



Setting up and running regional networks for bereavement organisations

Introduction

The National Bereavement Alliance brings together national organisations supporting bereaved people, and membership organisations for those working in this field. The Alliance also includes local and regional bereavement networks for organisations across a particular geographic area.

These local and regional bereavement networks help foster collaboration. While each organisation has its own focus and catchment, most can benefit from working more closely with other organisations in their local area. Historically, networks have formed as part of local end of life care pathways, or as a group of local bereavement service providers who wish to link together to provide best practice. Sometimes, networks or consortia emerge more quickly in response to a local tender or other funding opportunity.

By connecting as a network with the National Bereavement Alliance via a local or regional network, local services can have a voice in shaping national policy and practice, and get updates about national developments.

About this briefing

This briefing is aimed at anyone thinking about setting up a local or regional bereavement network. It draws on the learning from existing networks to outline helpful approaches, anticipate some of the challenges, and help find a way forward.

Benefits of local and regional networks

- Services that work with people bereaved in specific circumstances are often contacted by people who are outside their referral criteria: being familiar with other local provision makes it easier to signpost on quickly and appropriately.
- Organisations that work in a particular way may need to refer some people on to other organisations for different types of support (e.g. peer support rather than 1:1 support).
- Services may need to work in partnership to meet the specific cultural, communication or other needs of bereaved people, and to encourage them to take up support.
- When statutory bodies issue tenders for area-based bereavement care, there may be no one local organisation that can meet all the requirements: a partnership approach will be needed.
- Established relationships can help local services respond together to large-scale emergencies and challenges such as the coronavirus outbreak.

Ultimately, working together can improve outcomes for bereaved people in the area.

First steps

If you are thinking about setting up a local or regional bereavement network, start by having exploratory conversations with other organisations in the area. Talk about the benefits you think this approach could bring: see whether these are shared, and if there are others who are willing to work with you to realise your vision.

If there seems to be an appetite for collaboration, identify some key individuals or organisations to invite to an initial meeting. Even at this early stage, it is worth thinking ahead to the future make-up of your network. For example, if you think your network might be specifically for voluntary sector organisations, consider limiting the meeting to representatives of these. You can always widen membership in the future – this is much easier than narrowing it.

This initial meeting can be used to discuss and agree the purpose of the suggested network. Different individuals may have different motivations for setting up the group and it is useful to discuss these early. Common motivations for setting up such a network include:

- Creating a more coordinated approach to supporting bereaved people in the area
- Learning more about one another's services to improve signposting and referral
- Sharing skills and expertise
- Pooling resources e.g. training budgets, signposting tools
- Joining together to run events, for example during Dying Matters Awareness Week, Children's Grief Awareness Week or National Grief Awareness Week
- Providing a collective voice for local bereavement services in conversations with key decision-making bodies such as Clinical Commissioning Groups (CCGs), local government, education and social services.

Frameworks

In 2014, Cruse and the Bereavement Services Association published the Bereavement Care Service Standards (BCSS).

These identify seven areas for consideration of best practice when providing a bereavement service and can provide a useful framework and focus for a regional network. Some regional networks have chosen to form their work plan and meeting agendas to incorporate these seven work streams, to help identify any gaps in service provision or support needed to reach minimum recommended standards.

The outcomes of this initial meeting can inform wider conversations to gauge interest and resources, identify priorities and open up the group.

Identifying your footprint

Deciding what area to base your regional network on may be straightforward: perhaps aligned with the local authority, CCGs or Sustainability and Transformation Partnership (STP). Other organisations also have regional structures in place, such as the Association of Bereavement Services Coordinators in Hospices and Palliative Care Teams (ABSCO), the Association of Palliative Care Social Workers (APCSW) and local Strategic Clinical Networks. Other considerations might include

- Distance to travel to meetings if these will be held in person rather than remotely
- Existing strong relationship and networks
- Striking a balance between keeping the network small enough to be manageable and individually useful, yet large enough to provide and support networking and cross sector working.

Membership

Some regional networks include only voluntary sector organisations: others have a wider membership. The purpose of the network will help to determine this. Suggested groups to involve include:

- Local branches of national bereavement organisations including Cruse, Survivors of Bereavement by Suicide, SANDS and others
- Local organisations providing bereavement support as part of their wider work e.g. MIND, Age UK
- Local commissioned and funded services for bereaved children and adults
- Suicide post-vention services
- Hospices
- Funeral directors
- Child Death review panel
- Acute trusts: Patient Affairs and Bereavement Officers, Midwives, mortuary staff and others
- Medical examiners
- Local faith groups and leaders
- Independent established counselling organisations providing bereavement support
- Carers' organisations
- Local adult mental health team and CAMHS
- Local commissioners
- Council Bereavement departments
- Representatives of other statutory services in touch with bereaved people e.g. police, social work, schools
- Researchers from local universities with a strong interest in bereavement
- People with lived experience of bereavement, and of using bereavement services

Local Strategic Clinical Networks

Some local strategic clinical networks have established bereavement representatives involved in their work stream on end of life care. If this is not established, it is recommended these links are made. Local hospices are well placed to do this.

Involving commissioners

Regional networks are an opportunity to establish connections between local commissioners (e.g. in end of life care, mental health or children and young people's services) and bereavement service providers. This can help commissioners to understand the need for – and landscape of – bereavement services locally, helping them to commission appropriately, and keep local services aware of opportunities. While commissioners' capacity to attend meetings will vary, getting permission to include them on the email distribution list is can be helpful.

Structure

Chairing the local regional networks is a rewarding role that requires perseverance, optimism and patience! The process for electing chairs can be set out in your Terms of Reference, or there can be a less formal arrangement with a rolling chair. It can be useful and supportive to have co-chairs sharing the role: perhaps from differing boroughs, types of service or experience. Chairs of regional bereavement networks can find support and templates for these documents from existing regional networks, who are listed on the National Bereavement Alliance website. Some of the responsibility of organising and minuting meetings and following up on actions can be shared between the group members.

If the network is has a more formal purpose and will be raising or holding funds, it may need a host organisation which can hold funds on its behalf. This organisation can also act as the Data Controller for keeping personal information such as the email distribution list.

Activities

Keeping in touch

Keeping up with the natural turnover of staff, and generating and retaining the interest of services within organisations requires a certain level of co-ordination and administration. Ensuring the meetings are useful and relevant will help. Setting up an email distribution list to send group emails and invitations will help keep busy service providers in touch with updates and news.

Running meetings

Setting dates for meetings at the beginning of the year helps maximise attendance. Some networks meet quarterly for around 1.5 to 2 hours. A pre-set agenda sent to the distribution list prior to the meetings acts as a useful reminder and prompts members to submit information for the meeting if they are unable to attend.

If meetings are being held in person rather than virtually, it can be helpful to vary the location of the meetings across the region to keep time of travel equitable for all attendees (and chairs). This also helps members get to know one another's settings better which is useful for establishing partnerships and being confident about cross-referring. A variety of venues are often available in faith establishments, community hubs, funeral directors, hospitals, hospices and other organisations.

Education

One of the work streams in the BCSS is the provision of education. Some regional networks work together to provide a joint education programme of researched and up to date bereavement education packages, aimed at staff and volunteers in member organisations, and also at wider local groups, helping to resource, upskill and empower them to support bereaved people.

Local resource directories

Working together to identify the variety of bereavement support on offer locally can be helpful in improving signposting between organisations, and can form the basis of information to be given out by the local acute trust, funeral directors and registrars. However, the signposting websites AtALoss and the Good Grief Trust carry information about local services and it may be more cost-effective to ensure that local information is up to date on these sites.

Case studies

Cornwall Bereavement Network

The Cornwall Bereavement Network was established in January 2020 by Becky Thomas, Family Services Manager at Penhaligon's Friends. Its purpose is to promote and develop a collaborative approach to supporting bereaved people in the county. The drive to create the network came from an initial meeting of bereavement services held by Penhaligon's Friends, where it became clear that Cornwall needed a central resource to bring bereavement services and organisations with an interest in bereavement services together for this purpose.

The network's main activities include providing signposting for those who need to access bereavement services, provide people with the full range of options available without endorsing a particular service or provider, as well as fostering a mutually supportive environment for professionals working in the bereavement sector and identifying gaps in service provision across Cornwall.

The network has around 85 representatives from across the sector, and its resources kept up-to-date by a voluntary advisory group which includes professionals with experience in supporting bereaved people, from across the public and private sector. The advisory group intends to meet 3-4 times a year.

Leeds Bereavement Forum

Established in 1996, Leeds Bereavement Forum (LBF) is an unincorporated charitable organisation, currently in the process of becoming a Charitable Incorporated Organisation. LBF's aims are to signpost individuals to the most relevant bereavement support, offering training, information, events and conferences to people interested in knowing more about supporting bereaved people. LBF is an active member of the Leeds Dying Matters Partnership.

LBF's membership consists of over 100 individuals and local third sector, statutory and commercial organisations, and hosts the Leeds Citywide Bereavement Services Forum, whose members meet twice a year (monthly during the COVID-19 outbreak). This forum includes 13 third sector Leeds-based bereavement organisations – both adult and children and young people's services, the local hospices; Cruse Bereavement Care Leeds, local groups focussed on bereavement by suicide or supporting carers. This group provides opportunities to network and updates about organisations' work across the city.

LBF also works with Leeds City Council Bereavement Services who manage the OrthoMetals grant funding, available to Leeds-based groups since 2016. LBF are currently working together with the CCG and Leeds City Council to represent the third sector and plan for future bereavement support for anyone experiencing loss in the current climate.

Oxford Bereavement Alliance

The Oxford Bereavement Alliance (OBA) was established in 2013 by Marilyn Relf following the completion of a mapping exercise commissioned by the Oxon Primary Care Trust. This brought together people whose work included providing bereavement care either as a primary or secondary purpose ranging from specialist mental health through structured bereavement services to small mutual help programmes. Meeting together to explore what was available proved interesting and created a desire to continue to meet and the OBA was established under the umbrella of the National Bereavement Alliance.

The OBA aimed to strengthen bereavement care in Oxfordshire and to provide a voice for bereavement services across the county. The OBA brings together all organisations involved with bereavement care providing support to bereaved people.

Central to the group are the three hospices in Oxfordshire, Cruse (bereavement support for adults), See-Saw (bereavement support for children) and Age UK, who have a network of 'Late Spring' groups across Oxfordshire that offer more informal social support to older bereaved people. Other smaller organisations and people from different parts of the health services in Oxfordshire have also attended. Members agreed in the early meetings that the purposes would cover networking, sharing information about their services, identifying gaps in services, and meeting national requirements by keeping up to date with policies, standards, research and best practice.

The group generated a number of ideas for collaborative working to strengthen bereavement care in Oxon, including the development of the Resources for Bereaved People booklet. This lists all the Bereavement Services available in Oxfordshire that bereaved people can access.

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