- Make a clear accurate and legible record of all medicines prescribed
- Where a clinician is NOT following common practice, the reasons for prescribing an unlicensed medicine and explicit account of the potential risks and benefits of the course of action followed.

Susan Salt Medical Director
January 2018