

Appendix 3

Hearing the views of bereaved people

Introduction

There were two aspects to this part of our work. The first was a focus group meeting on 21st April in Banbury, to which eight people came and shared their experiences of bereavement services in the Banbury area. As we agreed with the group that any comments made would be non-attributable, we are not including a list of names of the attendees.

The second aspect was gathering personal stories from four individuals in four separate interviews. Their stories are found in their entirety in Appendix 4. Again, these individuals have been assured of their anonymity.

A. Focus Group Meeting

The purpose and guidelines for the focus meeting can be found in Appendix 5.

We invited attendees to complete a short questionnaire (the template is in Appendix 7) giving us some brief information about themselves and their experiences. The group consisted of 3 men and 5 women, with an age range from 54 to 94. 3 were in their 50's, 2 in their 60's, and 1 each in their 70's, 80's and 90's. They all identified themselves as white and British and had been bereaved in the period 2013 - 2016.

1. Services that supported them in the Banbury Area

Cruse, Late Spring (Age UK), RVS, Restore, counselling via the doctor.

"(the Cruse volunteer) let me talk a lot and get it out of my system"

"...a listening ear, genuinely compassionate and caring that I can offload to"

"I didn't feel anyone really knew how I felt before I went to Late Spring"

"(Having a group) ... wake up to the knowledge you're not the only one hurting"

"...being able to talk to a stranger can be good - you don't feel you're burdening family"

2. What they found helpful - what encouraged them

Most people reported that friends and family and neighbours were the most helpful to them in their bereavement.

"My family weren't there for me, but my neighbour was"

This was followed by the Funeral Director, the Cruse helpline, and others in a similar situation.

"Person I spoke to put me at my ease"

"...offloading how you're feeling and getting a compassionate and caring response"

"...not necessarily coming up with answers"

"...sharing is halving..."

3. How did people help themselves

Social activities, hobbies, meeting others in the same situation, getting out of the home.

4. What did people find unhelpful and what was missing

- **Lack of understanding from others, insensitive professionals**

"It would be very helpful for people to follow-up"

"A phone call would be a good idea"

"Someone to have a listening ear... and person at the other end is compassionate and caring"

- **Long waiting-time for services**

"It seemed like a perfunctory offer (leaflet re Cruse) especially as it was in Oxford"

"(On telephoning Cruse) was told however long you have to wait, so I didn't bother"

- **Lack of information; no clear direction to services**

"Something simpler, not lots of information, too much to deal with"

"The only time I found out (about Cruse) was when I went to the Probate Office"

"..would be helpful to have something online" "...more and better signposting"

- **Specialist service for 18 - 80 for people with learning difficulties**

- **Cruse office in Banbury**

5. What would help - ideas and recommendations

- **Shorter waiting times**, but people recognised that some services depend on volunteers.

- **Options** to be seen at home or elsewhere.

- **Sharing facilities** with other services or even using local business premises.

- **Clearer signposting of information** with leaflets about emotional and practical

issues and how to meet other bereaved people

- **Bereavement packs** available following death in hospital, which should also be available to registrars, funeral directors, GPs and other key places.
- **One contact point**

"Shame there can't be some sort of amalgamation of services - GP, Funeral Director, Hospital, Bereavement Service - they might be able to assess level of need"

- **More Step 2 services that are local and timely**

B Talking with individual bereaved people

The powerful and moving stories told by three individuals who have experienced bereavement are reproduced in their entirety in Appendix 4.

Here are some notable quotes from these stories about the effect bereavement has on a person, and what their experiences were of seeking support.

1. About the effects of bereavement:

"...when R died, I went into a state of deep shock and despair"

"As my wife was dying, I felt we were both on a precipice looking down into a crevasse where there was no light - there was lots of snowy blizzard though."

"I'm sure my loss will continue to impact my life but I am still here still alive and the tears still make tracks down my face"

2. What helped me

"Writing poetry about R with tears streaming down my face, reading familiar books, prayer and Buddhist thinking and mindfulness helped bring some relief into my life"

3. What help I sought and received

"Although I was supported by my friends, I knew very soon after R died that I needed extra help..... I contacted Cruse very soon..."

"I enabled myself further by rekindling and old friendship"

"What did help was becoming a Cruse client"

"My counsellor was so kind, flexible... caring and professional"

"...my counsellor suggested I look at the WAY Up online group.... this national online

support forum was a lifeline"

4. What was not helpful

"I had to wait 6 weeks"

"I did feel let down by the lack of support from my doctor and surgery."

"...lack of choice..."

"...empathy and care was poor"

5. Ideas and recommendations for improving services

"...it could be of help to others if there was an opportunity to receive counselling via group sessions"

"...it would have been helpful if there had been a local Cruse office where I could have perhaps gathered more information and left messages more easily for my counsellor"

"I believe that what is missing in the Banbury area is a Cruse office, where people can pop in, call, be heard and understood. I had to go to Oxford for help and it's quite a way"

"I wish GP's, particularly those with decades of experience, would watch out for complacency and attend regular training..."

C Conclusions

While it is difficult to weight the wide range of comments and recommendations from bereaved people, there are three main issues that emerge from the above consultation:

Information: this needs to be timely, accurate, widely available and comprehensive.

Access to services: information needs to lead to people being able to access the appropriate service for them, through an assessment process and sign-posting.

Capacity to respond to need: people need a rapid response from the service they choose which means the services need to have capacity, in terms of people and accessible local venues.

One idea that was mentioned which would address the first two issues is a **single contact point**, where good information is available and an assessment of needs can be done in order to help people to find the most suitable service for them. This contact point could be a physical place and/or a telephone helpline.