

ANNEXE B – FAMILY AND CARER INVOLVEMENT PROTOCOL**1.0 INTRODUCTION**

- 1.1 Dealing respectfully, sensitively and compassionately with families and carers of dying or deceased patients within the NHS is crucially important.
- 1.2 The Trust is committed to engaging meaningfully and compassionately with bereaved families and carers in relation to all stages of responding to a death and will operate according to the key principles outlined below:
 - 1.2.1 Bereaved families and carers should be treated as **equal partners** following a bereavement;
 - 1.2.2 Bereaved families and carers must always **receive a clear, honest, compassionate and sensitive response** in a sympathetic environment;
 - 1.2.3 Bereaved families and carers should receive a **high standard of bereavement care** which respects confidentiality, values, culture and beliefs including being offered appropriate support. This includes providing, offering or directing people to specialist suicide bereavement support;
 - 1.2.4 Bereaved families will be informed of their **right to raise concerns about the quality of care** provided to their loved one;
 - 1.2.5 Bereaved families' and carers' views will **help to inform decisions about whether a review or investigation is needed**;
 - 1.2.6 Bereaved families and carers should receive **timely, responsive contact and support in all aspects of an investigation process**, with a single point of contact and liaison;
 - 1.2.7 Bereaved families and carers should be **partners in an investigation** to the extent and at whichever stages that they wish to be involved as they offer a unique and equally valid source of information and evidence that can better inform investigations; and
 - 1.2.8 Bereaved families and carers who have experienced the investigation process should be supported to work in partnership with the Trust in **delivering training for staff in supporting family and carer involvement** where they want to.
- 1.3 The Trust will act at all times in accordance with the principles of openness, honesty and transparency as set out in the Duty of Candour in all dealings with bereaved families and carers.
- 1.4 This Protocol will apply to all deaths occurring in an in-patient facility of EPUT and to deaths of EPUT patients in a community setting which are deemed to be a "serious incident".

- 1.5 The purpose of this protocol is to set out the actions which should be taken by staff in terms of family and carer involvement following the death of an in-patient or a death in the community deemed to be a serious incident.
- 1.6 Family and carer involvement processes for deaths of patients outside of an inpatient facility and in the community which are not deemed to be a serious incident are being developed.
- 1.7 This protocol applies to all workers within the Trust either permanent or on a temporary basis and to volunteers.
- 1.8 This protocol should be read in conjunction with other policies and procedures relating to mortality review, adverse incidents, Duty of Candour and care of the deceased patient.

2.0 FAMILY AND CARER INVOLVEMENT AND SUPPORT IMMEDIATELY POST- BEREAVEMENT

2.1 All inpatient deaths and deaths classified as serious incidents:

Following the death of a patient, the senior clinician on duty will make contact with the appropriate family member / carer immediately after the death to inform them of the death.

2.2 Families can expect that:

- The Trust will engage them in a sensitive and transparent manner and offer sincere condolences for their loss.
- They will be informed immediately or as soon as possible after a death - where possible this should be done in person in a private space.
- The staff member conveying this news will give as much information as they can about the circumstances of the death and answer any questions raised by the family that they can.
- They will be told at the first point of notification that they can comment on the care of the person who has died, and raise any concerns. This should include information on the ways they can comment or complain in line with Trust Procedures.
- Communication will be clear, sensitive and honest giving as much information as possible in line with the Duty of Candour. It is important for people who are bereaved for others to recognise and acknowledge their loss.

2.3 Every effort should be made by the senior clinician on duty to hold these discussions in a private, sympathetic environment without interruptions.

- 2.4 The primary objectives of this discussion are to:
- inform the family / carer of the death;
 - offer the bereaved family / carer immediate support;
 - signpost specialist on-going bereavement support (see section 3.0 below);
 - check their preferred method for keeping in touch into the future (e.g. letter, email, telephone etc.);
 - advise them that they can also make contact at any time with the Ward / Team Manager.
- 2.5 The senior clinician will give the family / carer the Trust's "Bereavement Support Information". This contains practical information in terms of bereavement support and signposts local and national support. It also includes points of contact for any questions or concerns and information on how the family / carer can give feedback in terms of the quality of care provided to the deceased patient should they wish including the ability to raise any concerns.
- The Bereavement Support Information will be available in paper form on Wards and on the intranet for Wards to print as and when required.
- 2.6 Paying close attention to what bereaved families and carers say can offer an invaluable source of insight to improve clinical practice. Should significant concerns in terms of the quality of care be raised, the senior clinician should advise the family / carer of the opportunity to raise a formal complaint via the established complaints procedures and give them the Trust leaflet outlining what to do to raise a complaint. Irrespective of whether the family / carer wish to raise a formal complaint, any lessons learned from this initial conversation should be followed up appropriately by the senior clinician (e.g. referral of the information to the Serious Incident team for consideration for a detailed review if significant concerns in terms of care are raised, individual staff/team meeting discussions to reflect on practice etc.).
- 2.7 If other patients and service users are involved or affected by the death, they should be offered an appropriate level of support and involvement. This will be discussed with them initially by the senior clinician above and appropriate actions then taken.
- 2.8 **For deaths which are deemed to be a "serious incidents"**, families will also be supported by a designated Family Liaison Officer (FLO) from the Trust who will be available to them for advice at any stage. The FLO will provide support to families / carers through the investigation process and will also be able to signpost them to other support available to them. The family will be advised of the details of their FLO by the Serious Incident Team who will also send them a copy of the national "Information for families following a bereavement" leaflet.

3.0 BEREAVEMENT SUPPORT

3.1 Bereavement can influence every aspect of wellbeing. The Trust will therefore offer information on bereavement support for families and carers of people who die in an in-patient facility or in a community setting deemed to be a serious incident. This will be in the form of the Bereavement Support Information which signposts various sources of additional support.

3.2 For deaths deemed to be serious incidents, bereavement support will also be provided by a nominated Family Liaison Officer for the family / carers (see section 5.0 below). This will include offering support, information and guidance in a caring and empathetic way. This will include advice and information to help families and carers through the practical actions they need to take following the death of a loved one such as:

- Arranging completion of all documentation including medical certificates;
- The collection of personal belongings;
- Post mortem advice;
- Deaths referred to the coroner;
- Collection of the doctor's Medical Certificate of Cause of Death and information about registering a death at the Registrar's Office;
- Details of the doctor's Medical Certificate of Cause of Death (which is needed to register a death at the Registrar's Office); and
- Basic emotional support and information in terms of accessing bereavement counselling should they wish.

Information on many of the above elements is included in the Trust's Bereavement Support Information.

3.3 Family Liaison Officers will also ensure they take account of the following possible requirements when providing their support:

- Timely access to an advocate (independent of the Trust) with necessary skills for working with bereaved and traumatised individuals. Family Liaison Officers will have details of a number of such advocates to which the family can be signposted to access support.
- Support with transport, disability and language needs.
- Support during and following an investigation of the death. This is outlined in more detail at section 4.0 below. This may include counselling or signposting to suitable organisations that can provide bereavement or post-traumatic stress counselling, paying attention to the needs of young family members especially siblings.
- The need to arrange meetings with the other organisations involved or support in liaising with other agencies such as the police.

3.4 The Trust will ensure that the Public Health England Guidance on Suicide Bereavement Support is followed.

- 3.5 Depending on the nature of the death, it may be necessary for several organisations to make contact with those affected. Where this is the case, the designated Family Liaison Officer will discuss and agree a co-ordinated approach with the bereaved family and carers and organisations involved.
- 3.6 If an inpatient of the Trust is transferred to the acute Trust and subsequently dies within an acute Trust inpatient facility, the acute Trust will be the primary provider of bereavement support in accordance with their protocols. The Trust will advise the acute Trust on request of a nominated staff member's contact details that they can provide to the family / carers should they have any queries about or wish to speak to anyone about services provided to the deceased patient whilst an inpatient within EPUT.

4.0 FAMILY AND CARER INVOLVEMENT IN THE INDIVIDUAL DEATH REVIEW PROCESS
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- 4.1 All bereaved families and carers will receive information in the Trust's Bereavement Support Information about the Trust's approach to reviewing individual deaths to ensure learning and continual improvement of the quality of services for our patients.
- 4.2 The Deceased Patient Review Group will make a recommendation to the Mortality Review Sub-Committee in terms of what grade of review a death should be subject to in accordance with the Trust Mortality Review Policy. The grades of review are detailed in section 5.4.3 of the Policy. In making this recommendation, they will take account of any information sent to them in terms of any concerns raised by the bereaved family or carers (see paragraphs 2.5 and 2.6 above).
- 4.3 Should a Grade 3 (Critical Incident Review) or Grade 4 (SI Investigation) review be approved, the procedures for these reviews as outlined in the Trust's Adverse Incident Policy (CP3) should be followed. This includes the process for bereaved family and carer involvement. Essentially, for Grade 4 (SI) investigations this includes:
- Making the bereaved family / carers aware (in person and in writing) as soon as possible by the designated Investigating Officer of the purpose, rationale and process of the investigation to be held.
 - Giving bereaved families / carers an opportunity to be involved in setting any terms of reference for the investigation which should describe what will be included in the process. This will include giving bereaved families / carers a copy of any terms of reference to ensure their questions can be reflected and giving a clear explanation to bereaved families / carers if they feel this is not the case.
 - Giving bereaved families / carers expectations about the timescales for the investigation including the likely completion date.
 - Asking the bereaved family / carers for their preferences as to how and when they contribute to the process of the investigation.

- Keeping bereaved family / carers fully and regularly informed, in a way that they have agreed, of the process of the investigation.
 - Giving bereaved family / carers the opportunity to express any further concerns and questions and offering a response where possible, with information about when further responses will be provided.
 - Giving bereaved family / carers a single point of contact to provide timely updates, including any delays, to provide the findings of the investigation and factual interim findings. In doing so, there is a possibility that there will be a disclosure of confidential personal information for which consent has been obtained or where patient confidentiality is overridden in the public interest. This should be considered by the Trust's Caldicott Guardian and confirmed by legal advice in relation to each case.
 - Giving bereaved families / carers an opportunity to respond to the findings and recommendations outlined in the final report.
 - Informing bereaved families / carers not only of the outcome of the investigation but also what processes have been changed as a result and what other lessons the investigation has contributed for the future.
- 4.4 Should the Trust consider that it is appropriate to obtain legal advice in relation to a death under investigation, this will be communicated to the family and carer/s clearly from the outset so that they can understand the reasons for the involvement of lawyers and have the opportunity to arrange their own advocates in the process should they wish. The Trust has a network of advocates to whom family / carers can be signposted should they wish.

5.0 IMPLEMENTATION

- 5.1 The Trust will provide appropriate information resources to support Ward Managers and senior clinicians in terms of providing support to families and carers immediately post-bereavement. This includes the provision of the Trust's Bereavement Support Information Pack for passing onto bereaved families and carers.
- 5.2 The Trust will identify an appropriate number of staff to be "Family Liaison Officers" (in addition to their substantive role) in the case of deaths deemed to be serious incidents. Basic training will be provided to an appropriate cohort of staff to equip them with the necessary skills, expertise and knowledge to engage with and support bereaved families and carers should there be a requirement to undertake the role of Family Liaison Officer.
- 5.3 Bereaved families and carers will contribute where possible and appropriate to the design and delivery of training relating to family and carer involvement to ensure that it includes real experiences.
- 5.4 A central list of staff who have received the Trust Family Liaison Officer training will be held by the Serious Incident Team.

- 5.5 The Trust recognises and supports the time required by Family Liaison Officers out of their substantive role to fulfil the required roles to support bereaved families and carers in the event of deaths classified as serious incidents.
- 5.6 The Trust will monitor the effectiveness of its involvement of bereaved families and carers via seeking their feedback in appropriate ways. This feedback will be collated centrally by the Serious Incident Team. The Trust will take action to improve processes based on this feedback.

6.0 GUIDANCE AND ADVICE

- 6.1 Guidance and advice in terms of the involvement of bereaved families and carers can be obtained from:

Serious incident team – [REDACTED]

7.0 PROTOCOL REVIEW

- 7.1 Any amendments to this protocol will be submitted to the Mortality Review Sub-Committee for approval.

APPROVED BY THE MORTALITY REVIEW SUB-COMMITTEE: January 2019