

Everything Has Changed

Perspectives of those who have been bereaved on the need for bereavement services in the HSE Dublin Mid-Leinster area

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Feidhmeannacht na Seirbhíse Sláinte
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Foreword

The Bereavement Care Liaison Project is a partnership between the HSE local health areas of Laois/Offaly and Longford/Westmeath and the Irish Hospice Foundation. The project aims to develop capacity and co-ordinate efforts around the most appropriate support for those bereaved and those charged with supporting them. The vision is:

That the normal life events of loss and bereavement are met with informed compassion, and with sensitive, appropriate support and levels of care regardless of the circumstances surrounding a death (sudden death, death by suicide) and the services involved

For three years our local health areas have had the opportunity to be proactive about caring for our bereaved citizens, putting information, services and training in place. The project officially started in June 2008 when the Bereavement Care Liaison Officer came into post. The Bereavement Care Liaison Officer, Maria Costello, works with a Project Advisory Group, comprising representatives from a range of local services, both voluntary and statutory. Soon after the commencement of the project a public consultation day was held.

Bereavement is life-changing and may be characterised by loneliness and despair. While there is an emerging body of evidence on what constitutes good bereavement care, development initiatives should reflect local priorities and, in line with health policy, be truly person-centred. The Project Advisory Group saw the involvement of those who experienced bereavement as integral to the development of the project. Because of the sensitive nature of the subject the use of focus groups was seen as the most appropriate way to elicit views.

Consequently, this report sets out the bereavement experiences and views of a range of people from the local health areas of Laois/Offaly and Longford/Westmeath. The focus group sought to tap into these sometimes painful experiences in order to identify the gaps with particular reference to information and services.

The report details some of the impacts a death may have on people and includes descriptions of pragmatic issues and emotional responses to loss. Descriptive accounts leave a clear impression of people's pain and hurt, their natural coping skills and the issues that further challenged them in bereavement.

Findings suggest that the grieving process is influenced by the care received by a family before death - where illness precedes death, care is very much patient focussed and therefore tends to stop when the patient dies leaving some families feeling abandoned. Social support from friends and family is forthcoming and needed but requires some coordination. There may be added responsibility in terms of looking after family, making decisions, and dealing with financial and legal matters. Preparing for the funeral may be really difficult and while a lot of help is generally available with this, afterwards one is expected to get back to normal

All groups felt that children might be likely to need help and this requires an appropriate response which may not necessarily involve psychological intervention, but more advice on how to talk to and support children.

The findings from this report have been incorporated into the work plan of the project and many are currently being implemented. The recommendations are clearly wide-reaching and they will be dispersed across the relevant health care sectors - in hospitals, community and

primary care. We also welcome developments such as the Hospice Friendly Hospitals initiative that will form a context for bereavement care development in the three acute hospitals.

I would like to extend my thanks to all those who participated in the focus groups. I would also like to thank the members of the Project Advisory Group and the research team. The preserved words of participants speak clearly through the pages of the work and convey the overall impression that for those bereaved *everything had changed*.

Dr. Phil Jennings,
Director of Public Health

Project teams and Acknowledgements

Steering group

- Ms Carmel Brennan, Project Specialist, Department of Public Health, Tullamore
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- Ms Mary Delaney, Community Services Manager, Laois/Offaly
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Research team

- Mary Hegarty, Lead Qualitative Researcher, Department of Public Health, Tullamore
- Maria Costello
- Carmel Brennan
- Orla Keegan

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Chapter 1: Introduction

Bereavement care and support has been highlighted in Ireland in recent years, particularly by the services related to palliative care and suicide. The National Advisory Committee on Palliative Care examined the need for bereavement services as part of its review of palliative care (NACPC, 2001). Bereavement care services in the HSE/SE region were reviewed by Carroll, Keegan and Delaney (2005). A review of bereavement support and services for individuals following suicide bereavement was published in 2007. This followed publication of *You are Not Alone- Help and Advice on Coping with the Death of Someone Close* (National Office for Suicide Prevention, 2007). All reports highlight the need for appropriate bereavement care support for individuals where such support is not readily available in the immediate social support network.

A Bereavement Care Liaison Project Dublin Mid-Leinster Advisory Group was established through a partnership between the Irish Hospice Foundation (IHF) and the HSE in 2008. A Bereavement Care Liaison Officer (BCLO) was appointed to lead the project. Phase one involved a year-long consultation process with a wide range of stakeholders drawn from voluntary and statutory sectors. This aimed to describe the range, availability, nature and extent of bereavement information, care, support and counselling/therapy services in Laois/Offaly and Longford/Westmeath.

The Bereavement Care Liaison Project Advisory Group was keen to involve service users in its deliberations. After considering various methods of achieving this, it was agreed to carry out focus groups to provide information in relation to bereavement support and services and related issues.

1.1 Levels of bereavement support

A public health approach to bereavement care is supported by the literature e.g. NACPC (2001; p.99), NICE Guidance (2004), Schut and Stroebe (2005), Currier and Neimeyer (2008) the Petrus Review (2008). While these reviews endorse a tiered model of bereavement care there is some variance in the terminology used to describe the tiers and their scope. Schut and Stroebe (2005) refer to primary preventive services at level one, secondary services providing extra care for those at risk and tertiary services for those experiencing clinical difficulties with their grief. A later review by Currier and Neimeyer (2008) referred to universal bereavement care, selected bereavement care and indicated bereavement care. In the main the evidence preserves three levels as providing a framework for pathways in bereavement care.

- Level 1 involves making accurate normalising information available, facilitating rituals, memorials and practical support.
- Level 2 is the availability of volunteer support and well informed professionals who can gateway to other services if required.
- Level 3 is the provision of tertiary services including more intensive psychotherapy and requires referral to specialist health professionals.

1.2 People's own views on bereavement support

While there is a range of literature outlining theoretical approaches to bereavement support and a number of guideline documents on service developments, there is little published research on bereaved people's own preferences for grief support, on what they perceive as required and on what type of services are acceptable to them.

In Australia, Currow (2008) population study showed that 13% of relatives of patients who died from an expected cause sought help from others. This help extended to support from friend/family members (10.7%); grief counsellors (2.2%); spiritual advisers (1.9%); and nurses/doctors (1.5%). Twenty five respondents (1.3%) had not sought, but would have valued help with their grief.

Research from specific services suggests higher preferences for help, e.g., within a Swedish palliative care population, two thirds of families returning questionnaires to a service said they would like to receive home-based follow-up after bereavement (Milberg et al., 2008).

A requirement for practical support extending to financial support and access to financial counselling are highlighted in two recent studies which set out to examine the economic costs associated with spousal bereavement in the UK (Corden, 2010) and with death of a child in Australia (Stebbins & Batrouney, 2007). The extent to which these practical issues are integrated into community based bereavement support is unclear and it may well be argued that some bereavement care is provided on the basis of the service preference rather than client need.

The ability to develop responsive services rests in part in identifying people's own views and this study sets out to map the experiences of bereaved people residing in the Midlands.

1.3 Current bereavement services in the Midlands

The BCLO has reviewed the bereavement services in the Midlands (Costello, M. 2010). Bereavement follow-up visits from the palliative care team, information provided in hospitals and annual ceremonies of remembrance (held by various care settings in the November period) are the current mainstay of **level one** statutory bereavement support in the region. The BCLO has identified a range of relevant literature and makes this available on an ongoing basis.

For the duration of the project the BCLO acts as a clearing house for the provision and replenishment of hard copy service directories and information on grief and loss. The BCLO is supported in this goal by the Suicide Prevention Office. The IHF/ HSE range of bereavement leaflets is now downloadable from www.hse.ie and they have been delivered to over 100 stakeholder sites in the region. Information resources are supplemented in the region by national help lines such as those established by Barnardos, Teen-Line, Console, ISANDS (now 'A Little Lifetime Foundation') and Meningitis Trust etc.

Level two listening support is available in the Midlands from the following voluntary services;

- Portlaoise Parish Bereavement Support Group
- Tullamore Parish Bereavement Support Group
- Bethany Bereavement Group, Mullingar
- Bethany St Camillus, Killucan
- LARCC, Ballinalack
- Ferbane Parish Bereavement Support Group.

There are a number of formal posts in the statutory sector which can guide and direct at this level. They include the Staff Nurse Counsellor for Bereavement in the Midland Regional

Hospital at Mullingar, the Primary Care Social Work posts and the Palliative Care Social Work post in Laois/Offaly.

At **level three** the voluntary hospice funders and cancer care centres provide resources for counselling and therapy services which supplement the HSE mental health, psychiatric and psychological services in the region. These include counsellors in north and south Westmeath hospice groups, counsellors at the Cuisle Centre, Portlaoise; Dochas Cancer Care Centre, Tullamore and LARCC Cancer Care Centre, Ballinalack. Counselling is also available from the community resource centres in the region, though this may not be bereavement specific.

1.4 Information on bereavement

Information on bereavement support and advice is currently available from the Citizens Information Board (http://www.citizensinformation.ie/categories/death/bereavement-counselling-and-support/bereavement_counselling_andsupport_services accessed Apr 20th 2010). Their booklet covers the relevant practical details that people need basic information on when they are bereaved. Topics covered include funeral arrangements, registering the death, post-mortem, financial issues and dealing with the estate. It also gives some contacts for support and counselling. The booklet is also available from Citizens Information Centres where there are trained volunteers who can discuss any issues with members of the public.

Chapter 2: Methodology

2.1 Aim

The aim of the research was to explore people's awareness and experience of bereavement services in order to inform the development of services in the HSE Dublin Mid-Leinster area.

2.2 Method

The methodology used was qualitative - employing focus groups using vignettes to facilitate discussion.

2.2.1 Sample

Sampling was purposive i.e. people were invited specifically because they had experience of bereavement. Local bereavement-related services were identified as potential recruitment sources and these were contacted by the BCLO. Follow-up conversations explored the potential of these services to invite participants who met the study inclusion criteria. One further focus group was recruited through a HSE mailshot with responses being made directly to the BCLO. Consideration was also given to geographic spread and rural/urban location.

Invitation procedure

A letter explaining the research was forwarded to the co-ordinator of each of five recruitment sources/ services. This local co-ordinator distributed a second letter to each invitee. This explained the research and contained details of the time and venue. It was signed by both facilitators (with contact details included).

The letters advised recipients that facilitators would welcome the opportunity to clarify any issues. Emphasis was placed on ensuring that the participants fully understood the purpose of the group. In the case of one of these groups, the co-ordinator identified literacy difficulties as a possible issue. Therefore, it was agreed that the co-ordinator would meet or telephone each participant and read through the invitation letter to provide for a fuller understanding.

In the case of the sixth group, recruited via mailshot, respondents were screened for meeting inclusion criteria by BCLO and letters of invitation (as above) were issued. Where participants did not meet the inclusion criteria a number agreed not to take part and others were invited to inform the bereavement care liaison project using other channels. All were offered information on grief and loss and service directories.

In all, six focus groups were convened with 32 participants - 26 females and 6 males. Two groups each were held in Offaly, Laois, and Westmeath. Attempts were made to organise a group in Longford but this did not prove possible in the timeframe. Two of the groups were conducted with bereaved people who were part of an existing support group programme. Two others were hosted by organisations providing ongoing bereavement support and the participants had either availed of their services in the past, were availing of them at present or had contacted the service for information. A further group was recruited through the Palliative Care Service and the remaining group consisted of random respondents to a mailshot.

Inclusion criteria

The main inclusion criteria were that participants should:

- Be an adult i.e.>18 years.
- Have been bereaved for a period of > 3 months and < 18 months.

- Be able to speak and understand English.

Following the first group, when it became clear that these criteria were difficult to establish, a protocol was developed to ensure that they were met as far as was possible and that participants were safe. The length of time since bereavement was a particularly difficult criterion to establish and uphold. The inclusion criteria had been determined as it was established that at less than three months post-bereavement participants might be unable to be involved in a group discussion on the topic, while at over 18 months accurate recall could be a problem. In actual fact, some participants had suffered more than one bereavement and these spanned a long time scale, certainly over 18 months.

There was more concern in relation to upholding the lower limit. Information on potential participants was not available to the facilitators prior to the focus group itself, so it was not always possible to pre-determine whether participants met the inclusion criteria. The co-ordinators of the groups were advised of the inclusion criteria. The protocol was as follows:

1. If possible identify that all prospective participants are within inclusion criteria ahead of the focus group.
2. If a participant who has been bereaved within past three months attends, the BCLO will discuss their participation with them, explain the nature of the focus group and discuss whether it is compatible with their needs at this point.
3. Final decision on participation to be left with the prospective participant.

With regard to the group recruited through mailshot, the BCLO was in a position to glean personal history prior to the group discussion via the screening process.

2.2.2 Instruments

1. Information sheet distributed at the meeting (Appendix I).
2. Consent form covering participation in the research and the audio-taping of the discussion (Appendix II).
3. Topic guide focussed on the following areas: overall experience of bereavement itself and bereavement services considering awareness and knowledge of services, access, appropriateness/suitability, service delivery and any shortfall or failure to meet needs. If participants had no experience of service, the discussion would explore experience in terms of any implications from lack of service (Appendix III).
4. A selection of vignettes designed to facilitate discussion within the groups (Appendix IV).
5. Brief questionnaire to capture basic demographics and service details (Appendix V).

2.2.3 Procedure

- Information sheet explaining the research and an invitation were issued to participants prior to the focus groups.
- The purpose of the research was explained again prior to obtaining consent at the group discussions.
- Groups were facilitated by two people, one to lead the discussion (BCLO) and the other to act as scribe (researcher). Facilitators were substituted for two of the groups where availability was an issue.
- Discussions were audio-taped with the permission of participants.
- Arrangements were made for refreshments etc.

2.3 Ethical considerations

The main ethical considerations were:

- Informed consent, anonymity and confidentiality.
- Provision for supporting any participant. This would be provided by the BCLO who was qualified to provide such support and would make ongoing referral if required. In the event, no participant required such support.
- Appropriate dissemination of findings.

2.4 Follow-up

As part of the follow-up procedure for four of the groups the BCLO informed the co-ordinators of the focus groups by phone of general needs identified within the discussion. They agreed to address these and pathways were identified. Co-ordinators received a letter of thank you for their collaboration. In addition, these hosts were furnished with a thank you letter which they were requested to forward with a bereavement pin to participants. This letter suggested to participants that they should contact the BCLO in the event of having any further need or query. The BCLO issued follow-up letters directly to the participants in the case of the other two groups. All parties were advised to contact the BCLO in the event of having any further query.

2.5 Limitations

This research represents the views of the participants in the focus groups and may not be representative of the views of the general public. This is particularly true as most of the groups were convened through bereavement services with which they already had contact. However, the insights gained provide a rich depth of understanding of the participants' experience of bereavement.

The focus groups were facilitated by the BCLO who had experience of bereavement services and, while this may have influenced the discussions at times, this was more than balanced by the fact that she was qualified and prepared to support the participants should the need arise. The scribe was an experienced researcher who took this influence into account in analysis.

2.6 Analysis

Outline reports were prepared and delivered to the steering group after groups 1, 3 and 6. Transcriptions of the discussions were analysed to identify and categorise emerging themes using NVIVO 6.

Chapter 3: Participant profile and bereavement details

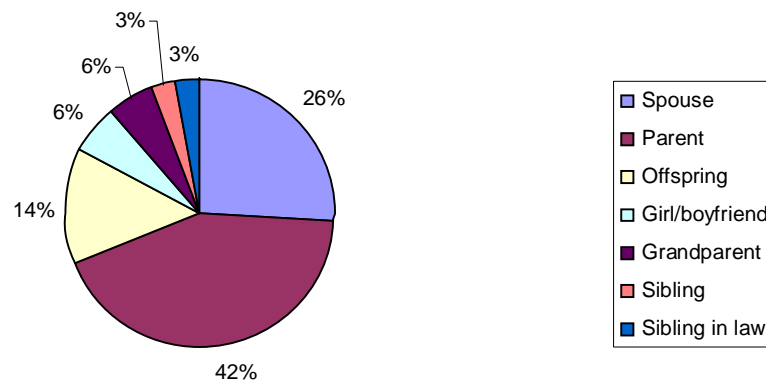
3.1 Participant profile

The six focus groups were attended by 32 participants of whom 26 were female and 6 were male. Almost half of the participants were aged from 45 years to 64 years. Two participants were under 24 years with a further ten aged from 25 to 44 years.

Just under one-fifth of the participants were from Longford. The remainder were fairly evenly spread across Westmeath, Offaly and Laois. Twenty of the participants (62.5%) were residing in urban areas, 12 (37.5%) were residing in rural areas.

3.2 Bereavement details

Figure 1: Relationship of deceased person to participant (n of responses= 35; n of participants = 32)



Some participants reported more than one bereavement and so the percentage is of the 35 responses. The deceased person was a parent in 42% of responses and a spouse or girl/boyfriend in 32%.

However, this does not provide the full picture of the bereavements experienced by participants; other bereavements, occurring some years before, were discussed by some. These seemed to be more intense bereavements for the participants than the more recent one.

Two-thirds of deceased relatives were aged over 45 years and three were under 24 years. A further seven were aged from 25 to 44 years.

Type of death was illness of long duration in 21 cases; illness of < 6 months in four; sudden death in seven.

Length of time since bereavement:

The number of months since bereavement ranged from two to 60 months. Where the participant reported more than one bereavement they were asked to indicate length of time since the most recent one. The overall range was from 2-60 months. The mean number of months was 21.09 (SD15.88) while the median number of months was 15.0 (IQR 9.0 ó 35.5).

Place of death:

Place of death is detailed in Table 1 below. Over half of deceased relatives had died in their own home.

Table 1: Place of death

Place of death	Frequency	Percent
Deceased's own home	17	53.1
Hospital	10	31.3
Nursing home	2	6.3
Hospice	1	3.1
Other*	2	6.3
Total	32	100.0

*both cases sudden deaths

3.3 Information and bereavement services

Just over two-thirds of participants had access to information in relation to bereavement services while a similar proportion were aware of bereavement services, and just under half had availed of some bereavement services (two of the latter indicated that this involvement was very recent). Seven participants indicated that they had no information or awareness about services.

Chapter 4: The group discussions

Introduction

The topics discussed in this chapter are categorised from the themes that emerged from the six focus groups held between September 1st and November 30th 2009.

There were 32 participants in the six groups of whom 26 were female and 6 were male. The membership of the groups ranged from two to eight participants. The length of discussions ranged from 35 minutes to 75 minutes with the larger groups taking longer. One group was time-limited as participants had a commitment following it.

It emerged in some of the focus groups that some participants perceived the purpose of the gathering to be 'a group like this here tonight that's going to help one another'. Where this became apparent, the facilitator reiterated the purpose of the group and clarified that the focus group discussion was being held for research rather than therapeutic purposes.

The discussions elicited the participants' thoughts on:

- coping with illness and death,
- the support people need in this area,
- information and awareness of services.

Participants were also encouraged to make suggestions as to what type of services might help people who have been bereaved.

4.1 Effects of the illness

Dealing with a loved one through a serious illness was seen as emotionally draining, time consuming and life changing. It could involve giving up work and curtailing social life. There may be increased financial pressure with reduced income and increased expense.

The strain of dealing with the illness itself, of knowing that recovery was not possible, of dealing with doctors and hospitals, of wondering what the future held, all tells emotionally and physically. There might be less time to give to children and this might create relationship difficulties with them later. Added to this is the worry of what, when and how to tell the children. There might also be hope that someday an answer would be found and recovery would be possible.

4.1.1 Professional support in the home and in hospital

The Palliative Care team, PHN, GP, priests, neighbours, friends and family were praised highly by most participants. Support centres like LARCC were invaluable to those who had used them. The benefit of palliative care nurses and provision of equipment, liaison between hospital, GP and palliative care were highly commended. These contributed immensely to helping people to manage in the home and allowing patients to stay at home. Respite services were very helpful where they were available.

"They (palliative care team) showed me how to manage the medication; to me it was like rocket science at the time there was so much. I learned, and they thanked me for my help, and my husband was able to stay at home and he died at home where he wanted to be, but he had all the care and attention that he would have had if he was in a hospice from these nurses and doctors that called. It was wonderful really".

Having a nurse call regularly was regarded as very important and extremely beneficial. The Home Help Service was cited as being helpful although participants were not clear about how

to access this. For one person who received this service, the PHN arranged it after the patient left hospital.

“But you don’t know about these (home help) services, and you may not qualify for them”.

“When my relative was sick even though she survived her cancer, I remember the nurse coming from Dublin to see me for a day because I had to clean her (medical equipment), and I remember that particular day because after the chemo they can get temperatures, so you were brought then to (local hospital), but it would be great if you had even your local nurse, some kind of a nurse coming in every second day or so just to see how things are going”.

4.1.2 Social support

Support from family and friends was invaluable at this time. Participants were conscious of the effect on other people when someone was seriously ill and noted that although the immediate family were a priority, others were also affected and being able to give practical help can make a real difference to them too.

However, sometimes people who are caring for others do not know what they want and how they can be helped. Participants emphasised that it can be extremely frustrating when people ask what they can do to help. This is because those who do the caring may not be able to identify what needs to be done. The participants articulated a need for someone to take the initiative in identifying how best to help people who are looking after someone who is very ill. One participant recommended a book that was of great assistance in this regard, *What Can I do to Help?* (Hutton, 2005). Help with school runs, laundry, shopping and other general chores all make a difference. Setting up a blog which could let friends and family know what was happening was also suggested.

“Sometimes you don't know what you want and the worst thing is when people ask what can they do to help, and you feel like screaming 'I'm dealing with all of this and you want me to make up your mind for you about what you want to do to help'”. One of my friends found a book called 'what can I do to help' ...there were things in it like 'are there young children in the house? then organise yourselves in the school run' they have to be taken to school and picked up, 'have they got a dog? a goldfish? Make food', 'if you haven't got time and you have money, pay for a cleaner', 'if you're techy minded set up a blog so that they can write in what happened today if there was an appointment so there isn't 20 phone calls to make when you come home from the hospital' ... and it was a book that somebody had to buy, but it could have very easily been something that the hospice nurse or the district health nurse could organise”.

The PHN, palliative care nurse (PCN) or someone in the wider family were identified as people who could initiate this sort of help in homes. It was mentioned that there are services in every town if you know where to look, and that the PHN and the Citizens Advice Centre would be the place to look.

4.1.3 Travel to and from hospital

Exhaustion and access to transport were major issues for people who need to get patients to and from hospital as comfortably as possible; even when they can drive and have their own transport, journeys can be very tiring on top of caring for a very ill patient. Illness itself may cause circumstances which add stress to journeys, e.g. where changes of clothes etc are necessary. Help with the transport, e.g. a pool system, would make a major difference to people in this situation. Help in the home on return after one of these tiring days would also help.

“I was just thinking, it's five years ago since my (relative) died, and sometimes I just didn't know how I got home - I didn't remember coming down the road, I didn't remember things that happened, I was just going out of my mind trying to keep him going, trying to keep talking to him trying to keep him up, and you do get the strength, but when the whole thing is over you wonder where you got the strength

from. I remember one day ... and diarrhoea was a big part of it and we forgot to bring a change of clothes and we had to turn back and ring them in Dublin, he was all keyed up, he had to be there at a certain time to start his treatment – it's just horrible, your energies are going all over the place, they are going for him, they are going for ... (pause). You need someone to say 'I'm here for you now' ”.

4.1.4 Other things that could help

Participants highlighted some issues that could be improved to make things easier for people who have relatives with very serious illness. These included:

- Appropriate and sensitive communication of information in relation to diagnosis/prognosis and treatment.
“One thing that was said to me when my mother was very sick, the doctor came in and said ‘if your mother stops breathing we won't be bringing her back’; I didn't need to hear that he was telling me that he just wasn't going to resuscitate, I thought that was dreadful, he just told me straight out, I wasn't happy with the care she got anyway”.
- Ensuring smooth transition from hospital to home could make things much easier on patients and families.
“We left Dublin, and the social worker and psychiatrist were coming down to speak to him, ... they kind of handed us over to Tullamore to try the palliative chemo ...so you're kind of left in between having left chemo and before the palliative care team comes, you were just floating, no one offered any support, after being told this is *it*, go home and die basically”.
- There is a need for a fast-tracking system for patients who are diagnosed with an illness and have to return to hospital at times. This should make provision for patients to attend hospital without the necessity to give full medical history in both the Emergency Department and again on the ward. It is preferable to have a pathway for these patients to be admitted directly to wards rather than having to have dying relatives admitted to a casualty ward where perhaps there is a lot of chaos and drunken people getting sick. There was evidence of other pathways in some hospitals, e.g. direct to the ward, or through the GP making particular arrangements. The patient needs to be treated by health professionals who are familiar with their case; the Palliative Care Team and the GP understand but there can be problems with MIDOC services and hospitals who don't understand or know the patient.
“We would have had to go into Casualty on numerous occasions, waking up in the middle of the night, my husband would need attention and we'd call the out-of-hours doctors, they'd send us to Casualty, with someone who was dying and it would start from scratch; and I remember one doctor asked, ‘does your husband know he has cancer?’ Although he had been being treated there for cancer, there was no record that showed this up. They wouldn't know what was causing the trouble but all you needed was an x-ray, and there didn't seem to be a palliative fast-track, and it was one of the really bad things those trips - just having to answer whole medical history from scratch every time”.
“And when you go up to ward, it's the same all over again. You don't need this, you've told the history once”.
- “The biggest thing I was angry about when my son was sick was on a bank holiday weekend, we had to bring him to (Dublin) hospital on a Friday evening it was like we were in a war zone for the night. Our GP phoned and said he was having treatment on Tuesday and he'd be very vulnerable with regard to infections etc. and he was in middle of guys getting sick, being drunk and lying in Casualty with all this, and he just said ‘Ma there's no one in charge’. And that's exactly what it looked like. I know they had no bed to put him into but it was just absolutely horrific, to see your dying son lying there and still having to go through this bloody bureaucracy and all that goes with it. There has to be some way of fast-tracking in cases like this”.

"The Casualty people will say 'Deal with people who cause trouble first', people who really, really need help have to wait".

"If you were using MIDOC, the doctor wouldn't know where he was going".

4.2 The effects of the death

As expected, the effects of the death depends on several factors - how close the deceased person was, the nature of the relationship, the age of both the bereaved and deceased persons, marital and family status, area of residence (this was particularly related to transport and inclusion issues).

In a close relationship the loss could change one's whole life. The immediate response is one of emptiness, loneliness and despair. Those who lose a spouse and who have children, now find themselves as a single parent, with added responsibility and less support in making decisions. There is a lot of support in the immediate aftermath of the death, but as time goes on people are expected to learn to live without their loved one.

"You are trying to carry out a 'normal' role when it feels anything but normal".

"I think when it's all over it hits you, you go through the motions with funerals, and that sort of thing, everything is kind of done for you, but it's afterwards, after all that activity you're on your own".

Preparing for the funeral can be extremely difficult e.g. the undertaker needing to remove the body and the reluctance to let the body go.

"He was laid out at home, the undertaker said he had to take him away to prepare him and all the rest, and I said I would prefer if you didn't move him out of the house, because I said I couldn't bear the thought of him coming back dead, you know, I didn't want it, but of course he had to take him".

4.2.1 Afterwards - How life has changed

In the home there is a huge sense of loss because routines and habits are all affected by the loss. In the wider sense, social life may be affected and it may be difficult or impossible to pick up the threads again and carry on as before.

"I would always go to bed first, because he would always make sure that everything in the house was OK. He always maintained that everything must be locked up and no matter what time, and we never went to bed early, I don't know why. Then when I'd go up to bed, he would come up after me and I'm still watching that door, waiting for him to come through that door at night, that's very hard. It's extremely hard".

"You lose everything really, your social life is finished, and you're on your own for good so the old haunts you used to go to, you can't go there, you wouldn't bother going there. I don't think that will ever come back to me. I just wouldn't be bothered going anywhere now, my social life is finished; I can't see that coming back in the near future anyway".

4.2.2 Emotional issues

Participants discussed some of the emotional issues that arise for people. They discussed finding themselves in a confused state, longing for the presence of their loved one, regrets over things said or unsaid, and dealing with the loneliness.

Participants gave descriptions of feeling very confused at times, not being sure of what they wanted and generally finding things emotionally difficult.

"I don't know where I'm at, to tell you the truth now, there's no easy answer to this, I don't know, there are times I'm grand, I try to get out, I've great friends, ...oh, but there are times, and it's rough".

Some participants clearly felt the presence of the deceased person long after the funeral was over, and the mixed feelings involved, wanting the person there, and experiencing the hurt over and over again when they are not.

"I do think she's in the house, I do have the feeling she's there, not all the time, but most of the time, she's always there. I just wanted her coming in, I would keep watching the door for her to come in, but she didn't and that's the hurting part of it, even up to this day, she died last year, I still think every time the door opens that it's her that's coming in, It's too hard, (almost a whisper). It's too hard to get over a thing like that, I don't think I ever will".

There may be regrets when someone dies, for instance if there had been any ill feeling in the immediate time preceding the death. This arose more in the context of sudden death.

"I have to say I looked back and have dreadful regrets, I often hurt her, I know that ... sometimes people have that feeling (of regret) and it's an awful feeling".

"We had a row the weekend before and ... he was on his way down to me and ... I never got a chance to say sorry".

4.2.3 Financial and Legal issues

Participants felt that "there is a whole lot of administration and insurance companies, the mortgage, the house" to sort out after the death. This was traumatic for most people, unless they were the person who normally dealt with these matters in the household. Getting the death certificate was harrowing for most. Post-mortems were another issue for some participants, particularly in terms of waiting for information and reports and the difficulty in even starting to sort things out until this process is complete.

Dealing with financial and legal issues was easier for people who had been bereaved when arrangements were made prior to the death. In many families this was difficult to do as "death is a taboo subject" that people find difficult to talk about, and particularly to a very ill person. Participants felt it may be easier in many instances if this was brought up with the patient by professional people (e.g. the GP) or by other friends and family who would not be seen to have a vested interest.

"It's the shock of having to deal with stuff you've never dealt with before, going to solicitors, going to banks, insurances, all that legal end...to me banks, solicitors, these wouldn't have been people I dealt with and I found that very, very stressful."

It is essential to have somebody who knows the system to co-ordinate or navigate it to ensure that the bereaved person gets his/her full entitlements. A social worker might be helpful, but participants were not sure where to access one. The community welfare officer was another possibility but not everyone knows of this service either. People need someone to make them deal with things (financial and legal) rather than putting them off because they may not feel like doing them and the situation can get worse if they are not attended to.

"Help with the practical things is important, if you don't get on track very quick, you can spiral into debt or something like that. Things can get on top of you pretty quickly".

4.2.4 Urgent needs

The main circumstance in which people's needs are more urgent is where people are not coping and/or have little or no family/social support available to them. Bereavement following the death of children could lead to urgent needs. There were different perspectives on whether the age of the deceased person could make a difference; some felt that the death of a younger person is harder to get over, particularly where this is a child. Others felt that for older people who have lived their lives together the loss of one partner is huge and at this

age people may be less likely to have as many outlets and sources of support as younger people, especially if they live alone.

Living in a rural area could make a difference for people who do not drive, services like MIDOC might find it hard to locate them, and living in a town or village can give people more independence, mainly because of lack of transport in rural areas.

4.2.5 Experience of sudden death

Where the death is sudden, the perception of the deceased as a previously healthy person makes it harder to believe they are gone, particularly if they are young. Discovering or being informed of the death was characterised by feelings of shock.

“It took me a long time to get it into my head what has happened; he looked healthy, and he was such a young chap too”.

“I didn't find out until the day after he died, the guards came to the door... I had no family or no one to ring, to come for me, the guards told me...I sat in the house all day and just cried”.

“I think, what's different ... it just happened, one day he was out mowing the grass and the next day he was dead”.

“I suppose you'd be traumatised, you just can't, it just doesn't sink in, you don't ever think of it happening at your own door, shock, the reality of it doesn't sink in, even though you've people coming in and out with you and supporting you, it's up here, (pointing to head) is it really happening? Are you just dreaming about this, or ... it's a thing you can't put it into words, I mean, in my case anyway, everyone was there but, I didn't want them, you know, I wanted to be on my own for it to, try and sink in, so I can imagine the way she was especially with children and that and trying to explain to them, and you know?”

Further discussion on the difference between bereavement from sudden death and bereavement following an illness period elicited different perspectives. Some felt that the shock of a sudden death would make the needs greater, while others felt that a loss is a loss no matter what and that the manner of death doesn't affect the grieving process.

Many of those who had gone through lengthy illness periods valued the fact that they had time to get used to the idea, and also that the time before a death which people know is coming is very precious. The time to say goodbye was also very important. There may be more time to come to terms with the death. It may help to have time to make practical, financial and legal arrangements, even funeral arrangements ahead of time. However, while this may help with the overall burden suffered because of bereavement, it does not necessarily help with the grieving itself. It can be very hurtful when people say that the effects of bereavement are somehow lessened just because the death was anticipated.

“People say that with a long illness you are ready for it, but you're not. One of my children died when he was ten, that's quite a few years ago, and there was a nephew of my husband killed last summer, in a car accident, but there was a stupid person in our house, who said 'it wasn't as bad for ye, ye knew what was coming', I was so hurt by it (the insinuation), you know, the fact that my son was sick for so long, we didn't feel the same feelings you know when they draw the last breath”.

For yet others, a long illness doesn't necessarily mean that death is being prepared for as hope that treatment will work may remain until quite soon before the death.

There may be more likelihood of regrets with a sudden death e.g. no time to say ‘sorry’

There was also a perception that there is little support available when the death is sudden, even when it happens in hospital (specific instance was ten years ago).

4.2.6 Suicide: Rationalising the death and 'guilt'

One thing that appeared distinctive was related to bereavement as a result of suicide. People who had suffered bereavement through suicide articulated the rationalising of the death, trying to understand what their loved one was thinking, what was going on in their minds and the futility of having no answers.

"We don't know what's going on in their heads; we know people say you should accept this and all that. We don't realise what way their head was, messed up you know, so we have to try and understand that, that was their only way out. They didn't do it just for badness or anything else, it's just that they couldn't help themselves".

"Why did she do it? You get no answers for it; you don't get any answers ..."

Participants also spoke of the *guilt* that was felt following bereavement through suicide.

"Was there something I did? Was there something I didn't do?"

This was also connected to another difference to having a long illness period; with an illness like cancer, there often isn't anything which can be done to prevent it, it is something that is ordained elsewhere, whereas with suicide, people always wonder if they could have done something.

"I often sat down at home and said is there something I shouldn't be doing? Or what did I do wrong to make her do that?"

Participants felt there should be appropriate help for people with drug problems, although they were not sure exactly what would have made a difference.

"There should be places for people like that (with drug problems) where they could go into to get help".

"There are clinics but he couldn't be at a clinic, he knew it, 'mammy' he said 'I couldn't handle it'. A lot of people maybe can't, we don't know what they're going through. It's easy for us to say 'put them in to a clinic, and get him help', but we don't know what way they are, whether they'd be able to handle that or not or. It's obvious that he couldn't handle it."

4.2.7 What helps – coping strategies

Participants spoke of the dealing with the loneliness and the loss and it was clear that people adopt various strategies in this regard - sitting in *his* armchair, leaving the radio on when leaving the house.

"We have two armchairs each side of the fire, ...I have to sit in his armchair now because I can't look across and see him not there, you know, and even still, I can't sit on my own armchair because I'd be looking for him".

"I find when the person is gone, going back into the house seems lonely. I knew one man who left the radio on so there was a voice in the house when he came back. Occasionally now I put it on at night as well".

Going to the cemetery really helped some people while this was very difficult for others.

"Well we go to it (cemetery) every morning, we never miss a morning without going, and when you go to that graveyard it's completely different, once you sit down in the graveyard you have peace and comfort, but when you come back in to your own house it's a different story, because you don't want to come back into the house, because you're looking at photographs and things in the house, things like that".

"I get great comfort out of visiting the cemetery, and sit there and talk to him. I'd have a conversation with him as if he was at home in the house. I'd tell him everything that's going on, all that's happening in the area, you know".

Some things take on a major significance for people e.g. dealing with the personal effects of their loved one.

"I was thinking of getting rid of the clothes, and sure I'm in shock still, and I was in shock, and I suppose I still am, so they're there and they'll stay there for a long time possibly, I don't know what, no, I don't know".

4.2.8 What was unhelpful - the loss of contact with services following the death

Visiting professionals such as the palliative care team, PHNs, GPs provide great service to those caring for their loved ones at home, but when the death occurs there is a void. People understood the services have to withdraw but felt it was a bit 'abrupt'. This is also the time when professionals such as social workers may be needed again. Some participants reported that a social worker called in the beginning and gave them a list of what they were entitled to, but they did not see them again after that.

"One thing I was thinking about coming in here was the palliative care team and how great they are and they call to the family, and then the person dies and you don't see them (teams) anymore, and your GP will have been calling every day and phone every night to see if everything was all right, and all of these people that, bit by bit, you were handing enormous responsibility over to for decisions that were being made and then they've all disappeared. It was, it was really tough - it was such a calm, steady presence, and you were at sea, it's like your anchor didn't turn up. They always made us concentrate on each other and the things that were important towards the end ... and then they went, you couldn't expect them to stay in touch, but it was very abrupt".

4.3 Information and awareness of bereavement services

4.3.1 Accessing services

Access to information and services was perceived to be better where support organisations (those mentioned were the Irish Cancer Society, the Irish Kidney Association and the Alzheimer's Society) were well developed and involved in providing the service. Where these services or the palliative care nursing service are involved, the offer of bereavement services generally, though not always, appears to occur.

Beneficial services included availability of a social worker, counsellor and booklet that covers entitlements financially and in relation to services. Some participants also mentioned the Public Health Nursing service (more in relation to illness than bereavement) though there was a lot of uncertainty as to whether they could be approached about this, and also as to whether people were entitled to services like 'home help' and if so, how to access them. There was little evidence of information evenings and some had seen little about bereavement groups.

There was a feeling that while services were better in the Midlands where cancer was involved they were less well developed where the cause of death was other than cancer. Support following suicide was mentioned as an area of particular need, one where there is a dearth of trained people to provide services. However, in one group it was felt that this was one of the areas where there would be services available.

There were three main issues in relation to accessing services, the first was having the information; the second was realising that you needed a service and the third was being encouraged to avail of one.

A) Discovering bereavement services

For those participants who had availed of services, some were made aware of bereavement services through information given by the palliative care service during the illness period. Although this did not appear important at that time, the information was later found to be very useful. Some discovered services by word of mouth, while others only found out about bereavement services a few months, or years, following the bereavement.

"It (bereavement counselling) saved my life really. I had no idea I might need this beforehand".

It is important to realise that even if information in relation to bereavement services is left with families during the illness period, they may not always be in a frame of mind to register this and may not always link this with their needs afterwards. It is notable that one participant reported not being aware of any bereavement services although he/she had earlier reported that the PHN had left information leaflets and bereavement books.

B) Recognising that you need a service

Some people are aware of counselling services but do not realise they need them. This applied even to the extent that they might encourage someone else to go for counselling even though they did not feel the need to attend themselves.

"I sent everyone else belonging to me to counselling but I felt I was able to deal with this; I deal with it every day of the week. I went up thinking I was going to help everyone else, but I was the one who was in floods of tears, I couldn't speak, I couldn't ... I wasn't going to go back again, but I went the next night and it was a bit better, but I had thought I was coping and didn't need help".

Others may have heard of bereavement groups but might not have had the 'courage' to go along. In discussing this, participants articulated a need to be 'invited' or 'encouraged' to avail of bereavement services.

C) Being encouraged to avail of services

There is a need for a lot of emotional support, a sense that people may not feel able to access help even though it's there - people need an invitation, someone to reach out to them rather than the other way around. Services may not be published enough; local newspapers, radio and GP surgeries were suggested as ways of promoting knowledge of the services. Participants suggested a 'call out' service through which someone trusted would call and see if the person is all right; this could be linked with other local parish and/or bereavement services. There was evidence that community groups can sometimes be instrumental in placing bereaved people in contact with bereavement services, so community knowledge is important.

"Sometimes it's very hard to get up and go and get that help. You just want to go into your cocoon, unless a letter or something comes inviting you. Sometimes, to get up and go and look for it, it's the last thing you want to do".

"I knew the counselling was there, I had done a course in counselling myself, so I knew, it was in the back of my head, and a friend of mine said 'do you not think you should go', so I needed that little nudge ..."

"Yes, I don't think it's emphasised enough, even in local papers that there is such a group ... even if there was a meeting once every six months or that for people who had been bereaved... I think that would be helpful, someone who had experienced it might be able to help someone else".

"...you have to go seeking it (bereavement counselling) out, and if you're emotionally fragile you don't want to do that, you just don't want to enter it".

4.3.2 Potential effects of not having a service

There were also issues around the potential effects of not having received a service, particularly in relation to the overwhelming need to discuss all of the issues related to bereavement. One participant only discovered bereavement services after she developed a serious illness herself and attributed at least some of the cause of this to stress induced by bereavement. In another case a participant reported disharmony in personal relationships because of not being able to deal with the bereavement.

"I know I was ready to kill my (spouse) and my (spouse) was ready to kill me for months and even years after ... you take it out on nearest to you - really we had to go away, it was the only time we would actually talk about what had happened, and I really do feel that people should have someone that they could say look, 'we're having problems here'. And we don't want our child's death to be the cause of us, you know..."

4.3.3 The value of appropriate services

While participants highly valued both social support and specific bereavement services, they discussed the distinction between them. The social support networks which help around the time of illness and immediate bereavement period tend to withdraw in the following weeks and months, people are expected to -get on with it and -get back to normal. For the bereaved person however, life is not normal, there is a loved one missing from it and 'everything has changed'. While the support of family, friends and neighbours was highly valued by participants, it was clear that they may not always have the listening and counselling skills to provide adequate support. There was also a perception that they might not 'understand' if they hadn't been in the same situation. "They will tell you to 'be positive', 'you have a negative attitude' ". Some participants highlighted the value of professional counselling and also felt that they could open up with a stranger more easily than with family and friends because of 'trying to protect other people' or 'needing to say the right thing'.

"You get support from families as well as friends, but (you need) someone from outside as well, like the bereavement counsellor here - somebody that's outside of the family focus and friends, someone you can actually speak to frankly without having to watch what you're saying, or who'll say 'god this one's crazy', someone who understands is important, who is not connected".

"... they (counsellors) understood me and this was very important because I couldn't think straight and I was all confused and mixed up - they gave me the support to help with my illness".

The value of shared common experience in group work was also recognised.

"Counselling (group) kept me sane... I realised we were all in the same boat, I wasn't going mental, so you were able to see what the process was, and you weren't going cracked. Because, when you're on your own your friends start to drop you, and they don't want to know, been there done that, that's over like".

On the other hand, some participants felt they did not need any services and attributed this to their social support networks and their own ability to cope.

"I didn't look for anything, I was well prepared, she was three years sick and eight weeks in hospital so it was kind of a happy release, and I was well ready for it you know. It's just me, my outlook on life, I never felt that bad that I needed anything".

"I think It depends on where you are in life, if you have family around you and if you have somebody close to you ...but there are lots of people and they have nobody, and for those people I think it's very important that they have somebody they can contact ...or who can contact them, sometimes people just need somebody to listen to them".

4.3.4 Difficulty accessing services

Some participants reported having difficulty in accessing services while others had been completely unaware that there were any services in the aftermath of their bereavement or

were unsure which services are applicable, for example whether palliative care bereavement services are available to people who are bereaved for reasons other than cancer.

"I go to a cancer conference every year since my mother died and I asked about groups and he tried all over and he couldn't get me one. And then, LARCC is only for cancer bereavement".

(Several of the participants spoke together here expressing some doubt in the group as to whether this is the case).

Some participants felt they would like a choice in type of service e.g. whether this would be one-to-one or a group service; a general service or more specific. The importance of timely approach and response to bereavement needs was also emphasised. One participant reported inability to access services for four years, while another had an appointment within two days of the initial phone call.

"That is only one-to-one, and I didn't want to do this, I wanted a group. There were no groups at that time; it took me four years to actually get a place."

"I got information from the palliative care service about two months after my (relative) passed away, they came into the house, to see how I was coping and suggested I come over to LARCC, so I came over two days afterwards".

4.3.5 Who could signpost where to go

Participants felt that a close friend or relation could signpost where to go, but it would most likely be a professional. It is crucial to have someone because after bereavement everything 'goes by in a blur' and 'you don't know where to go for anything'. Participants felt that people might approach social welfare services about entitlements but were not too sure that this is much help. The undertaker and the TD (elected political representative) were identified as people who could help as would a pack containing the relevant information. Form filling is traumatic for some people.

"I didn't have money to pay for a funeral; my (relatives) were about six months dead before I knew I could get a death grant, because when they died, I didn't have the money to pay for a coffin straight away, so I said to yer man is there any way I could pay for this, something every week off it. When I went up to the undertaker to pay the last payment, he said to me, 'did you ever get the death grant?' Death grant? What's that? You know, I didn't know anything about it, had to borrow the money to pay for it. Undertaker got me the forms, and the TD as well, he helped me fill them in".

"There should be a pack or something; it's not the first thing you think of but a couple of weeks after..."

4.3.6 Voluntary support services

Not all participants were aware of volunteer services. For some participants who had availed of them there were mixed feelings about the services - some finding them excellent, and others less so. The volunteer services were not regarded as appropriate for all instances, e.g. for suicide, and sometimes more specialism was required, e.g. cancer patients. There was also a need to have services provided by professionals who were not previously known to the bereaved person or likely to be involved in their locality.

"I went for parish support first for the bereavement, and it got me through until I got cancer and then I knew I needed more. I used to be very bad when I got chemo, I'd be in bits and I'd be so weak and so, you know sick, and to try and cope with that, to get over the next lot of chemo and I found I got the help I needed here. It was great. They understood me where somebody else outside wouldn't understand".

"It (voluntary bereavement service) saved me ...I thought I was going absolutely bonkers, because I couldn't focus, I'd go into a shop to buy something and come out and forget what I went in for, I just couldn't function, that was the bottom line".

There was a perception that one had to go through it to understand. This was in part related to people's own experience and knowing that they themselves could provide more appropriate support to other bereaved friends now that they had suffered bereavement themselves.

"It's when you're going through it, that you find you can help somebody ... I would never have appreciated that people's mother had gone from their lives but you really had no idea what they were going through. But you use things that happen to yourself and you're much more sensitised to friends. You can empathise much better with them, I can empathise much more than I did before I lost ..."

4.3.7 HSE staff services

For staff members within the HSE, the *Employee Assistance Service* was mentioned, and they felt that the fact that they were HSE staff also gave them access to other services through others who knew of them. These participants felt they would not know where to go if they were not employed by the HSE. They also felt that staff could have difficulty in accessing counselling within their own organisation because of discomfort about the possibility of knowing the professionals involved. Staff need to be aware of provision of external counsellors where this is available.

"I'd know how to access the advice systems that are there and I know that as part of their service you can avail of bereavement counselling, but I know that's internal ... but I wouldn't have known where to go, or I don't know if any of my family who aren't working in the HSE would know where to go if they wanted to".

4.3.8 Dissatisfaction with services

Dissatisfaction with services was apparent mainly where the service was not appropriate to the needs of the bereaved person, i.e. when the counsellor did not understand their situation. There were issues about counsellors who might have had little or no experience of death themselves and a perception that it was only people who had gone through it who could understand.

"Sometimes if they go to a counsellor, these counsellors often have no experience of death, or things like that... but in the end, it was only people who had been through all these things that I could go to".

4.3.9 Ceremonies of remembrance and rituals

There were mixed feelings in relation to ceremonies of remembrance generally with some valuing them highly and others finding them upsetting and unable to bring themselves to attend.

The support of religion was very important to some people in providing a framework for accepting the death. It was clear that things like anniversary masses were highly important in supporting and encouraging family members to help and comfort one another. At the same time, traditional sources of support, like people meeting informally after mass are not always available anymore. While there is a lot of ritual around death, there is less opportunity for informal support around it.

4.3.10 Services suggested by participants

Some people prefer working in groups; others may prefer to work on a one-to-one basis. Some participants felt they would not find it helpful to listen to other people's stories while others would find this very beneficial. Informal meetings may suit some people better than formal group counselling.

The need for weekend services was mentioned in one group as something that could help families where children are now adult but may return home during these periods. This would facilitate siblings to attend services together or to attend at times when their lives were less busy.

4.4 Children's needs

All groups felt that children would be likely to need help to get over the death of a loved one. Children may have been neglected a little or have received less attention during the illness period of a parent or sibling and they may be very traumatised by sudden death. Children will experience lots of emotions ó for example, they may be angry or they could feel deprived at the loss of their loved one. These feelings are normal and children need to understand that.

The main issues were:

- Concern about children
- Identifying, in children, the need for help
- Appropriateness of services for children
- General support for children in relation to bereavement
- Retaining memories of loved ones
- Particular needs of young people

4.4.1 Concern about children

Participants were very concerned about children, about being able to explain things to them and answer their questions.

"It's just, you see her coming in the door, she's only six, she didn't realise, she didn't know what was going on, and all I wanted to do was hug her and not let her go. It was terrible (you can hear distress in participant's voice). Yeah, you know, to try and explain, she was just staring at you, and wondering why is my nana crying, and why is everyone crying, she understands now, but at the time, it's terrible, you don't know what to talk about, you don't know what, you just want to run and hide, be on your own ..."

4.4.2 How to identify if children need help

Some participants felt that it was difficult to tell when a child needs help; others felt that some change in personality or behaviour would be seen if children required services. There was also a sense that receiving appropriate help in time might prevent them from experiencing distress in later life.

"In our case we had a daughter ... but you don't know when it's actually affecting them, is it at the time, or afterwards, when are you supposed to send them for bereavement (counselling) or ..."

"You'd know by the way they are down in themselves, crying to themselves the whole time or, they talk about them a lot and you could see the tears coming out of their eyes, they definitely need help. Because when they get older you don't know what they're going to ... are they going to keep hurting inside? That's all".

4.4.3 Appropriateness of services for children

Some participants had come to the group specifically because they were interested in helping their children in relation to bereavement. This was sometimes related to the participant feeling that the needs they experienced after bereavements they suffered as children went unmet. It was considered important that this help would be appropriate and not involve unnecessary psychological intervention.

"The reason why I am here is I have a six year old child and I'd be more interested in what I'm going to do with her ... how do I tell her, it's not natural for her, at (my) age you can be widowed, you can have bereavement. When I lost a parent myself at sixteen, I thought there was nothing out there, and

that carried on into my marriage and into my life, and into the situation I'm in now, so I think there is a cumulative loss, and there is certainly very little out there for children who are traumatised... I don't want my kid at psychologists or cognitive behaviour therapists, she doesn't need that".

"I had two children, when my child died, but I never thought about what happened to them, because you know, I didn't know what was going on, and I was listening to the radio one night and they mentioned about something being set up in (local town) for children who were bereaved and I thought, well what happened to my two, (now adult), but I'm just wondering if there's something there, and is there anything I can do at this stage?"

One group questioned whether children's counselling services are suitable for all children as they may deal with children of separated parents as well as bereaved children in a group; the problems and the levels of adjustment may show considerable variation. Private counselling was mentioned for children, as were services provided by Bethany House and Barnardos.

4.4.4 General support for children in relation to bereavement

Participants felt that there was a need to communicate with those who might be able to flag something, e.g. school, friends, GP, parents of other children. Children may need support at school as well, and it was considered important that this would be available from someone who understands children and can "speak to them in their (children's) language". It was considered particularly important that teachers in particular would be informed if a child had suffered bereavement as they can make appropriate allowances if required. While it was felt that this happens in some schools there may be children whose parents communicate less with schools. Career guidance teachers were seen to have a role to play in this regard in secondary schools; while it was thought that primary schools may have a bigger problem as they may not have a specific position within which this role could be assumed.

"And the teacher should know, they could be daydreaming and it's not that they're not listening, but for the moment they have lost concentration and are tuned out. The teachers need to know to make allowances for you for that, it's important that the information goes to the school, that's huge".

4.4.5 Retaining memories of loved ones

One group noted that memory boxes are a good idea and could be encouraged by schools, but they emphasised the need for them to be done early before someone clears out some of the items that could be useful for this. Useful techniques like this can be suggested by bereavement services (e.g. Rainbows), and information in relation to them could be contained in a bereavement booklet. The timing of giving information also needs attention and while specialist services often are aware of the appropriate time to provide options, this is not always the case for those not so involved.

"We talk about doing a memory box, because some people come in and they clear everything away, but it's very important that children have memories, photographs and that, some aftershave maybe, because memory fades in time".

Participants also felt that it is important to keep memories alive for children in other ways.

"I bring her (granddaughter) to the cemetery, and she keeps his photograph with kisses on it, and she tells him she loves him and there are photographs all around the house, and she's not let forget him".

It was also apparent that children sometimes use their own strategies to help them deal with their loss, e.g. putting photographs to music on a laptop or setting up a dedicated altar in the home. While these activities appeared to help the children, the parents sometimes found them quite difficult.

4.4.6 Particular needs of young people

Young people (teenagers) can often be lost following a bereavement when their much needed friends often do not know how to support them. In some circumstances (those mentioned were drug abuse, pregnancy, suicide) they may find it very difficult to discuss their issues with their parents. The home school liaison officer was identified as a helpful adult in these circumstances.

“I was too young to know (about bereavement) at the time, I was only 16, I didn't even know what bereavement meant, so I tended just to stick to friends ... I never really told my parents about it until last year. It might have been easier if I had told them about it, but you wouldn't know how they would react...I did suffer terrible, from anger to everything; it was just so emotional. I kind of just locked it away, then my (family member) died, and that was even harder, I was very close to him, so I said I had to get some help so I came here (to the centre)”.

Chapter 5: Conclusion and recommendations

This document reports the experiences of bereaved people from the area Longford/Westmeath and Laois/Offaly. The descriptions identify a range of responses, needs and views of services received. The study set out to hear people's views on need and on the provision of services locally to meet those needs. It is not the intent to develop a picture which can be fully generalised, but rather to identify the range of experiences.

The six discussions spanned age ranges and types of loss, including expected deaths and sudden deaths - accident and suicide.

The report details some of the impacts a death may have on people and includes descriptions of pragmatic issues and emotional responses to loss. Descriptive accounts left a clear impression of people's pain, their natural coping, and the issues that further challenged them in bereavement.

In presenting the findings from this work the research team are acutely aware of an overarching impression from those who gave so generously of their time that for them "everything had changed".

From a bereavement service design perspective there are important lessons about how services (and lack of services) can be interpreted and experienced by people.

5.1 Pre-death care

(a) Information:

The main gap identified was information on entitlements and where to access that information. This is particularly important because changing circumstances nationally may affect entitlements e.g. medical cards.

Recommendation:

- *Make available to people a comprehensive menu of information on services, e.g. home care package, personal care, respite care, twilight nurses, long-term care options, medical card issues, legal and financial advice. While there are some central resources such as the HSE information line these need to be further advertised and promoted.*

(b) Social support:

People reported feeling well supported during the illness period. While neighbours, friends and family are willing to help, this willingness may benefit from some co-ordination - including identifying the practical tasks that need to be done and who can do them.

Recommendations:

- *In the pre-death period visiting health professionals e.g. palliative care nurse, social worker, PHN and family support worker should initiate conversations to help identify the challenges ahead and identify resources needed.*
- *Co-ordinate practical and social support for families by helping them to review their needs and the resources available to them in their networks.*

(c) Professional care:

Excellent pre-death care is appreciated and a form of solace to people.

Those who availed of palliative care services in the community reported satisfaction with professional help and the practical provision of equipment. Many of the reported issues of concern in relation to services arose from contact with the acute hospitals, in particular, direct access to beds for palliative care patients.

Withdrawal of care services aimed at the patient can leave bereaved family members feeling abandoned; these experiences seemed particularly to relate to palliative and primary care in the home.

Recommendations:

- *Implement a pathway whereby patients, with serious illness or expected death, have direct access to hospital services rather than having to go through the Emergency Department.*
- *Consider the development of a patient-held record system to ensure that all health professionals involved in the patient care have access to all relevant information and a copy of the care plan. This could help ease the transition from community to hospital care.*
- *Fully inform families and patients about transition from hospital care to home care, especially with regard to services and named contacts and the process involved.*
- *Engage with the family in the aftermath of a death to plan the transition and withdrawal of formal care and clarify the process of 'leave-taking' over time.*
- *Provide information to the family on all aspects of bereavement and support systems in the community.*
- *Provide the family with a named contact for follow-on or future direction.*

5.2 Post Bereavement

(a) Information

Little mention was made about information as a service impacting on the emotional aspect of grief. Information about death grants, finance and practical matters, however, was mentioned repeatedly as an important service and different sources were identified ó e.g. funeral directors, TDs and hospital staff. While some of this information is available from Citizens Advice Centres in booklet form and on the website, the extent to which people are aware of it and accessing it seemed low. Hard copy information is only one route and sometimes it may be preferable to go through these with people where appropriate.

Recommendations:

- *Endorse proactive provision of information on the sources of information about death grants, financial and legal and practical aspects of death and dying as a core part of the role of all relevant stakeholders, undertakers, social workers, community welfare officers, hospital discharge policy and general practice staff.*
- *Continue the role of the BCLO as a source of information.*
- *Identify and develop, in liaison with existing service providers, ways of developing community knowledge about the availability of this information.*

(b) Social and family support

Family and informal supports were highly appreciated around the time of death and in the immediate aftermath; some mention was made of informal support being adequate and a 'protecting' factor meaning that counselling was not required.

On the other hand, there were indications that people are expected to get back to normal before long. In particular it appears that while people who have been bereaved still needed opportunities to discuss the bereavement and associated issues some time afterwards, those in their social circle did not always have the capacity to support this. Participants suggested informal groups where people support one another.

Recommendation:

- *Support and promote public education initiatives about the nature of grief and information events which also provide opportunity for meeting with other bereaved people.*

(c) Help and help-seeking

The complexities behind looking for help and finding help were well described. Some experiences reflected a difficulty in finding out about bereavement services while other people described the struggle in coming to the realisation that they needed help. Some participants felt strongly that there was scope for professionals or 'others' to encourage bereaved people to access services. In general the participants were very well disposed to bereavement supports but generally referred to these as 'counselling'.

The value of external support services was in providing a support outside of the family, providing access to someone whom it was felt could understand some of the experiences the bereaved person was going through. Some of the difficulties in accessing services or supports revolved around confusion as to who was eligible to attend (e.g. cancer only bereaved supports) and the lack of a preferred service (e.g. group unavailable). Finally, timing of services was not always convenient, with few weekend services.

Voluntary bereavement services were accessed and most of those who used them found them relatively helpful. Some people were willing to travel to receive appropriate support, and 'local' was not always seen as being an advantage to voluntary support because of perceived concerns about confidentiality. The perceived lack of anonymity of local services, even through HSE, was also alluded to.

There was a perception that to be helpful there was a need for professionals, or indeed those providing social support, to have experienced bereavement themselves in order to understand. Those working in formal health services felt they had better access to and ability to negotiate support structures and recognised it would be harder for others to do so.

A perception exists that there is a hierarchy of support for bereaved family members such that cancer and palliative care deaths have a better care infrastructure.

The particular issues in relation to 'rationalising the death' and 'guilt' that have been noted in the literature as relating to complications in grieving, were highlighted through the conversations.

Recommendations:

- *Ensure that services are appropriate to the needs of the bereaved person and are delivered by trained personnel.*
- *Proactively disseminate information to educate about the responses to bereavement.*
- *Develop a menu of services to meet preferences ranging from information talks, one-to-one voluntary support, affordable bereavement counselling and group work.*
- *Consider whether weekend services are appropriate and/or viable.*
- *Equip general practice staff and other professionals with the skills to initiate conversations around bereavement and the range of service options.*
- *Make it routine practice that those coming into professional contact with bereaved people will 'signpost' the range of bereavement care and consider the 'best fit' for individual needs.*
- *Clarify the goals of different supports while acknowledging that a range of services are needed to reflect requirements for shared experiences, peer support and professional counselling services.*

(d) Sudden death

Participants appreciated that sudden death through accident and suicide brought a different set of challenges. While it is not right to say this is a worse type of bereavement, it was clear from the accounts here that people felt they had different needs, particularly in the short term. There was less agreement as to whether a different type of support or service was required after a sudden death. The sudden and traumatic death of a child was described by some participants.

Recommendations:

- *Implement public awareness and education that focuses on loss as an individual experience thereby promoting sensitivity and awareness about bereavement.*
- *Include linkage and information about available resources in the planning of first response services. First-response services, such as hospital, police and paramedics, represent an important contact point when a sudden death happens.*

5.3 Children's services

Talking to children about death was a difficulty for many people, while other accounts showed participants going to great trouble to normalise the loss and to keep the memories of a dead parent alive for the child.

Accessing child-appropriate services was also a challenge and, in particular, getting advice on the best service.

A range of school, parish and health services were mentioned but there was no sense of a coherent map of childhood bereavement services in the area.

Recommendations:

- *Review information about children's bereavement supports.*
- *Extend access to relevant children's literature, and identify simple sources of information for families to help them to talk to children about death and dying.*
- *Address the under-supply of children's bereavement services in the area by increasing availability and supply and identifying providers from existing services.*
- *Investigate the potential of integrating a once-off psycho-educational consultation into an existing service for families who may benefit from having this.*

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Appendices

Appendix I: Information for participants



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

26th August 2009

Re Proposed Bereavement Focus Group

Dear Participant,

The HSE Dublin Mid Leinster in collaboration with the Irish Hospice Foundation launched the Bereavement Care Liaison Project in Laois/Offaly and Longford/ Westmeath in 2008. The Bereavement Care Liaison Project seeks to raise awareness about appropriate bereavement care (including information and resources) and to help develop the capacity of a full range of local services.

We wish to explore the need for bereavement services through learning from those who have already been bereaved. I am aware that you have expressed an interest in taking part in the focus group and would like to invite you to do so.

The focus groups will involve discussion of people's experience related to bereavement such as information and support that might need to be available and about who and what can help in these circumstances. The discussion will take approximately **one hour**.

Participation is voluntary and all information received through both interview and questionnaire shall be treated in the strictest confidence and only amalgamated data will be reported.

I would like to thank you for your interest in participating in the research. If you have any queries regarding the research please feel free to contact me at the address below.

Kind Regards

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Appendix II: Consent Form

Bereavement research: Focus group consent form

I have had the purpose of today's focus groups session explained to me. I understand that we will be discussing areas related to bereavement and the supports required for people who may be bereaved. The session will be recorded on audio-tape. All information will be treated as confidential by the researcher(s). I also agree not to discuss what other group members say today outside of the groups.

I understand that my participation is completely voluntary.

I consent to take part in today's discussion and abide by the above conditions.

Signed/Initialled

Date:

Appendix III: Topic guide

Bereavement services research: Focus Group Topic Guide

We've asked you here today as you all have your own story. We are interested in the sorts of things you found helpful and unhelpful during the days, weeks, months and maybe years of your bereavement. We are wondering what it is like to be bereaved in the Midlands, how easy or difficult it is to get information or any type of support.

1. What would Mary's life have been like during Mike's illness
2. What effect do you think Mike's death would have had on her?
3. How do you think Mary feels at this stage
 - Probe - what sort of problems does she have?
4. What needs does Mary have as a result of her bereavement?
5. Do you think Mary would have been able to access information in relation to these services, or to bereavement generally?
 - Probe if any of you were able to access information how hard /easy was it to access this?, was the information useful?
6. What can be helpful? Are there any bereavement services available to her?
 - Probe: What is the understanding of voluntary and parish support, the use of volunteers. Has anyone used volunteer counselling? Would anyone use it? What is the image of and the impression of availability of these services?
7. Are there any other services that could help her?
 - Probe: what about doctors and counsellors and other professionals? Are they needed during bereavement or has anyone experience of help with bereavement from any of these professions?
8. Do her children need help? Is this available? Who can provide it?
9. Where do you think Mary could have turned to for support
10. Would her needs be the same if Mike's death had been more sudden? If she lived in the country? If she had no children? City like Dublin or Cork?
11. Are some people's needs more urgent or severe than others e.g. because of age or circumstances?
12. What else can help Mary now?

Appendix IV: Vignette

Mary is a 45 year old woman who lives on the outskirts of a town. Her husband, Mike, died six months ago after a long illness. Mary looked after Mike at home apart from his many visits to the hospital, particularly over his last year. Mary has two teenage children.

Appendix V: Questionnaire

Bereavement Services Focus Group Questionnaire - Draft

1. Are you a. Male b. Female

2. To what age band do you belong?

18-24 25-34 35-44 45-54 55-64 65 or over

3. In which county do you reside? _____

3a. Is your residential location Urban Rural

4. Have you had access to information on grief and loss? Yes No

5. Are you aware of any bereavement services? Yes No

6. Have you availed of any bereavement services? Yes No

7. Was your deceased loved one your

Husband Wife

Mother Father

Sister Brother

Daughter Son

Other (Please specify) _____

8. Please provide details about your deceased relative

(a) how many months is it since your bereavement? _____

(b) Age of deceased at time of death

Less than 18 18-24 25-34 35-44

45-54 55-64 65 or over

(c)Type of death Illness of long duration

Sudden death

Other (please specify) _____

(d)Place of death (e.g. at home, hospital, nursing home, hospice etc.)

Thank you for completing this questionnaire

