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| Topics: **Implementing best practices** |
| Type: **Workshop** |
| **Developing User-Lead Bereavement Support** |
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| **Objectives of the session** 1. To discuss  what support bereaved families need and how international differences might affect this ·         2. To explain a UK-based model for providing support to parents following a sudden infant death that continues as long as is needed and includes care of subsequent children ·         3. To discuss the different elements of an effective bereavement support package and the different formats these might take (e.g. digital, print) ·          4. To allow participants from countries with no parent support group to consider how to make a start to organise appropriate local support  **Content of the session** **What support to families need? (5 minutes)** An introduction by workshop leaders considering the nature of sudden death in infancy and how it might impact on families and require a specialised support programme.   The workshop leaders will introduce a number of possible themes and ask participants to think about which elements they feel are most important, which are most lacking in their country, and which families need in their country.     **Presentations: the UK model as an example (15 mins)**   **The Lullaby Trust’s model of bereavement support and what we can learn from its evolution:** The Lullaby Trust (formerly the Foundation for the Study of Infant Deaths) was founded by a bereaved grandparent in 1971 to promote research, amass and exchange information with other countries and to support bereaved families. The charity’s aims remain the same but in addition we are now able to promote advice to help prevent SIDS, which is an essential part of the bereavement support service. This is specific to the UK situation, where good procedures exist for when a baby dies and where there are clear statistics available and information on Safer Sleep practices. The model that has developed over the past 40 years has been driven by parental feedback on what they find more supports them and their needs, and this information will be shared with participants, specifically looking at a recent survey of bereaved families. The UK service has always including a combination of information support, listening and peer-to-peer support, although the methods of giving these services have evolved over the years.   **Care of the next infant (CONI):** CONI is a unique programme to support families with babies born subsequent to a sudden infant death, and participants will be given an introduction to the service.  In the UK there is a government funded national health service (NHS).  CONI is operated collaboratively between the Lullaby Trust and the NHS. The Lullaby Trust provides training, audit and expert advice on setting up the programme.  LT also helps to fund the equipment required to run the programme (breathing monitors, weighing scales and resuscitation dolls.) The programme is delivered via the NHS health visiting service.  A health visitor (HV) is a public health nurse mainly concerned with families with young children Each locality has a specially trained HV as a CONI co-ordinator who is responsible for enrolling a family on the scheme. Families are visited regularly by their own HV following the birth of their baby for about 6 months.  They are issued with breathing monitors, specially designed weight charts, symptom diaries and Baby Check symptom assessor. Parents are trained in resuscitation.  Babies can be assessed by a paediatrician as needed.  Parent feedback consistently shows that the monitor and the home visits by the HV as the most valued part of the scheme.   **Planning: Developing a new Bereavement Support Model (30 minutes)**  In this interactive part of the workshop, participants will be divided into 3 groups to consider elements of bereavement support. There will be three manned stations with displays of materials.  Participants will be split into three groups and spend 8 minutes at each station (plus 2 mins to allow movement between stations)   Groups will circle the room and add comments onto prepared worksheets that identify different elements of bereavement support. Considering the UK-model given and  priorities in their country and the need for support, they will be asked to consider under each topic: How do we find out if parents want this? How might this be achieved? What is the best way of initiating action in 2017?   The elements of possible bereavement support will be: 1.       Factual based information (on procedures and statistics for example) following the sudden death of a baby 2.       Peer to peer support and links 3.       Listening and/or counselling 4.       Family support for future pregnancies   **Next steps** (10 minutes) The concluding discussion will share ideas and planning what next in different countries – what have we learnt from the discussion? Groups will be asked to identify key points to develop into an action in their country.  **Method and extent of audience participation** Maximum number of 30.Our interactive workshop is aimed at participants interested to learn about how families bereaved by sudden infant death can best be supported. Participants will be expected to be fully involved in discussing what families need in their country and how this might be achieved. To benefit most from the workshop, participants should consider the main priories for their country before attending.  **Proposed content area and why it is important to participants** How can we best support bereaved families? We know that not all countries have a dedicated and established bereavement support programme for families who have a sudden death in infancy. Others do have established systems, and this workshop aims to have a discussion around some of the reasoning and methods for those systems and see if they can be used to develop models in countries that do not have them. The UK-model will be used as an example with discussion focussed on individual countries’ needs. . |
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