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BEREAVEMENT PROJECT

JULY 2003 – NOVEMBER 2004

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Sonnet LXXXIX
(From 100 Love Sonnets)

When I die, I want your hands on my eyes:
I want the light and wheat of your beloved hands
To pass their freshness over me once more:
I want to feel the softness that changed my destiny.

I want you to live while I wait for you, asleep.
I want your ears to still hear the wind, I want you
To sniff the sea's aroma that we loved together,
To continue to walk on the sand we walk on.

I want what I love to continue to live,
And you whom I love, and sang above everything else
To continue to nourish, full-flowered:

so that you can reach everything my love directs you to,
so that my shadow can travel along in your hair,
so that everything can learn the reason for my song.¹

PABLO NERUDA (1904 – 73)

Translated from the Spanish by Stephen Tapscott

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2. INTRODUCTION

West Cumbria Hospice at Home was established in 1987 and has responded to the needs of people in West Cumbria with a life threatening or terminal illness. Services include a medical director working five sessions a week, a nursing service for patients in their own home, day care centres and a lymphoedema service. The services provided have steadily increased and have included support for the bereaved. Staff and trustees became aware of the need to extend the service to meet the needs of families once their loved one had died. However they wished to review the services provided and gather information so that development of a bereavement service was informed. With that in mind, this project was conceived.

The project's remit was to:

- Map current bereavement provision in the area.
- Identify areas of need.
- Develop a strategy for bereavement provision within West Cumbria. Hospice at Home.

The mapping exercise identified existing services in West Cumbria. It also considered services in the East of the county and services that cover the whole of North Cumbria. Awareness of services throughout North Cumbria is important for the development of future services when trying to ensure equity of provision. Cumbria's geography and population is such that sometimes North Cumbria wide initiatives are appropriate in order to ensure adequate numbers. In other situations a locally based service is required.

A literature review has been part of the project. There is also consideration of Risk Assessment Tools that could be used to highlight those who might be vulnerable and therefore require specific follow up. Information about local need has come from the bereaved and from those professionals who come into contact with the bereaved. A service that is sensitive to local need must also have an awareness of national standards. The NICE Guidance on Cancer Services includes recommendations for bereavement services, and in 2001 The National Standards for Bereavement Care in the UK was produced by a mixed working party. They sought to introduce some consistent standards that could be applied to bereavement care throughout the UK.

I approached other similar organisations to ascertain what bereavement services they offer and also to learn from them which initiatives had proved successful and those that had not.

Finally I have made recommendations as to a strategy for bereavement care that West Cumbria Hospice at Home might follow.

2.1 Executive Summary

The first task of the project was to identify those bereavement services already in existence. The services currently offered by West Cumbria Hospice at Home were considered. Services offered throughout North

Cumbria were identified. This information will now be made available on the North Cumbria Health website and will also be circulated as widely as possible.

A review of the literature about bereavement and bereavement services was made. There is a huge body of literature, so for the purposes of this report a focus was made on implications for practice and on the provision of bereavement services.

The project has taken place at a time when there are various centralised attempts to introduce national standards to bereavement care. The report considers the relevant standards and their importance to service development within West Cumbria Hospice at Home. There are five documents considered:

- The Standards for Bereavement Care in the UK 2001, which consist of two main elements, Principles and Core Standards.
- The National Institute for Clinical Excellence Manual for Improving Supportive and Palliative Care for Adults with Cancer in March 2004 which include bereavement care for families and carers.
- The Department of Health issued the document “When Patients Die”. This describes the standards required of services provided by NHS Trusts when a patient dies. The document applies to the care given immediately following a death wherever a person dies. Bereavement support is identified as an issue important enough to require allocation to someone at Board level. “When Patients Die” was brought to the attention of the Trusts in its draft form, by the North Cumbria Bereavement Forum. Each Trust has already identified an Executive member of the Board to take on this responsibility.
- North Cumbria Mental Health Prevention Strategy recognises that bereavement is a risk factor for mental health and therefore promotes access to bereavement support. The North Cumbria Bereavement Forum is a group of people working in the field of bereavement and who share a commitment to promoting access to bereavement support and therefore aim to meet this objective. West Cumbria Hospice at Home has been part of this forum and should continue to be so.
- Child Bereavement Network: Guidelines for Best Practice are the standards for working with bereaved children that are seen to be the gold standard.

The perceived needs for bereavement services locally were considered by seeking comments from General Practitioners in North Cumbria and from informal feedback from bereaved people who have used the bereavement services provided by West Cumbria Hospice at Home.

A means of identifying those people who might be at particular risk of struggling to manage following a bereavement would be useful to West Cumbria Hospice at Home in planning development of services. Tools to do this were therefore considered. Feedback from other organisations who have

used such tools suggested they were of limited use. However, there was not conclusive evidence that they were of no use at all.

It has been useful to consider how other organisations have developed their services to the bereaved. Staff at both Eden Valley Hospice and Hospice at Home Carlisle and North Lakeland have been very willing to share information. The services they provide are described briefly and consist mainly of a volunteer bereavement counselling scheme. Eden Valley Hospice have an established group of volunteers who undergo training which is ongoing and who have regular supervision. Hospice at Home Carlisle and North Lakeland have recently established a volunteer scheme which will also provide a service with trained and supervised volunteers. Bereavement Services provided by staff in the East Riding of Yorkshire Health Authority were the subject of a report in 2000 and the gaps they identified are described. Most significantly, there was a consistent call for someone to co-ordinate bereavement services across the area. In the Isle of Man Hospice bereavement services are the responsibility of the social worker. She co-ordinates the service and as a part of this, has employed a counsellor to develop a team of trained and supervised volunteers. She also runs groups for the bereaved with members of the nursing staff, and offers individual and family support. She has often been involved with families offering practical and emotional support during the patient's illness.

Iain Rennie Hospice at Home in Tring has had a similar history to that of West Cumbria Hospice at Home. In both organisations bereavement support has always been offered by hospice staff. As the organisation IN Tring developed the need for a more formal system of support was identified. Iain Rennie Hospice appointed a Family Support Worker. She is involved with families prior to death providing practical and emotional support. Her responsibility is also to co-ordinate and develop services for the bereaved. She has introduced protocols, structure and boundaries in relation to the support offered to the bereaved whilst building on the strengths that already existed.

Iain Rennie Hospice are involved in providing an annual opportunity for bereaved children and their families to meet with others in a similar situation. Services for children are considered towards the end of the report. It is recognised that support can be given to children by anyone with whom they have contact. However, sometimes more specialist support is required. West Cumbria Hospice at Home should be a part of the development of such a service, but not a provider on its own.

A concluding chapter draws the findings together. It also highlights the importance of being aware of people's differences so that they are given the opportunity to make appropriate choices.

Finally a list of recommendations are made.

Recommendations

- A co-ordinator should be appointed to ensure the success of bereavement services. He or she should be responsible for co-ordinating services already offered by West Cumbria Hospice at Home and for developing new services.
- The co-ordinator should link with the two Bereavement Forums (Adult and Children), and ensure national and local standards are applied to all bereavement services.
- The co-ordinator should maintain an up to date list of relevant services that could be accessed and share this with colleagues
- The co-ordinator should liaise with other organisations that provide bereavement support to ensure equity of provision and avoid duplication. They should liaise with organisations that could assist in ways such as transport, information provision etc. This should avoid duplication of services and ensure imaginative use of existing services.
- The co-ordinator should aim to develop services incrementally. Initially focus should be on introducing a formal assessment at the time of death, including a risk assessment and documentation. Thereafter, planned contact at an agreed time after death, 6 weeks, 6 months, 1 year, could be developed.
- The co-ordinator should be proactive in promoting the Drop Ins creating links for the bereaved person and seeking ways of accessing transport.
- The use of the Drop Ins should be reviewed after a year of trying new ways of working.
- Consideration should be given to establishing a third venue for the Drop Ins if their use is seen to be successful at the time of a review.
- The co-ordinator should look at building on services to create a “tool box” that the bereaved and professionals can access.
- The co-ordinator should extend the bereavement support for children and young people in conjunction with other services in North Cumbria.
- The co-ordinator should ensure information about and opportunity for training is accessible to other staff.
- The co-ordinator should facilitate the development of volunteer bereavement counsellors.

- The co-ordinator should facilitate the development of group support for the bereaved.
- Part of managing the service would be administrative and organisational, but the future development of a variety of services would require this person to have the ability to work with and supervise volunteers, run groups and perhaps do direct work with individuals both adults and children.
- Service evaluation should be a priority from the start. A forum for service users and staff that meets regularly would be a useful source of service user involvement. This could inform practice within West Cumbria Hospice at Home.
- Geography is an issue. Innovative ways of addressing this difficulty will be required.
- Venues for groups to meet can also be an issue and flexible ways of addressing this will need to be found.
- Any bereavement services that West Cumbria Hospice at Home provide should be available to any bereaved person. Ways of achieving this may need to be explored with other organisations.

2.2 Acknowledgements

I have found an incredible willingness to share experiences and examples of good practice for which I am very grateful. There are many people to thank for their time and for sharing their knowledge. These are just some of them:

The staff and trustees of West Cumbria Hospice at Home.
 Fred Lightfoot, Palliative Care Education Facilitator.
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 Members of the Child Bereavement Group.
 Iain Rennie Hospice at Home, Tring.
 Hospice at Home Carlisle and North Lakeland.
 Eden Valley Hospice Bereavement Service.

3. MAPPING OF BEREAVEMENT SERVICES

3.1 West Cumbria Hospice at Home.

3.1.1 Drop In Centres

West Cumbria Hospice at Home have two Drop In Centres, one in Cockermouth and one in Whitehaven.

In the past the Macmillan nurse often accompanied a bereaved person on their first visit to the Drop In. The person who had died had not necessarily had care from Hospice at Home but may have been known to the Macmillan nurse. This system is thought to have facilitated the process. There is a view that the change in this system of referral, which ceased for appropriate workload management reasons, has contributed to what is felt to be poor uptake of the service. The Drop Ins are available to patients, carers and the bereaved. It is also important to note that they are offered to anyone who calls, regardless of whether they have received other services from West Cumbria Hospice at Home.

Whitehaven

The Drop In in Whitehaven moved premises some 2 years ago. This was partly due to an awareness that the group had become quite static with no new attendees. There was also the opportunity to move to a more comfortable centre at the Senhouse Centre. This move was combined with the establishment of complementary therapy sessions available to patients, carers and the bereaved. This system has been in operation for almost 2 years and there is still an uneasy feeling that this is not really meeting the needs of the bereaved as well as it might. There is a view that mixing patients, carers and the bereaved is not ideal.

Concerns are focused around the lack of new attendees. One or two recently bereaved people who have managed to attend a session, have been unable to continue to attend regularly due to difficulties with transport. There are two Hospice Nurses and a therapist at the Drop In. The therapist, who is also a Hospice Nurse, offers 4 sessions in the course of the morning. The nurses spend time mainly with the group, but are able to give individuals a period of one to one attention by using another part of the large room.

Cockermouth

The Drop In takes place in the Victoria Hall. A yellow Hospice at Home sign stands at the top of the lane, and another one hangs by the meeting room. One or two people have attended in response to seeing these signs. The group here is quite static with one or two members being part of the first group to meet some 8 years ago. However there are some regular attendees that have been bereaved within the past 12 months. I observed a group who greeted those who came through the door with words of welcome. Two

Hospice nurses attend each week so that if the bereaved were cared for by Hospice at Home, they may have already met one of the staff. Although most people only start attending once bereaved, the Drop In is offered to patients and carers as well as the bereaved. One person attended as a carer, her spouse having been cared for by Hospice at Home. When her husband died the carer only missed one week before returning to attend the Drop In. The now bereaved carer found it very supportive returning to a group of staff and other group members whom she already knew.

On both my visits to the drop in at Cockermouth I was able to speak to most of the dozen or so people there. The feedback was very positive. It was significant that there are a number of men attending and two spoke to me of their great appreciation of the support they had received from the other members of the group. One gentleman had been one of the inaugural members and another was much more recently bereaved. He reported how much he had appreciated the support of the group after being very low in mood following the death of his wife. He had particularly appreciated the guidance of the group when facing practical tasks such as cooking for himself.

The main issue already identified by staff is how to get the newly bereaved to attend. A home visit made by a staff member before someone attends the Drop In would perhaps make it easier to attend for the first time.

3.1.2 Hospice Nurses

Hospice nurses may attend the funeral of the person for whom they cared. They may also make one follow up visit if this is wished. It is not thought by staff to be appropriate for all hospice nurses to offer more extensive support. Not all Hospice Nurses would want to be offering bereavement support. Staff at Iain Rennie Hospice at Home found that using the Hospice Nurses had created an inconsistent service. Where nurses and relative had a comfortable relationship, follow up happened and perhaps went on longer than was appropriate. On the other hand if the relationships had been difficult, sometimes no follow up took place.

Other hospices use their hospice nurses where appropriate, but as part of a systematic service supervised by a co-ordinator.

3.1.3 Bereavement Counsellor

A bereavement counsellor with links to Cruse has been available to West Cumbria Hospice at Home clients for one to one counselling. There is a general view that this service is not accessed extensively and the counsellor confirmed this. It may be that the bereaved could be encouraged to access this service, when appropriate.

It was also originally envisaged that the counsellor could provide support for staff working with death and dying. However the Hospice Support Groups for nursing staff seem to meet this need.

3.1.4 Annual Service

Many hospices offer an annual service as part of their bereavement care. In December each year, West Cumbria Hospice at Home holds a service "Lights of Love". It is held in a different part of the area each year and it may be that in future years there will be more than one service held. People are invited to dedicate a light on the Christmas tree in memory of a loved one thereby celebrating the life of that person. They are also invited to make a donation.

3.1.5 Conclusion

Bereavement support is provided by West Cumbria Hospice at Home, but there is no doubt that this could be extended and accessed more routinely. There is a perception that more people might attend if they felt supported at the first visit to the Drop Ins and informal feedback from the bereaved supports this. In addition, support in accessing transport would benefit some people. Hospice and Macmillan nurses told me about bereaved spouses who would have liked to attend but who were unable to get there. One lady attended when a volunteer driver was arranged for some initial sessions, but was unable to continue attending when the arranged transport stopped.

3.1.6 Recommendations

- A co-ordinator should be appointed to take responsibility for arranging bereavement follow up.
- A system of recording a death and taking responsibility for follow up should be developed. This would be an administrative system but include professional assessment. This would allow staff who feel comfortable, or who have the space, to continue to offer follow up visits. It would also ensure that this support would be assessed as appropriate or not. In those circumstances where staff are not able to offer follow-up, the co-ordinator would ensure that this was done, either by him or her self or by another staff member for whom it was appropriate.
- The pattern of support offered is indicated in the proposed pathways in Appendix 2. It would take the form of recording the date of death and other details. Contact would be made within days of the death offering information as to what services are available. Risk assessment would be part of this process. My view would be that this would be completed with the bereaved person. An agreement would be reached with the bereaved person as to whether further contact could be made. The co-ordinator would then ensure contact at certain times, such as 6-8 weeks after the death, 6 months after and then again at 1 year after.
- A co-ordinator should be responsible for either supporting a bereaved person to a Drop In at a time that felt comfortable for that person or for ensuring that another staff member was able to do this. It may be that in

some circumstances one of the Hospice Nurses could visit the bereaved person at home and then accompany them to the first visit. The important factor would be that one person has responsibility for ensuring the service is offered and provided, but not being the provider.

- A co-ordinator should address issues of transport. This could be done through liaison with existing schemes. Within Hospice at Home there are volunteer drivers and it may be that at times of good cover this service could be accessed.
- In order to ensure more equal access the possibility of another Drop In, strategically placed in the area covered by West Cumbria Hospice at Home, should be explored.

3.2 North Cumbria: Services for the Bereaved

There are several services for the bereaved in both East and West Cumbria but the difficulty in finding information was striking. It is also important to note the difficulty of ensuring that available information is up to date.

Initially, I approached the libraries, PALS (Patient Advice and Liaison Service) and CAB (Citizens Advice Bureaux). The library information was accurate and telephone numbers were current. Some of the telephone numbers were national. PALS do not have a countywide or national database upon which to draw so each office gathers information. PALS at West and East Cumbria have had referrals where there has been a death but these have tended to be in situations where there may be a complaint. CAB offices proved very difficult to get through to by telephone, although they have an excellent national database.

The North Cumbria Bereavement Forum was established several years ago to draw together those people working with the bereaved in order to share good practice. Most members of the Group are working with the bereaved as part of their work and few provide a service solely for the bereaved. A Children's Bereavement Group developed from the original group, whose membership work with children and young people. Both groups include representatives from the Acute Trusts, the PCTs (Primary Care Trusts) and the voluntary sector. The North Cumbria Bereavement Forum is currently working towards ensuring that national standards are applied to bereavement work as part of a local strategy or framework.

3.2.1 Services provided throughout North Cumbria

The detail of specific sources of support is listed in the Directory in Appendix 3. Cruse is the main source of support in North Cumbria. Eden Valley Hospice Bereavement Support will take referrals from all over the area but in reality does not receive such referrals. The Siskyn Centre is a charity, based near Wigton, which intends to establish a hospice type environment for children and their families. Initially their plan was to establish a telephone

support line for bereaved families, but at the time of writing this service has not been developed.

There are several national support groups that offer local contact numbers, such as SANDS (Stillbirth and Neonatal Death Society), Foundation for the Study of Infant Deaths and SOBS (Survivors of Bereavement Following Suicide). These numbers are not always up to date and using a national number in information given to people is advisable.

Some GPs have access to a Counsellor although waiting lists are often long, and in some circumstances people are referred to either a Psychologist or Community Psychiatric Nurse. Again, the waiting list can be long.

3.2.2 Services provided in East Cumbria alone

In East Cumbria a bereavement service is provided by part of Hospice at Home (Carlisle and North Lakeleand). It is initially limited to those who have received Hospice at Home, Macmillan and Day Hospital services. At the Cumberland Infirmary there is a Bereavement Co-ordinator for Maternity and Family Services. Eden Valley Hospice has a bereavement service which provides one to one support from trained volunteers and group support.

3.2.3 Services provided in West Cumbria alone

Services provided by West Cumbria Hospice at Home have already been described. In addition there is a Bereavement Counsellor for Maternity Services based at West Cumberland Hospital.

In Maryport there is a bereavement group which was started by the district nurses 12 years ago. It is now run by one of the original group members. She describes it as an excellent source of social support for those who attend. However, it has had no new members.

3.3 Other sources of support

3.3.1 Church

In North Cumbria many people receive support from their local church even if they do not attend church regularly. However, I have not been able to identify a route for referral that can be used by individuals or professionals. Contacting individual vicars is the most likely route. I am not aware of any groups run by churches locally specifically for the bereaved. I am sure, however, that if people are already part of a group such as the Mothers Union this will be a source of support.

3.3.2 Chaplains

Within both the West Cumberland Hospital and the Cumberland Infirmary there are chaplaincy teams. The spiritual support of these teams is available to all who come into contact with the hospitals. There are chaplaincy teams

who also have links with Community Hospitals. It is important to be aware that chaplains are there to offer spiritual support as well as support in one's faith.

3.3.3 Other

Many other professionals provide bereavement support as part of good practice within their job. There are many examples of such practice. In the Accident and Emergency Department at West Cumberland Hospital there is a scheme for supporting a person whose relative died within the department. The staff offer to be available to answer any questions. In practice few take advantage of the offer. The staff are developing this scheme.

In the Intensive Therapy Unit at the Cumberland Infirmary staff have begun to hold regular memorial services. Relatives of those who have died on the unit within a 6 month period are invited.

North Cumbria Renal Services also offer routine follow up to the bereaved. This is co-ordinated by the social worker but it may be nursing staff who maintain contact.

3.4 Conclusion

There is a lot of activity in North Cumbria both maintaining and developing bereavement services. It is not easy to find out about these services, even when one has the luxury of dedicated time. In addition information is often not up to date.

3.5 Recommendations

- A bereavement co-ordinator would be able to maintain a list of up to date information and thus guide colleagues and the bereaved to appropriate sources of support.
- A bereavement co-ordinator would be able to maintain contact with other providers of services and thus develop West Cumbria Hospice at Home Services further in a strategic manner.

4. LITERATURE REVIEW

The volume of literature addressing the issue of bereavement is vast and fascinating, ranging through personal descriptions of the experiences of individuals² to the research conducted around the question of appropriate and effective therapy and support.³ For the purposes of the project, I read a wide range of literature, but for the purposes of this report I will focus on the implications for practice and for bereavement services.

It is widely accepted by bereavement researchers and practitioners that in order to adapt to loss, and to avoid suffering from lasting mental and physical health consequences, we must confront and speak of our feelings and reactions to the death of a loved one. But it is difficult to find evidence to support this.

Evidence is required for various reasons. We need to be sure that treatments or therapies are not harmful. Organisations also need to be able to prioritise in terms of service provision.

Walter⁴ states that although it is reasonable to conclude that everyone grieves differently, it is also true that:

“people need to have some idea of what to expect when they, or others, are grieving.”

He points out the difficulties of greeting each client as totally unique. He also highlights the pressures of accountability that will:

“tempt public-funded agencies into generating ever clearer criteria for what constitutes pathological grief and healthy resolution.”⁵

4.1 The Theory

There are many academic papers considering the theories of grief and it does not seem useful to review them here.⁶ Most useful is to consider the ways in which grief can affect people and in her book *Then, Now and Always*,⁷ Stokes summarises these so well. I will repeat them here as a reminder of the experiences people may face.

She says grief manifests itself in *feelings* such as sadness, anger, guilt, loneliness, fatigue, shock, yearning, emancipation, relief or numbness. In *physical sensations* such as hollow stomach, lump in the throat, tightness in the chest, breathlessness, lack of energy or co-ordination, or a dry mouth. In *cognitions* such as disbelief, confusion, preoccupation, and a sense of presence of the deceased or hallucinations. In *behaviours* such as sleep or appetite disturbance, absent mindedness, social withdrawal, lack of interest in activities previously enjoyable, dreams of the deceased, crying, avoiding reminders, searching and calling out, sighing, restless over activity, visiting places and cherishing objects that remind one of the deceased. Not all of these are necessarily distressing. Grief can also express itself in *social* ways,

such as difficulties in inter personal relationships or problems in functioning within an organisation. It can also express itself in *spiritual* ways searching for a meaning or hostility towards God.

Woof and Carter ⁸ reviewed the literature on the psychological theories that help explain the grieving process and also the health consequences experienced by the bereaved. They concluded that:

“research methodological problems made it difficult to confirm statistically the increased risk of death that follows bereavement. However, it is becoming increasingly possible to conclude that the bereaved are at a greater risk of death in the first year of their loss, and that men are at greater risk than women, although the risk remains small in absolute terms.”

They feel that it is reasonable to conclude that various adverse health consequences are associated with bereavement especially clinical depression and also increased anxiety, the use of alcohol, prescribed drugs and suicide. ⁹

Early models of grief used a stage approach and criticisms of these theories of bereavement are that they can be used prescriptively and insensitively and can be used to label grief as normal or abnormal. For the bereaved they can be experienced as denying the uniqueness of an individual loss. However, they can act as a guide, as a shared road and can therefore provide comfort and reassurance to the bereaved.¹⁰

Walter wrote an article in 1996 in which he analysed his own experience of loss and considered other contemporary research papers:

“which suggest an alternative, more sociological, model. Survivors typically want to talk about the deceased with others that knew him or her. Together they construct a story that places the dead within their lives, a story capable of enduring through time.” ¹¹

Personally I see this view of grief as complementary to other theories, the main difference being the emphasis on moving on but with the deceased person as part of future life rather than being left behind.

It has been said that interventions with the bereaved have been designed to help survivors break their bonds with the dead in order to establish new bonds that allow the survivor to live fully in the present. However more recent theorists have looked at a process of grieving that allows the bereaved person to continue their relationship with the deceased in a different way but as part of their present and future.¹² Attig uses the idea of grieving, as a movement from “loving others in their presence to “loving them in their absence.”

All these views of grief seem to support the view that having someone to talk to about one's grief and about the deceased person are part of a positive approach and beneficial to the bereaved person.

4.2 Does Bereavement Counselling work?

Parkes' article in the BMJ stated that many studies had confirmed the increased risk of psychiatric and psychosocial disorders associated with the death of a loved person.¹³ Writing in 1980, he commented that it was only recently that interventions had been assessed and proceeded to review the information available at that point. Some said, and still do say, that anticipation reduces the trauma of bereavement but he indicated that he was not confident that there had been satisfactory evaluation of this. He concluded that services provided by professionals, and professionally supported services and self help groups, are capable of reducing the risk of psychiatric and psychosomatic disorders resulting from bereavement.¹⁴ He suggested that those who felt unsupported by their families or who were thought to be at particular risk were most likely to benefit from such support. He also stated that we should not assume that every bereaved person needs counselling:

“but that those who do need it seem to benefit from opportunities to express grief, reassurances about the normality of the physiological accompaniments of grief, and the chance to take stock of their present life situation and to start discovering new directions.”

In their paper on the counselling and therapy of the bereaved, Raphael et al conclude that:

“There is a lack of agreement over basic definitions of grief itself let alone its pathologies and none of the studies has clearly defined in operational terms specific bereavement outcomes.”¹⁵

However, in the same article the authors conclude that there is much supportive evidence indicating that bereavement counselling is effective, both as a preventive measure for bereaved people who are at high risk and as a therapeutic intervention.

A constructivist approach¹⁶ sees a role for grief therapy as enabling the bereaved person to answer the question, “Why did the person I love die?” and also the question, “Who am I now?” The loss of someone close can make one question the ideas that one had about oneself and the world around. This process can be an opportunity for growth but it can also be a time of struggle. Therapeutic support in looking at the meaning made of the loss and the life remaining to the bereaved could be beneficial. Various authors have suggested techniques for ways of working in this narrative way, which include writing a letter to oneself in the future or in the past, and writing to the dead person.¹⁷ Others may employ a poetic or story telling way of making sense of what has happened.¹⁸

Neimeyer has questioned the apparent assumption:

“that grief counselling is a firmly established, demonstrably effective service which like psychotherapy in general, seems to have found a secure niche in the health care field, at least in North America.”¹⁹

He carried out a study, which included control groups and his conclusion was that grief therapy is appropriately offered to mourners in certain circumstances such as those experiencing protracted, traumatic, or complicated grief reactions. Neimeyer is concerned that:

“A close review of the most authoritative and reliable research currently available leaves us with sobering conclusions about the general effectiveness (or even advisability) of grief counselling and therapy, as well as a few clues as to when professional intervention might be more clearly indicated.”²⁰

The conclusions of different studies are certainly different.

4.3 Volunteers

Many hospices have established a service that uses volunteers to provide one to one counselling.

Parkes²¹ found in his study that a volunteer counsellor took about a year to become proficient. He felt that once proficient volunteers rivalled professionals who often had less experience in working with the bereaved. His view was that the professional had a role in ensuring that the introduction of such support was made in a way that minimised the intrusion. He also commented that home visits were more effective than office or telephone calls and that support prior to the bereavement also improved the “chances of success.”

Another paper looks at the training offered to potential bereavement volunteers.²² They suggest an ABC approach of acquiring, building and cherishing volunteers. The cherishing involves making sure they have the opportunity for personal and professional growth by providing training and support.

4.4 Groups

Many hospices have also initiated groups, some of a social nature others more therapeutic.

Some people choose to attend a support group whilst others choose not to. One study explored the reasons why some bereaved parents participated in a self help support group and others did not.²³ Having adequate support in their immediate environment was the reason stated by most for not joining a group.

The study concluded that parents were more likely to join a group when the circumstances of the loss of their child had been particularly traumatic and they do not find others who have suffered a similar loss within their social network.

My view is that people seek the mutual support of others who are in a similar situation when they attend such groups. Of course the shared experience is not always enough to ensure the group meets the needs of everyone. Given that these people will be vulnerable, skilled facilitation by professionals may be beneficial.

4.5 Conclusions

There has been an assumption that offering the opportunity to someone who has lost a loved one to talk about their situation is beneficial and can prevent future physical and psychological problems. More recently this assumption has rightly been challenged. Conclusions from various studies have been conflicting and the evidence is not there that such support is harmful. Neither is the evidence conclusively there that it can help.

In practical terms the choices for a service are:

1. to only offer support to those people who show distress and ask for help,
2. to offer a service to those identified as at high risk.
3. to offer a service proactively to all the bereaved with which the organisation has contact.

4.6 Recommendations

- An individual responsible for managing and co-ordinating bereavement services must keep up to date with theories of bereavement, and studies evaluating bereavement interventions.
- The evidence is not great enough to dismiss the premise that one to one support is beneficial. A system of volunteer support would be an appropriate development for West Cumbria Hospice at Home to provide.
- There should be routine evaluation of any services provided. This may include collection of data that is robust enough to be incorporated into a subsequent controlled study.

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⁴ Walter, T, On Bereavement: The Culture of Grief, Open University Press. 1999 p 208

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- ¹⁷ *ibid* p171-184
- ¹⁸ Booker, Glenys, The Journey, an article written by a mother after the death of her 3 year old son. © Glenys Booker can be contacted via e-mail glenbooker@hotmail.com
- ¹⁹ Neimeyer, RA, Searching for the meaning of meaning: Grief Therapy and the process of reconstruction in Death Studies, Sept 2000. Vol 24, Iss 6, P541
- ²⁰ *ibid* p 558
- ²¹ *ibid* p6
- ²² Osborne, C The ABCs of Bereavement Volunteers: acquire, build and cherish. American Journal Hospice Palliative Care. 1999. 16 (1) p 380-385
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5. NATIONAL STANDARDS

This project takes place at a time when there are various centralised attempts to introduce national standards to the area of bereavement care. These apply to the information, advice and choices given to the bereaved immediately following a death, through to bereavement support available from groups and individual bereavement counselling.

5.1 Standards for Bereavement Care UK

In 2001 a National Bereavement Consortium initiative produced *Standards for Bereavement Care in the UK*.²⁴ The document was produced by representatives from the London Bereavement Network, Cruse, the National Association of Bereavement Services, and the National Council for Hospice and Palliative Care Services. At the time of publication it was hoped that there would be a National Council for Bereavement Care that would continue to review and revise these guidelines in response to feedback. It seems that the standards have been produced but that the establishment of a council has not yet happened.

The standards themselves are comprehensive and aim to ensure:

“that bereaved people in the UK can be confident that the support which they are offered will be safe, appropriate and ethical.”²⁵

They consist of two main elements, the Principles and the Core Standards. The Principles will underpin all work with bereaved people and adherence to them is essential. They apply to anyone who claims to offer support to any bereaved person whether support is offered one to one or within a group. The Principles cover issues such as confidentiality, being responsive to individual need, respect of peoples’ differences, being clear about boundaries and a culture of self evaluation, monitoring and training. The full list is in Appendix 1.

The Core Standards cover aspects of service delivery and states that service providers must have agreed policies and protocols. They are seen as generalised rather than prescriptive statements that should be adapted to individual circumstances and services. They indicate what is essential for bereavement support to be effective. They should complement organisational and operational standards, which should be constructed by each organisation. They address such issues as confidentiality, equal opportunities, health and safety, record keeping, administration, being open and accountable, selection, recruitment and training of volunteers, statement of purpose, support and supervision. They also consider issues such as boundaries, referrals and assessment, monitoring, evaluation, and stakeholder involvement.

West Cumbria Hospice at Home is subject to the policies and procedures of Eden Valley PCT and these cover many of the relevant issues such as confidentiality. It will be important to consider them with regard to further service development.

According to the *Standards for Bereavement Care in the UK*,

“It is estimated that 80% of bereavement support is delivered by the voluntary sector, and 90% of it by volunteers.”

The authors of the Standards, although mainly working in the voluntary sector, anticipated that they should apply to bereavement services provided by both the statutory and voluntary sectors. These standards are regularly cited as those to which service providers should adhere, most notably in the *NICE Guidelines on Cancer Services*.²⁶

5.2 NICE Guidelines for Improving Supportive and Palliative Care for Adults

The National Institute for Clinical Excellence produced *the Manual for “Improving Supportive and Palliative Care for Adults with Cancer”* in March 2004. Chapter 12 “Services for Families and Carers, including Bereavement Care” states:

“Grief is a normal response to human loss, and while bereavement represents a significant challenge, the majority of people have sufficient resources to enable them to respond and adapt to this life transition. Most find a way of adjusting to the loss, but some may find it too difficult or traumatic without additional support.”²⁷

The *NICE Guidance* goes on to say that bereavement gives rise to a wide range of needs – practical, financial, social, emotional and spiritual. Paragraph 12.10 states that:

“Inequitable distribution of bereavement services and their varying quality are ongoing concerns. Families and carers, particularly of patients who are not receiving specialist palliative care, may never undergo screening to assess their level of vulnerability.”²⁸

West Cumbria Hospice at Home will need to consider whether new bereavement services they provide will be available only to those who have received palliative care, or whether they wish to extend their service to those that the National Institute for Clinical Excellence see as potentially more vulnerable. The stated relevant aims or objectives in the Guidance are that:

“those who experience bereavement receive support to facilitate grieving, to prevent the detrimental consequences of

bereavement “ and that “health and social care workers can access support to enable them to come to terms with loss and bereavement issues they encounter in their work.”²⁹

For West Cumbria Hospice at Home the importance of providing staff with support in relation to loss and bereavement is already recognised. Staff have access to the support of a counsellor, however, he has not often been approached. His view is that the Hospice Nurses feel well supported by their support meetings. It might be appropriate to make the monitoring of and awareness raising about such support the responsibility of a co-ordinator. The provision could continue as it is.

The *NICE Guidance* recommends that Cancer Networks adopt the three component model of bereavement support developed in the Bereavement Care Standards UK.³⁰ The three components are as follows.

1. General Support - where it is recognised that grief is normal and most people will manage without professional intervention. However information about the experience of bereavement and how to access forms of support should be available to all.
2. Psychosocial Support - where some people require a more formal opportunity to reflect on their loss and experience, but this does not necessarily have to involve professionals. Volunteer bereavement support workers, self-help groups, faith groups and community groups will provide much of the support at this level. It is important that those offering this level of support have systems in place that ensure appropriate referrals are made for level 3 support.
3. Mental health - the third group of people will be a minority. This group will benefit from mental health services, psychological support services, and specialist counselling/psychotherapy services.

The *NICE Guidance* does not expect all providers to offer all three levels of service.³¹ It seems appropriate that West Cumbria Hospice at Home would look to provide a service for groups 1 and 2. Children are seen as a specialist category even where only general and social support is provided. Some services for children should also be a part of Hospice at Home's remit, but children requiring specialist services would need to be referred on appropriately.

Awareness of issues of consent and data protection should be considered carefully.³² This should be noted as it has implications for the completing of 'Risk Assessment Tools' and reinforces the need to do this with the bereaved person rather than about them.

The *NICE Guidance* finally looks at implications for the workforce and research. Specifically mentioned is that any organisation offering specialist bereavement services should:

“be sufficiently resourced to enable them to contribute to the preparation and ongoing support of health and social care professionals in relation to this aspect of care”³³ and that where “volunteer support workers are included, mechanisms for recruiting, training, supervising and managing volunteers are in place.”³⁴

With regard to research NICE say that evaluative research is needed to compare different models of bereavement support for different groups. There is extensive discussion about the difficulties of research in this field and the studies cited are at most non-randomised controlled trials or observational studies. A significant point is made that:

“the evidence on terminal care supports the view that it should be seen as part of bereavement care, as carers’ levels of emotional distress are affected by the care provided before death.”³⁵

Hospice at Home is already addressing this issue. The few studies cited are not so helpful in informing choices about the type of bereavement follow up that Hospice at Home might offer.

“Research on bereavement counselling found no impact for those involved,[B] whereas a study of telephone contact between ward nurses and grieving families found this reduced sense of despair and attachment.[B]. Involvement in a support group has been shown to have a statistically significant impact in terms of satisfaction and diminished needs for other support, although such positive effects may take some time to appear.”³⁶

Rather than providing a service model that suits one type of bereavement or bereaved person, a service that offers a choice of services is the most likely to be effective. Ongoing service evaluation and assessment should ensure optimum service.

With regard to the use of Risk Assessment tools as a way of identifying those most likely to need bereavement support, NICE conclude that:

“Individual clinical judgement is currently the most effective way of identifying those at risk, as risk assessment tools cannot be relied upon as a predictor of outcome.”³⁷

However, in the chapter on Risk Assessment Tools I conclude that such tools do have a role in ensuring that consideration is given to appropriate bereavement follow up and that this is documented. This is likely to be enhanced if completed with the bereaved person rather than about them.

The *NICE Guidance* emphasises the need to ensure training and support for those involved in this process. It also mention the cost implications of

providing this care and point out that the cost benefits of selected 'at risk' people whose use of health services may be significantly reduced are not known and have not been taken into account.

The Northern Cancer Network has not yet worked on specific protocols or recommendations with regard to bereavement. They have been awaiting information from the Strategic Health Authority to inform any protocols they develop.

5.3 Department of Health “When Patients Die”

Around the same time that the *NICE Guidelines* were produced the Department of Health issued draft standards for consultation titled “*When Patients Die.*” The document was intended to replace previous documents describing the standards required of services provided by NHS Trusts when a patient dies. These standards apply to the care given immediately following a death wherever a person dies. The issues of organ donation, identification, registration, post mortems and the sort of information that should be provided to carers are addressed.

The Department of Health intends to issue the finalised document to all NHS Trusts including Primary Care Trusts. The importance of the document is the explicit expectation that each trust will identify someone at Executive level who will be responsible for ensuring these standards are met. Trusts have a responsibility to have

“a nominated executive lead whose portfolio includes executive responsibility for the corporate delivery of services relating to death and bereavement.”³⁸

Responsibility for the implementation of good practices will be delegated within organisations.

The North Cumbria Bereavement Forum was fortunate enough to have the standards introduced to them by the author. The forum then forwarded a copy to the Chief Executive and Risk Manager of each Health Trust in North Cumbria. The final document has not yet been issued but locally both the Acute Hospitals Trust and North Cumbria PCT have included the responsibility in the portfolio of the Director of Nursing. The Ambulance Trust has also identified an Executive member of the Board to be responsible.

5.4 North Cumbria Mental Health Prevention Strategy

The subject of bereavement services also arises in the North Cumbria Mental Health Promotion Strategy produced in 2002. This sought to address the first standard in the National Service Framework for Mental Health. The standard

“To promote mental health for all, working with individuals and communities, and, to combat discrimination against individuals

and groups with mental health problems and promote their social inclusion.”³⁹

Promoting access to bereavement support is included within the objectives for Neighbourhoods and communities.⁴⁰ Ways of improving mental health by addressing the needs of the recently bereaved, are seen as increasing staff knowledge and skills, and promoting access to specialist sources of support.⁴¹ The development of a special interest group is listed as an indicator of progress. This group, the North Cumbria Bereavement Forum continues and has recently reviewed its aims and objectives.

5.5 Child Bereavement Network: Guidelines for Best Practice

*Services for children are mentioned in the NICE Guidelines and in the National Bereavement Standards but acknowledged to be a specialist area of work. Each document refers to the Guidelines for Best Practice produced by The Childhood Bereavement Network (part of the National Children’s Bureau) as the gold standard for work with children. Workshops in different parts of the country have looked at how these can support and inform the development of services for children. The Guidelines are divided into four sections which are safety, practice context, quality and accountability, and equality.*⁴²

The development and provision of services to children is specialised and existing local services and potential services that might be provided by West Cumbria Hospice at Home are considered in Chapter 9.

5.6 Conclusions

It is clear that nationally there is a push for the further development of bereavement services within the palliative care setting. There is also some acknowledgement that offering such a service only to those whose relatives who receive specialist palliative care can result in some people, who may benefit from support, not having the opportunity to access such a service.⁴³

There are also clearly identified standards to which a service should aspire and these should form the basis of a new service and be part of ongoing review and audit. The *NICE Guidance* recommends that each Cancer Network develop protocols

“to inform the level of bereavement support offered and the need for follow up and specialist referral particularly for those at risk of complicated grief reactions. They should apply wherever the patient dies – at home, in hospital, in hospice or care home – and should include a system to engage proactively with those assessed to be at risk, involving, for example, follow-up telephone calls or letters to individuals around eight weeks after death”⁴⁴

The *NICE Guidance* also mentions that issues of consent and data protection should be considered carefully, as has already been acknowledged.

The document encourages information to be standardised locally by those involved in the provision of bereavement services. Such information should inform the reader as to the feelings that might be anticipated and how to access local and national services.

At present there are such leaflets produced by the different organisations separately but it can be difficult keeping the information up to date. It seems that the information included is becoming more standardised as organisations work together through the North Cumbria Bereavement Forums and other multi-agency work groups. This approach to collaborative working needs encouraged.

The document talks of the difficulties in obtaining evidence for interventions in this field and the comments are reflected in the relevant part of the literature review.

5.7 Recommendations

- Clear responsibility for bereavement services should be identified at strategic and operational level.
- National Standards should inform the bereavement follow up offered by West Cumbria Hospice at Home.
- Current services should be reviewed in the light of the various national standards listed.
- West Cumbria Hospice at Home should nominate a representative on the North Cumbria Bereavement Forums (Adult and Children), possibly in conjunction with the Macmillan nurses.
- West Cumbria Hospice at Home should have an agreed approach to working with children. Numbers are small and the geography of the area is an issue. It is important that children and young people locally can access appropriate and effective support at the time of bereavement in order to prevent psychological or emotional difficulties in the longer term. Continuing links with the North Cumbria Bereavement Forum in order to influence and access any future services is important.

²⁴ Bereavement Care Standards UK Project. Standards for Bereavement Care in the UK October 2001. Available at www.bereavement.org.uk/standards 2001

²⁵ Bereavement Care Standards UK Project. Standards for Bereavement Care in the UK. October 2001. P 1 available at www.bereavement.org.uk/standards 2001

²⁶ Guidance on Cancer Services. Improving Supportive and Palliative Care for Adults with Cancer. The Manual. National Institute for Clinical Excellence. March 2004

²⁷ Guidance on Cancer Services. Improving Supportive and Palliative Care for Adults with Cancer. The Manual. National Institute for Clinical Excellence. March 2004. P 156 12.6

²⁸ ibid.p 156 12.10

⁴ ibid p 156 12.12

³⁰ Bereavement Care Standards UK Project. Standards for Bereavement Care in the UK. October 2001

³¹ Guidance on Cancer Services. Improving Supportive and Palliative Care for Adults with Cancer. The Manual. March 2004. 12.31 p 161

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- ³² ibid 12.33, p 161
- ³³ ibid 12.37 p 162
- ³⁴ ibid 12.38 p 162
- ³⁵ ibid 12.52 p 165
- ³⁶ ibid 12.52 p165
- ³⁷ ibid 12.53 p165
- ³⁸ NHK/DoH When a patient dies/Draft4.03/ p 3
- ³⁹ National Service Framework for Mental Health (Department of Health 1999)
- ⁴⁰ North Cumbria Mental Health Promotion Strategy February 2002 North Cumbria Mental Health Local Implementation Team p21
- ⁴¹ ibid p23
- ⁴² Childhood Bereavement Network. Belief Statement and Guidelines for Best Practice. Available at www.ncb.org.uk
- ⁴³ Guidance on Cancer Services. Improving Supportive and Palliative Care for Adults with Cancer. 12.10.p 157
- ⁴⁴ ibid p 12.33 p 161

6. WHAT SUPPORT AND SERVICES DO PEOPLE WANT?

6.1. Responses from General Practitioners in North Cumbria

6.1.1 Questionnaires.

A total of 208 questionnaires were sent to GPs in North Cumbria. The list of GPs was provided by North Cumbria PCT.

There were **127** replies (**61%**) which is a good response to a postal questionnaire. This is an analysis of the responses.

1. “Do you offer bereavement support yourself?”

The majority of GPs responding said **yes** they do offer bereavement support. (**80.3%**)

5 qualified this with the comment that it is part of a GP’s role.

25 said that this was only in the General Practice setting (and perhaps only once following a death.)

5 said they had a system in place that ensured that the bereaved were routinely assessed and follow up arranged accordingly.

10 said they made one post bereavement visit.

Other comments:

“No formal training to provide this support.”

“I don’t feel I have the time to do this adequately.”

“Limited and ad hoc.”

“One of the most supportive things I do in practice.”

“The bereaved are invited to make an appointment 2-4 weeks following the death.”

“Open door policy.”

“We do a visit once to assess extent of need.”

“Rather an omission.”

2. “Do you have access to a counsellor within your practice to whom you can refer for bereavement support?”

69.2% of responding GPs **do have access** to a counsellor within the practice that they can refer to for bereavement support.

29.9% of responding GPs do not have access to a counsellor.

There were 5 mentions of a Community Psychiatric Nurse acting as counsellor within the practice.

14 respondents said delays were a problem.

Other comments:

“Used to have a counsellor, much missed.”

“We have a counsellor but do not really use them for this.”

“Previous (effective) counselling service was withdrawn after cessation of commissioning by PCT.”

“We no longer have a psychologist attached - the previous one could be very helpful for long term bereavement reactions.”

“Voluntary bereavement counselling.”

“Refer to Cruse and myself.”

“Practice nurse is counsellor also.”

“General counsellor and local bereavement support group.”

“District nurses run bereavement support groups.”

“Student counsellor – temporary.”

“Cognitive Behaviour Therapy based counsellor will see patients with bereavement.”

“Waiting list long – these individuals often feel they need something to help now.”

3. “Do you refer to other professionals for bereavement support? If so please tick which profession.”

Macmillan Nurse, Community Psychiatric Nurse (CPN), Social Worker, Psychologist, and Other.

Of responding GPs:

56.6% refer to **Community Psychiatric Nurses** for bereavement support

50.3% refer to **Macmillan nurses** for bereavement support

26.8% of responding GPs refer to **Psychologists**

4.7% of responding GPs refer to **Social Workers**

23.6% of responding GPs refer to other professionals

District nurses were mentioned particularly in relation to the period immediately after a death.

Comments included:

“Macmillan nurse input wonderful.”

“Didn’t know any of these provided bereavement support other than psychologist - waiting list is 2 years, useless.”

“CPN very busy and only referred to if patient becomes ‘stuck’.”

“Practice counsellor-waiting list 4 - 6 months.”

“Have found bereavement services contacted through Eden Valley Hospice useful.”

“Neonatal bereavement counsellor.”

“Apparently there is a bereavement counsellor at CIC but GPs have not been informed of this referral route. Found out via CPNs.”

“Only if bereavement has progressed to secondary depression.”

“District nurses keep an audit of all bereavement.”

“Usually Eden Valley Hospice counsellor if cancer related death.”
“Eden Valley Hospice run an excellent bereavement counselling service.”
“Bereavement counsellor at Hospice at Home.”
“I would only consider referral to any of the above if grief reaction was abnormal. In all but a very few cases bereavement is a normal event and does not require such input.”
“Cruse Bereavement Care offer excellent support.”

4. “Do you refer to local support groups?”

Over half of the responding GPs said **no** they did not refer to local support groups. **(55.9%)**

Several qualified this with the comment that they were not aware of there being any local groups.

Comments:

“Lack of knowledge on my part as to what is available, but Macmillan nurse helpful.”

44.1% said **yes** and the group listed most frequently was Cruse.

Other groups or services mentioned were:

SANDS (Stillbirth and Neonatal Death Society)
Eden Valley Hospice
Brampton Bereavement Support Group
Age Concern
Hospice Drop In
Neonatal Bereavement Counsellor in Whitehaven
Penrith MIND
Compassionate Friends

Comments:

“Our hospice is fantastic.”

“Last referral to Compassionate Friends met with no response.”

5. “Do you give information about national support groups?”

The majority **56.7%** of responding GPs said **no** they did not refer to national support groups.

37.8% said **yes**

The groups listed were:

Cruse, most frequently
SANDS

Compassionate Friends
Cancer BACUP
Crossroads

Comments included:

“The national groups listed in the Help the Aged leaflet”
“The national groups listed in the Royal College of Psychiatry leaflet”
“Children’s death”
“But only after consulting with other health care professionals about local availability.”
“Might do if death due to a rare disorder for example where specific support services for the disorder not available locally.”
“Cruse and other support groups listed on EMIS PILS.”
“Stillbirths mainly.”
“Cruse – use printout.”
“If requested I would search for the most appropriate organisation.”
“Posters in surgery.”
“Specific services – have a good list on computer of self-help groups.”
“Help the Aged Bereavement leaflet that we use with the pathway for dying patient.”

6. “Do you have any other comments or views on bereavement services in North Cumbria?”

“Role of district nurse important here in first 24 hours.”
“Not sure how active some of support groups are.”
“On the whole have good working relationships with CPN team. However they are working hard and are stretched.”
“Would be nice for me to have a focus but people have a plurality of needs and in bereavement ‘one size does not fit all’.”
“Generally access can be achieved somehow but I feel GPs always have had and always will perform this function and be central to the role referring on as necessary bearing in mind not everyone wants bereavement support.”
“Any services provided must be easy to access and be able to respond quickly when patient seeks help.”
“Up to date local contacts would be helpful.”
“Poor provision. Lots of help for the terminal illness but relatives often left high and dry once the person dies.”
“Relatives who have contact with Macmillan during the terminal illness of a relative are much better supported than those who have none. There are few avenues of appropriate referral if one is not to medicalise bereavement.”
“I am keen to pick up on abnormal grief reactions.”
“It is important for the GP to see bereaved relatives, in the short term at least, but a readily accessible ‘local patch’ counsellor for longer term care would ease the burden on us.”
“We really miss our practice based counsellor in this area – referral was easy and patients liked seeing someone in the practice.”

“Good support from the Macmillan nurses and District nurses also very supportive.”

“Very patchy support. It would help to have a single point of access.”

“Waiting is always a problem.”

“Need leaflets to give to patients.”

“As with all counselling services, I feel demand is more than supply.”

“Would welcome some up-to-date information re bereavement services available. Ideally via email.”

“I do not feel a need for any extra provision. Most people seem to have the personal resources to cope with bereavement.”

“I would like to know a lot more about other services. I do not refer to local/national groups as I don’t know of their whereabouts.”

“Local ‘Cruse’ like branch would be helpful. Volunteer (non - medical) mutual support system would be good.”

“I should probably be more aware of what support is available locally and use these resources.”

“Hospice at Home well appreciated by relatives.”

“Lack of support for young people/children coping with loss of parent or sibling is lacking.”

“I have less time than formally to provide a ‘listening ear’. Further community support is required.”

“Hospice at Home staff ideally placed to offer bereavement support as they may have been involved with the family already.”

“Is this for people ‘stuck’. I do not necessarily think all bereaved need structured support. Clarify who for. Danger of deskilling ordinary people who do most of the support. Otherwise risk medicalising bereavement which is not a disease but a risk factor.”

“The whole of ‘end-of-life care is too fragmented:- Hospice at Home, Pecan nurses, Macmillan nurses, Marie Curie nurses, District nurse, GPs, Palliative Care consultants. I feel this leads to poor provision of care and needs to be brought under one umbrella.”

6.1.2 Summary of responses from GPs

It is worth noting that Cruse was consistently mentioned in all sections of the questionnaire. It is appropriately seen as both a local and national group.

It is inevitable that there are a variety of views as to services already available. There is a view that the bereaved do not need structured support and that to offer such support is to risk medicalising bereavement rather than viewing it as a normal process with which individuals cope.

A consistent theme is a lack of awareness of what is available and many expressed an interest in that information being provided. Some respondents identified the existing sources of that information such as the Internet, booklets already routinely used and professionals such as the Macmillan nurses and the mental health teams. One suggestion that this information be received by email will be followed up with North Cumbria PCT.

Comments were made about the problem with waiting lists for those services that are available. An emphasis was placed on a prompt response being required.

The services already offered by Eden Valley Hospice, the developing service at Hospice at Home (Carlisle and North Lakeland) and the Drop Ins offered by West Cumbria Hospice at Home are all commented on positively.

Several comments highlighted the fact that those families that had received palliative care services often also received bereavement follow up.

One commented that there was a lack of services for children and young people who lose a parent or sibling. This is considered in the chapter on children and young people.

6.2 Feedback from the bereaved.

Initially I hoped to complete a postal survey of people with whom West Cumbria Hospice at Home had had contact over a 12 month period. However, the difficulties associated with approaching such a vulnerable group meant that the timescale in which to complete this exercise proved too short. Initial advice was that an application to the research and ethics committee was needed. It seemed unlikely that a structured survey of the bereaved locally, would provide any additional information. However, during visits to the Drop Ins and in talking to staff members, I found that I received a considerable amount of informal feedback. In future, service evaluation would provide this information systematically.

At the Drop Ins, patients were positive about the support provided. They found the combination of professional input and the befriending of other members of the group beneficial. In Cockermouth there were a number of men for whom this was particularly true.

Several people had told staff members that they wished there had been more follow up from staff after the death. They had appreciated the contact that they had received, usually one or two visits or telephone contact. However, they would have liked further contact, perhaps some months after the death. These comments were not made as criticism of staff. People felt that staff had given a lot of time and understood that they were busy. Consequently, although the offer had been made that the bereaved person could contact Hospice at Home, the need for further contact never felt urgent or that it justified making that request.

Hospice at Home therapists at the Drop In session in Whitehaven had the opportunity to talk to patients, carers and the bereaved on a one to one basis. One young parent, whose partner had received therapy at the Drop In had continued to visit on several occasions after the death. He felt that his needs were met by being able to see a staff member at the Drop In, but did feel unsupported in relation to caring for his young children. He felt that contact with other people in a similar situation would have helped him and his

children. He felt contact with other young families, where a parent had died, required facilitation.

Sometimes the bereaved have been carers for a long time, maybe for many years. In such circumstances the loss creates a huge change in their circumstances. Suddenly they face a change in role, and they must adjust to having free time and maybe a loss of income (losing care allowances). A number of bereaved had very much appreciated the follow up provided by the Macmillan nurses, but recognised that the time they were able to give was limited as they had other patients and families for whom support was needed. The need identified here was for contact from someone who could guide them towards other sources of support or contact with others in a similar situation.

6.3 Conclusion

The feedback from bereaved people and from GPs did not identify a requirement for one particular service. The feedback I ascertained seemed to confirm the view:

“that those in most need may be among the least likely to seek, or even to be perceived as needing, help. For example, few would expect younger bereaved persons to be more vulnerable than older ones, who are already more frail, yet much research, including studies of the mortality of bereavement points to the former group as a high-risk one.”⁴⁵

6.4 Recommendations

- List of services should be placed on North Cumbria Health Service website. (see Appendix 3 for Directory)
- A request will be made that the same information be circulated to all GPs in North Cumbria by North Cumbria PCT (by email where appropriate.)
- A co-ordinator within West Cumbria Hospice at Home should be identified to ensure information about bereavement services is as up to date as possible. This information is needed within the organisation but may also be regularly circulated via the PCT if thought appropriate.
- Any services that are developed by West Cumbria Hospice at Home should bear in mind the diverse need of the bereaved and indeed of the professionals who already provide support. A ‘tool box’ of services on which the bereaved and other professionals can draw is likely to be most useful.
- Regular evaluation of services should be built into care provision.

⁴⁵ Stroebe, MS, Hansson, RO, and Stroebe, W, Contemporary themes and Controversies in bereavement research in Handbook of Bereavement Theory and Research & Intervention Ed Stroebe, MS, Hansson, RO, and Stoebe, W, New York: Cambridge University Press. 1993

7. RISK ASSESSMENT TOOLS

7.1 Evaluation

There is an increasing expectation that health care professionals provide a bereavement service but it should be aimed at those who are at risk. The question is who is at risk and how can risk be assessed? For the purposes of this chapter risk assessment tools are considered in isolation. *The Handbook of Bereavement Research: Consequences, Coping and Care* consider various interventions and approaches in far greater depth.⁴⁶

As long ago as 1983 St Christopher's Hospice was using a Risk Index tool to identify those who might benefit from bereavement services. The assessment was completed by the nursing staff caring for the patient and their families in the hospice. Someone scoring above a certain number was seen as "high risk" and in need of support. If the nurse themselves perceived the bereaved person as vulnerable they were also judged to be in need of support regardless of score. When evaluating the tool by means of follow up questionnaire it was found that the predictions were far from perfect.⁴⁷ Changes made to the tool and subsequent evaluation found that this tool produced significant association between the predictive score and the outcome. The question as to the nurse's view of the extent of risk of the person not coping was retained.

In 1995 a paper by *Robinson et al* in the *Journal Of Palliative Care* concluded that:

"The fact that high and low-risk groups could be identified with validity both prior to and following the spousal death suggests that bereavement intervention can and should be started as soon as possible."⁴⁸

Sanders lists risk factors in bereavement which can be picked up by a Risk Assessment Tool.⁴⁹ These are mode of death, ambivalence and dependency, loss of a child, concurrent crises, perceived lack of social support, age and gender, change in socio-economic circumstances and physical and mental health before the bereavement. However, it is also recognised that personality factors can play a part in how a bereaved person copes with the death of a loved one.

In 2002 *Caroline Melliar-Smith*⁵⁰ reviewed the usefulness of a bereavement tool at *St Ann's Hospice in Cheadle*. Her conclusion was that the tool and associated documentation had successfully managed to involve the multidisciplinary team in planning bereavement support for carers and relatives of patients dying in the hospice. It had also focused staff's attention on review and evaluation.

For the purposes of this report, I approached several other hospices to ask what Bereavement Risk Indicator tools were used. *Wigan and Leigh Hospice* had published details of their audit and I contacted their Bereavement Worker

who sent me details of the tool they use and of the most recent audit. She reported that although the Hospice are still using the tool, there was a general feeling that it has limitations and they were in the process of again reviewing its use. A questionnaire had gone to all clinical staff involved in completing risk assessments but the results were not yet available.

In *Northern Ireland Hospice, Belfast* a Risk Assessment Tool is used and again staff were not confident that it identified those at Risk. However, it continues to be used as it does gather information and ensures planning for follow up.

In *Iain Rennie Hospice, Tring* a tool is used but the Family Support worker feels uncomfortable with it being completed by the team in the office and hopes to review this process soon. At present she feels there have been enough changes and wants to leave time for some consolidation. However she anticipates that in future the tool will be completed with the bereaved person. This would have two benefits. It would address issues of confidentiality and data protection, and also open some dialogue.

7.2 Conclusion

There is not conclusive evidence that Bereavement Risk Indicators are totally predictive. However Payne's research concluded that:

“there were fewer problems associated with using a risk indicator than there were with relying on subjective assessment of need.”⁵¹

The professional view of the person completing the assessment can still be part of the assessment measurement.

If such a tool is used routinely then this does ensure that the assessment is made and that multi-disciplinary discussion takes place as to what support a bereaved person should be offered. It standardises that process and ensures that documentation takes place.

More recently, in 2003 a *National Postal Survey of Adult Bereavement Services in Hospice and Specialist Palliative Care Services in the UK* was carried out.⁵² It found that:

“Despite the debate about whether formal risk assessment should be used in hospice and specialist palliative care organisations to identify people most in need of bereavement support, 42% of the services used some formal method of ‘needs assessment’.”⁵³

The comment is made that there seems to be a demand for an effective assessment tool, although some people had expressed their opposition to the use of such a tool. The report seems to indicate that such tools should not be

used as a way of screening access to other activities but rather as a way of targeting one to one support.

7.3 Recommendations

- A risk assessment tool should be used for a trial period and reviewed.
- A suggested format is attached in Appendix 2

⁴⁶ Stroebe, M, Hanson, R, Stroebe, W, and Schut, H, (eds) Handbook of Bereavement Research: Consequences, Coping and Care. Washington DC American Psychological Associates. 2001.

⁴⁷ Development of Bereavement Risk Index in Recovery From Bereavement. Parkes, C M and Weiss, Robert S. 1983 Basic Books, New York.

⁴⁸ Robinson, Linda A, Nuamah, Isaac F, Lev E, and McCorkle R. A Prospective Longitudinal Investigation of Spousal Bereavement Examining Parkes and Weiss' Bereavement Risk Indicator in Journal of Palliative Care11:4.1995; p5-13

⁴⁹ Sanders, CM, Risk Factors in Bereavement Outcome in Handbook of Bereavement Theory, research and intervention ed Stroebe, MS, Stroebe, W and Hanson, RO, Cambridge: Cambridge University Press 1993

⁵⁰ Melliar-Smith, C The Risk Assessment of Bereavement in a Palliative Care Setting International Journal Of Palliative Nursing, 2002, Vol 8, No 6 p 287

⁵¹ Payne, S and Relf, M The Assessment of need for bereavement follow- up in palliative and hospice care. Palliative Medicine, 8,29-297, 1994

⁵² Field, D, Reid, D, Payne,S, and Relf, M. A National Postal Survey of Adult Bereavement Services in Hospice and Palliative Care Services in the UK, 2003. Palliative and End-of-life Care Research Group, University of Sheffield.

⁵³ Op cit p 13

8. BEREAVEMENT SERVICES IN OTHER AREAS

8.1 National

It has been useful to consider the range of bereavement provision that other areas provide. *Field, Reid, Payne and Relf*⁵⁴ completed a *National Postal Survey of Adult Bereavement Services in Hospice and Specialist Palliative Care Services in the UK 2003*. The conclusions of the first stage of *Field et al's report*, which sought to "identify the nature and extent of bereavement support services offered to people"⁵⁵ by hospices and specialist palliative care services in the United Kingdom, were various. Services had been running in the main for less than 15 years. The number of clients accessing services that were available varied widely, "with in-patient units typically having more clients."⁵⁶ The most commonly provided bereavement support was one to one support, although the questionnaire design meant that the detail about this was not available. Volunteers were used in most organisations, although they seldom took sole responsibility. Risk assessment tools were considered in Chapter 7.

The survey found that:

"a third of respondents (82) reported that they either had in place or were developing formal processes to provide feedback about their experience of using this form of bereavement support."⁵⁷

The authors comment that there is an expectation now that users are involved in auditing services and an increase in this sort of evaluation is likely to be required.

Three observations are of particular interest in relation to developing a bereavement service. Firstly they comment that:

"the lack of sufficient paid and voluntary staff may inhibit the effective delivery of existing services and be a constraint upon the delivery of other types of support and the expansion of bereavement support to potential clients."⁵⁸

Secondly several respondents felt that:

"their service would be improved by the appointment of a person to manage and co-ordinate bereavement support activities."⁵⁹

Thirdly the authors comment that:

"The lack of supervision for staff working with people who are bereaved is of concern as adequate supervision is an important ingredient in assuring the quality of bereavement support services and well being of the staff providing them."

8.2 Hospice and Specialist Palliative Care Services in North Cumbria.

Eden Valley Hospice has had a bereavement support service staffed by volunteers for several years. Two years ago a trained counsellor was appointed to manage the bereavement volunteers and develop the service. The volunteers now have a clearly defined training programme, which is continuous, and there is a system of supervision and support. There is a group running to support bereaved men.

Eden Valley Hospice also have a social worker in post who is often involved with families prior to death and where appropriate will offer bereavement support. Such support may be of a practical nature looking at financial and other implications of loss, as well as emotional support. It may be thought particularly appropriate for her to be involved where there are children and young people in a family. The social worker has recently accessed consultancy support from the National Children's Bureau for the development of support services for children.

Hospice at Home Carlisle and North Lakeland has established a bereavement service over the last 12 months. They have a co-ordinator who organises the service and are in the process of training volunteer visitors who will offer one to one support. At present this service is offered to all those families where North Lakeland Hospice at Home have been involved, where the Macmillan services have been involved and also where the patient was receiving care at day hospice in Penrith. The service may be extended in the future.

8.3 Bereavement Support in East Riding of Yorkshire Health Authority.

The Northern and Yorkshire Cancer Registry and Information Services completed a pilot Bereavement study in 2000, *The Provision of Bereavement Support Services*.⁶⁰ This study approached "114 health professionals working in hospital, community and primary care settings throughout the" East Riding Health Authority. Those interviewed included students, hospital and primary care nurses, doctors and chaplains, and voluntary organisations including Cruse and Macmillan Nurses. The study participants made several recommendations, including more specialist workers, improved services for children and young people, more self-help/support groups for people who are socially or geographically isolated, improved follow-up for the bereaved, improved levels of information for the bereaved, more information available for GPs about the bereaved from hospitals following a death, increased support for particular client groups (e.g younger to middle aged bereaved, women following terminations or miscarriage, and parents following the death of a child) and a Bereavement Co-ordinator across the Trust. The study also found that:

"most professionals felt they needed more training in bereavement counselling and clarification in how they could help either personally or by knowing enough about other services to be able to refer appropriately."⁶¹

This study looked at the bereaved generally and not only people whose loved one had received palliative care services.

8.4 Isle of Man.

There is one Hospice on the Isle of Man, St Bridget's Hospice, providing inpatient care and care at home. The role of managing the bereavement service is part of the social worker's remit. The hospice offers a range of services to the bereaved. The social worker provides practical advice and emotional support. She has often been involved with families prior to the death of the patient. Following the death, a risk assessment is completed with the rest of the multi-disciplinary team and arrangements are made for follow up care. The hospice has a team of volunteers who have had at least 30 hours training. They have continuing one to one and group supervision. Originally the service was run by the social worker but there is now a co-ordinator in post, who is a trained counsellor, and whose responsibility it is to train and supervise the volunteers and to allocate the work. In addition there is a monthly bereavement group that runs on an informal basis but facilitated by staff. People can come along to the group when they feel ready. They do not have speakers unless asked to organise one by group members. The group meetings are somewhere people go to share experiences and get support from others in a similar situation. The staff view is that the facilitation has proved useful on occasions to ensure that no one person dominates the group.

8.5 Iain Rennie Hospice at Home, Tring, Hertfordshire.

My search for a similar organisation that also provides a service over a wide area, took me to Tring in Hertfordshire. Iain Rennie Hospice at Home has parallels with West Cumbria Hospice at Home in both its development and geography. Information about the bereavement support offered by Iain Rennie Hospice at Home was available on their website.⁶² When I contacted the Family Support Worker she and her colleagues were keen that I visit so they could share with me the history of their service development.

Iain Rennie Hospice at Home was set up 20 years ago. Bereavement support has always been part of the care offered to anyone who has been significant to the person who has died. The demand for the service grew so much that it was decided to employ a family/bereavement co-ordinator, now called a Family Support Worker. She completed a review along with existing staff and in the words of one of the original Hospice nurses, she "introduced boundaries, protocols and structure."

Iain Rennie offers a range of services that have evolved over time. They have a group of volunteer bereavement supporters who undergo a 10 week training programme during which they are assessed. The trainees are not automatically seen as suitable to work with the bereaved just because they

have completed the training, and one or two people have been turned down at the end of the 10 weeks. The volunteers receive regular supervision from the Family Support Worker and meet regularly as a group, for support and further training.

The Family Support Worker and an experienced Hospice Nurse also run bereavement support groups. The first group was an informal group that ran for 4 or 5 years and became a social support group. It became difficult to make emotional space for the more recently bereaved, and eventually the group was drawn to a close. More recently a closed group structure has been tried. This allows a group of people who have been bereaved around the same time to come together for mutual support, with the process facilitated by staff. This has avoided the loss of direction that had occurred with the open group structure. However, one group had several young bereaved people and the intensity of emotion arising was so painful that members found the group offered limited support. The Family Support Worker and the Hospice Nurse who run the groups feel that they need to be able to allow some flexibility when running groups and use different models as appropriate.

The staff are aware of the particular needs of children and young people with regard to bereavement. They run an annual Chrysalis Club in conjunction with two other Hospices in the area. This is a weekend meeting to which bereaved children between the ages of 4-15 years are invited. The aim is to help children if they are feeling isolated in their bereavement. It is not a residential weekend and parents or carers are invited to stay for their own session on the first day. They hear about the activities planned for the children, and have an opportunity to talk to other parents and carers. The weekend finishes with a closing ceremony in which children and adults have an opportunity to release helium filled balloons in memory of the person who has died.

An Annual Thanksgiving Service is held in a variety of venues to acknowledge the diversity of faith backgrounds, and a Humanist Service is being considered.

Iain Rennie Hospice at Home decided to use a Risk Assessment Tool having reviewed the current research. The tool is completed by the nurses involved with the bereaved client. The Family Support Worker feels that the tool works reasonably well, having recently been modified. She did however highlight the issue referred to in the chapter on Risk Indicators that such assessments are completed about the person rather than with them. She is looking at a system that can be used with the bereaved person.

Daphne, who is one of the founding nurses of Iain Rennie Hospice at Home, was very clear in her view that someone is required to co-ordinate a bereavement service. She feels that the co-ordinator should be there to provide support to the bereavement volunteers and nurses, to introduce clarity about boundaries and equality of service, and to develop new services.

8.6. Recommendations

- Appoint a bereavement co-ordinator to formalise existing services and establish a system of risk assessment and audit.
- Expand the role of bereavement co-ordinator to develop further services. These would include group and one to one support. The former could be done in conjunction with other workers within West Cumbria Hospice at Home, and also from other organisations. The latter would mean either developing a system of trained volunteers or extending utilisation of individual counselling already available through West Cumbria Hospice at Home.
- Use a risk indicator tool that is completed with the carer where possible, as mentioned before.
- Make contact with the National Group of Bereavement Co-ordinators through Help the Hospices in order to share good practice and ideas for further developments.
- Extend the bereavement support for children and young people. This could be done in conjunction with other services in North Cumbria.

⁵⁴ Field, D, Reid, D, Payne, S, and Relf, M. A National Postal Survey of Adult Bereavement Services in Hospice and Specialist Palliative Care Services in the UK,2003. Report To The Respondents. Palliative and End-of-Life Care Research Group, University of Sheffield, Bartolome House, Winter Street, Sheffield S3 7ND.

⁵⁵ Op cit. p 2

⁵⁶ Op cit. p 12

⁵⁷ Op cit. p 12

⁵⁸ Op cit. p 12

⁵⁹ Op cit. p 12

⁶⁰ Northern and Yorkshire Cancer Registry and Information Service. The Provision of Bereavement Support Services. A Pilot Study. Available at www.nycris.org.uk p. 5

⁶¹ Op cit. p. 5

⁶² www.irrh.org.uk

9. CHILDREN

West Cumbria Hospice at Home provides nursing care for children with long term conditions requiring respite care. Generally children requiring acute or end of life care receive this care from the Diana nursing team and other carers such as the Rainbow Trust.

However Hospice at Home and the Macmillan nurses are often involved in situations where the patient for whom they are caring has a young family and therefore they are in a position to ensure bereavement support is available to children and young people.

9.1 The Need

The way in which children are treated when someone important in their lives dies has a profound effect on their future ability to manage their future. Barbara Monroe, Director of the Candle Project, St Christopher's Hospice states it is well recognised that:

“there are costs, often long term, associated with allowing children's grief to remain hidden and unsupported.”⁶³

Schuurman says in *Never the Same - Coming to Terms with the Death of a Parent* that:

“Without the right conditions for healing, children and teens will carry these emotional wounds into the rest of their lives. We know that children who have a parent die are at risk. They are more likely than other children to experience higher levels of depression; an increase in health problems and accidents; poorer school performance; more anxiety and fear; lower self-esteem; a destructive belief that all events in their lives are beyond their control; and less optimism about succeeding later in life.”⁶⁴

She goes on to provide evidence for these statements.

On a Channel 4 programme recently about young people facing bereavement the statistic was quoted that someone in the UK under 18 loses a parent every 30 minutes. Combine that with the statistic from the same programme that 150 people under 19 die every week and one can conclude that the number of young people facing bereavement is significant. The National Children's Bureau think that around 10 per cent of all children have lost a parent, carer, close relative or close friend.⁶⁵

At such a time there is agreement that children need information. This needs to be clear, simple, truthful and repeated and it needs to be appropriate to their age. They also need reassurance. This may be about practical issues, illness of themselves or others or others they love also dying. At a time that a bereaved parent may find it hard to give they need extra stability, routine and

affection. Finally they need parents to share their feelings. Children learn to grieve by observing others but they also need explanations about different adult reactions. Such guidance may come from a parent, from school, from a church group, or from a professional they already know. The important thing is that this support is available to them.

9.2 National Services

Nationally there are several examples of excellent practice providing specialist bereavement care for children and young people. Schemes such as Winston's Wish in Gloucestershire, the Candle Project in SE London and the Child Death Helpline based at Great Ormond Street Hospital, London provide specialist care to children and young people in their region. In addition they offer consultancy support and training to professionals working with bereaved children and young people in other areas. However, there is recognition that such support services for children do need extending. The Childhood Bereavement Network, part of the National Children's Bureau, is supporting the development of a consistent, proactive national system of support services that are accessible to all children and their carers wherever they live.

The Child Bereavement Trust aims to help bereaved families, parents and children, by improving the care offered to them. They provide training, resources and information to professionals working with bereaved children and their families.

9.3 Services in North Cumbria

In North Cumbria the Child Bereavement Group has been working towards developing services for bereaved children. This is a group of professionals who work with bereaved children as part of their professional role but who do not only work with bereaved children. They are often not in a position to take referrals specifically about bereavement from outside their respective agencies. Within their agency there will often be an issue of loss or bereavement to be addressed with clients referred for other reasons. This is true of the NSPCC Centre at Wedgewood Road in Whitehaven, where referrals are for issues of sexual or physical abuse, but often work on issues of loss and bereavement are a part of this. The Diana Nurses work with children with a serious illness and do therefore work with bereaved siblings. The Rainbow Trust also provide family centred care for children with life threatening or terminal illness and do provide bereavement follow up.

The group aims for equality of access to bereavement support for children and young people in North Cumbria. They are developing a support service to enable and support staff or carers who are already involved with a bereaved child to continue to support the child at a difficult time. They have produced a list of professionals who are happy to be consulted on issues of bereavement but who are not in a position to take referrals.

In addition they have developed a resource box which is available in several locations throughout the county. The box includes books and videos and is

accessible for reference in the Children's Wards and the Cancer Network Room at both West Cumberland Hospital and the Cumberland Infirmary, at Eden Valley Hospice, and in the Royal College of Nursing Resource Room at the nine community hospitals.

The social worker at Eden Valley Hospice is working towards extending support for bereaved children. She has obtained consultancy support from the Childhood Bereavement Network to assist with this.

The Siskyn Project, based in the Wigton area, has been running an appeal for a while and aims to provide Hospice and Respite care for Cumbrian children and their extended families. They also aim to establish a bereavement telephone support service.

The Child Bereavement Group is currently exploring the possibility of running a group session for bereaved children and young people. There are many operational and funding issues to address but there is enthusiasm and commitment to provide something specialised in this area.

There is agreement that a bereaved child initially benefits from the support of those around them who know them well and already have the skills to talk to them.⁶⁶ Locally, there is joint working between health and education in encouraging teachers to recognise their own skills as supporters of bereaved children and ensuring they have the necessary information and some understanding of the issues. Two Conferences have been held by Cumbria Healthy Schools initiative along with North Cumbria PCT in the past 2 years and they have been well attended by teachers and feedback has been positive. Members from the Children's Bereavement Group have provided training input to these conferences.

9.4 Conclusion

For West Cumbria Hospice at Home it will be important to continue to work with those children in families where there is a terminally ill parent. It may be that close liaison with the child's school, to ensure that appropriate support is being offered there, is what is required. In the absence of a specialist children's bereavement service locally the role of hospice staff would be to maintain up to date information about those services that can be accessed if appropriate, such as the Children's and Adolescents Mental Health Services. It will also be important to be aware of, or possibly be part of, services developing locally.

9.5 Recommendations

- Membership of the North Cumbria Child Bereavement Group should be maintained. A Macmillan nurse already attends.
- Someone should be identified as being responsible for ensuring there is follow up in those situations where there are children or young people.
- Contact with the Childhood Bereavement Network should be maintained in order to keep up to date with national developments and resources.

⁶³ Monroe, B, Sharing The Journey in Then, Now and Always, Stokes, JA, London: Caloustie Gulbenkian Foundation. 2004 p9

⁶⁴ Schuurman, D, Never the Same – Coming to Terms with the Death of a Parent. New York: St Martin's Press. 2003

⁶⁵ Stubbs, D, 'My Dad died but nobody ever mentioned it', Children and Bereavement, National Children's Bureau Spotlight, Iss 1, Dec 2003

^{iv} Lowton, K, Supporting bereaved students in primary and secondary schools. Practical advice for school staff. Kings College London and the National Council for Hospice and Specialist Palliative Care Services. 2004

10. CONCLUSIONS AND RECOMMENDATIONS

The earlier sections have illustrated the various findings made during the project. I have not referred specifically to inclusivity and diversity.

Inclusivity and Diversity

These factors are implicit in all the work of West Cumbria Hospice at Home but it is useful to highlight them in relation to bereavement. The area covered by Hospice at Home does not have many different cultures and therefore knowledge of different cultures and religions is needed infrequently. In some ways this makes it more difficult to ensure that appropriate choices are being offered to people. The distressing feelings of bereavement may be intensified for members of an ethnic minority community by lack of effective communication and possible lack of awareness and sensitivity about funeral rites and end of life issues amongst health care professionals.

It is also important to remember that being aware of people's differences generally is important. Diversity is about age, disability, gender, sexual orientation, race, religion and belief. Any bereavement co-ordinator will need to make sure that ignorance of differences in what is important to people does not contribute to a poor service.

One client group who are known to be often excluded from rituals when someone dies are those with learning difficulties. It is said only 54% of people with learning difficulties attend their parent's funerals.⁶⁷ It is important that those providing any sort of Bereavement Service remain aware of such issues. West Cumbria Hospice at Home do have resources for aiding working with this group of people and clearly the Learning Disability Team Staff would be available to advise.

Conclusion

In North Cumbria and within the area covered by West Cumbria Hospice at Home, there do exist a small number of bereavement services. In addition, bereavement support is part of the support provided by many professionals within their daily work. However, there is not as yet a coherent joined up service that is easy to access by both the bereaved and other professionals. This is true for adults and children and has been identified by both Bereavement Forums.

There is evidence to support the argument that bereavement support can be beneficial to the long term physical and mental health of an individual. Nationally and locally there are moves to improve bereavement services. The Northern Cancer Network will be developing the bereavement provision within palliative care, as it is a requirement of the NICE Guidance for Improving Supportive and Palliative Care. Other providers of palliative care are developing their bereavement provision and it will be important not to move forward in isolation. However my major conclusion is that West Cumbria Hospice at Home needs someone who can co-ordinate existing services and

develop new ones. West Cumbria Hospice at Home already provide some excellent support. In addition the Macmillan staff also provide follow up. There is though, a general feeling that it does not reach as many people as it should.

Similar organisations in other areas have identified the lack of a coherent joined up service available to all. We see from the chapter considering these organisations that they have given the responsibility for developing a more coherent service to one person. The ways forward have actually been similar with a range of services being developed.

In light of these findings recommendations have been made at the end of each section, sometimes duplicated because they are made for a variety of reasons.

Recommendations

- A co-ordinator should be appointed to ensure the success of any bereavement service. He or she should be responsible for co-ordinating services already offered by West Cumbria Hospice at Home and for developing new services.
- The co-ordinator should link with the two Bereavement Forums (Adult and Children), and ensure national and local standards are applied to all bereavement services.
- The co-ordinator should maintain an up to date list of relevant services that could be accessed and share this with colleagues
- The co-ordinator should liaise with other organisations that provide bereavement support to ensure equity of provision and avoid duplication. They should liaise with organisations that could assist in ways such as transport, information provision etc. This should avoid duplication of services and ensure imaginative use of existing services.
- The co-ordinator will aim to develop services incrementally. Initially focus should be on introducing a formal assessment at the time of death, including a risk assessment and documentation. Thereafter, planned contact at an agreed time after death, 6 weeks, 6 months, 1 year, could be developed.
- The co-ordinator should be proactive in promoting the Drop Ins creating links for the bereaved person and seeking ways of accessing transport.
- The use of the Drop Ins should be reviewed after a year of trying new ways of working.
- Consideration should be given to establishing a third venue for a Drop In if their use is seen to be successful at the time of the review.

- The co-ordinator should look at building on services to create a “tool box” that the bereaved and professionals can access.
- The co-ordinator should extend the bereavement support for children and young people in conjunction with other services in North Cumbria.
- The co-ordinator should ensure information about, and opportunity for, training is accessible to other staff.
- The co-ordinator should facilitate the development of volunteer bereavement counsellors.
- The co-ordinator should facilitate the development of group support for the bereaved.
- Part of managing the service would be administrative and organisational, but the future development of a variety of services would require this person to have the ability to work with and supervise volunteers, run groups and perhaps do direct work with individuals both adults and children.
- Service evaluation should be a priority from the start. A forum for service users and staff that meets regularly would be a useful source of service user involvement. This could inform practice within West Cumbria Hospice at Home.
- Geography is an issue. Innovative ways of addressing this difficulty will be required.
- Venues for groups to meet can also be an issue and flexible ways of addressing this will need to be found.
- Any bereavement services that West Cumbria Hospice at Home provide should be available to any bereaved person. Ways of achieving this may need to be explored with other organisations.

⁶⁷ Blackman, N, Loss and Learning Disability, Worth Publishing. 2003

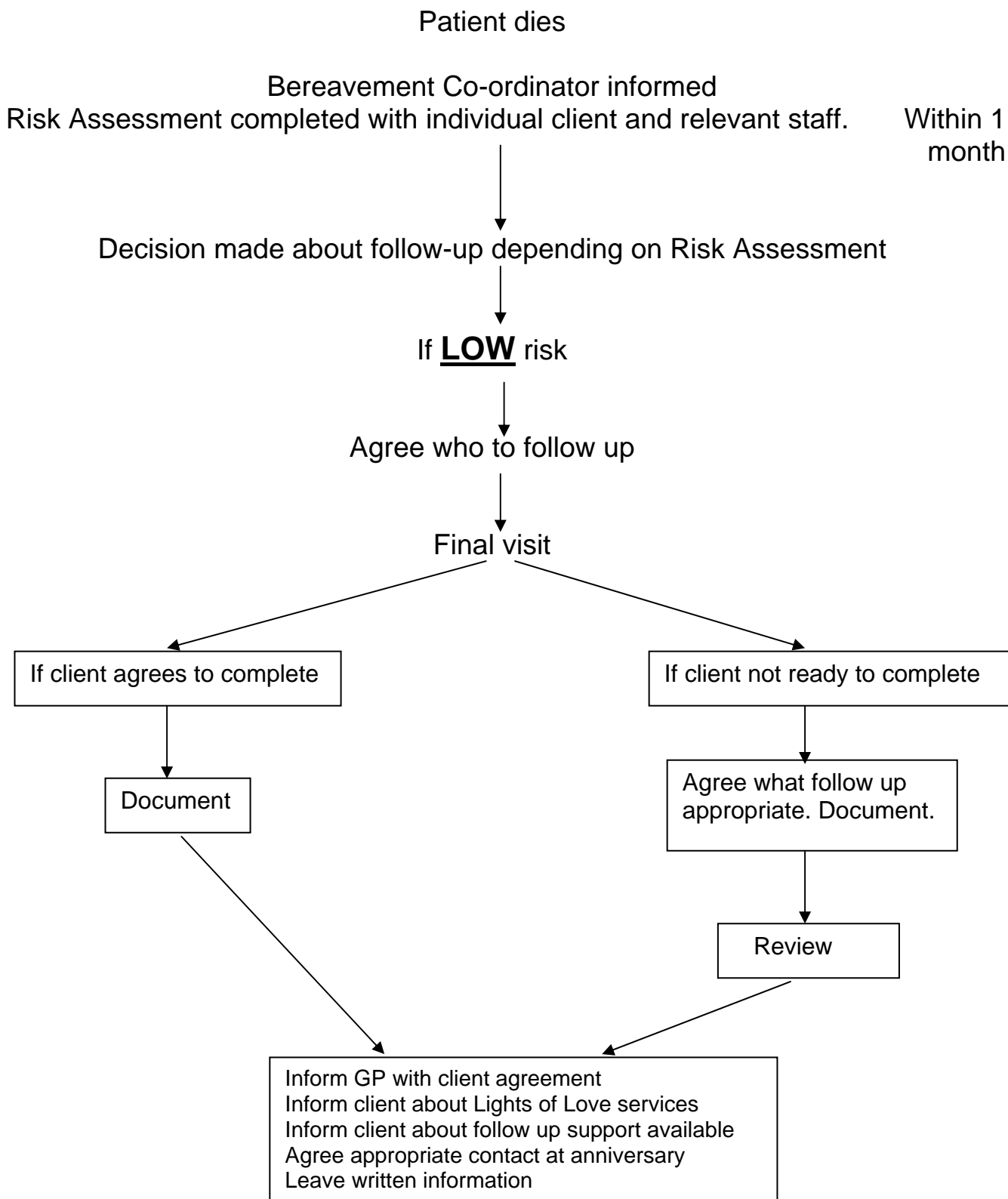
APPENDIX 1

The Principles state that providers of support to bereaved people should:

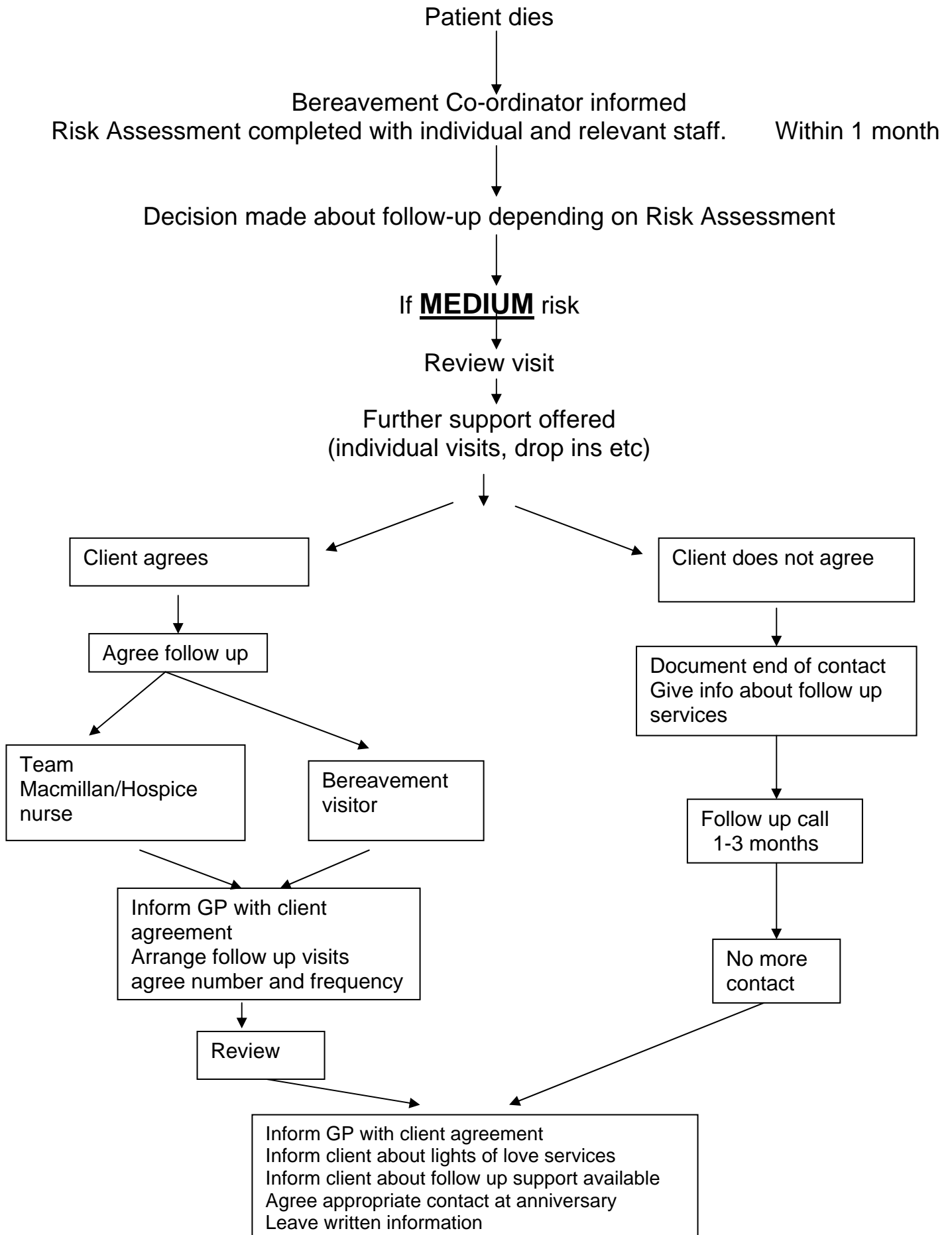
- a) be responsive to the needs of each bereaved person
- b) acknowledge and affirm bereavement as the pain of grief, as a natural part of human experience
- c) support each bereaved person in his/her ongoing adjustment to life without the deceased
- d) respect each bereaved person's choices and variety of expressions of grief consistent with different patterns of belief family, community, culture and religion
- e) be demonstrably non-discriminatory and deliver without prejudice, so that wherever practicable the bereaved person is able to access appropriate support regardless of their age, colour, disability, ethnic or national origin, financial circumstances, gender, geographical location, health status, language, marital status, religion or sexual orientation
- f) respect the confidentiality and privacy of each bereaved person and information shared by them
- g) minimise the risk of mental and physical complications that can be associated with bereavement
- h) ensure each bereaved person is aware of the support available to them by pro-actively disseminating information about their services to potential beneficiaries, including the bereaved, local agencies and health and social care professionals
- i) be clear about the boundaries of the support offered to each bereaved person and offer information on services available elsewhere to meet the needs which are beyond their services scope and abilities
- j) ensure that volunteers and paid staff are educated and trained appropriately to consolidate, develop, maintain and enhance their knowledge and skills in bereavement support, loss and grief
- k) ensure that volunteers and paid staff receive appropriate levels of supervision and support, relevant to their involvement in working with bereaved people
- l) encourage reflective practice to validate and, where possible, improve on current practice
- m) involve all stakeholders in planning, design, development and delivery of services
- n) collect data to monitor and evaluate outcomes leading to effective change, including feedback from clients, volunteers and paid staff, referral agencies and supervisors
- o) be organisationally open and accountable

APPENDIX 2

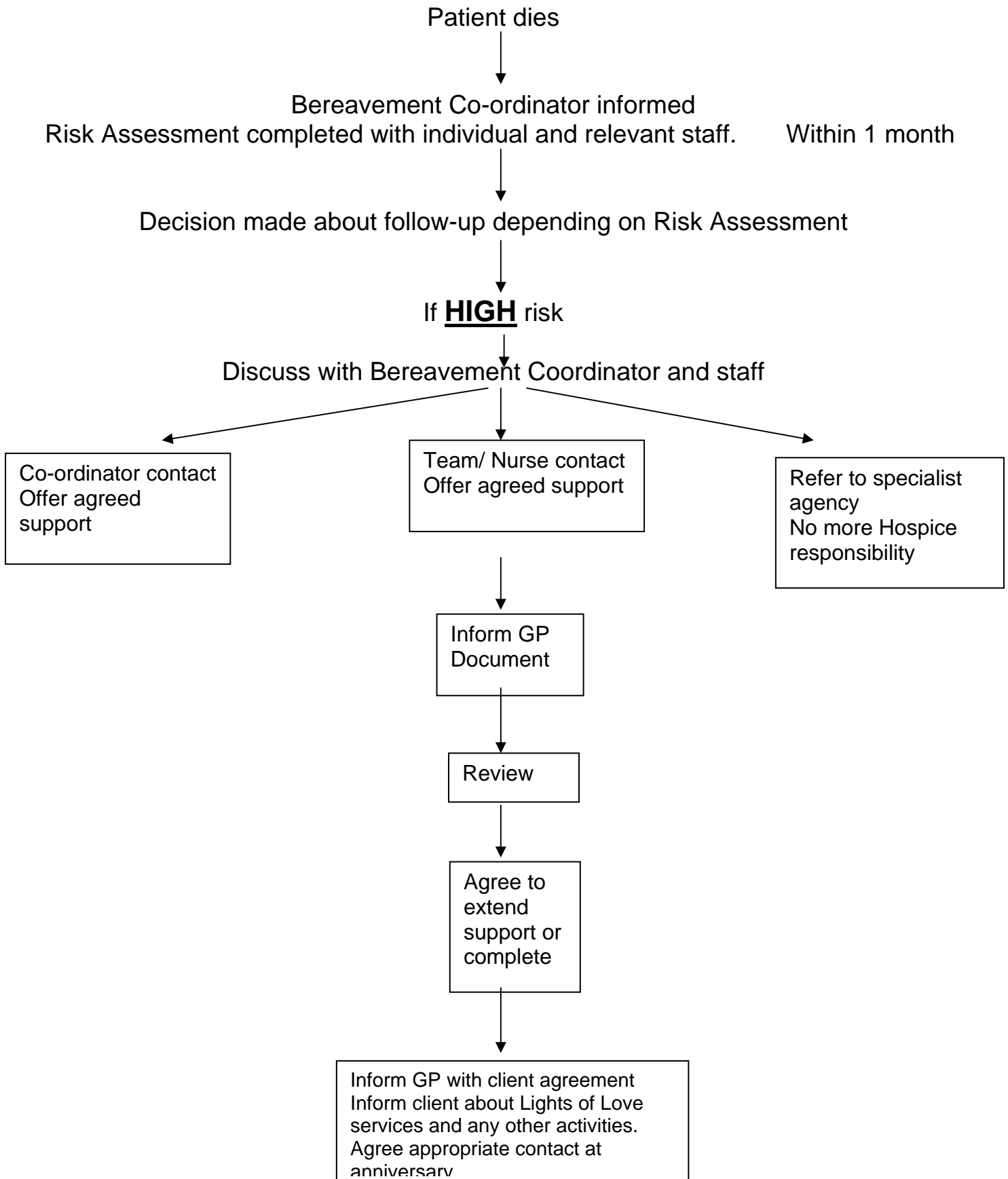
Pathway for Bereavement Care



Pathway for Bereavement Care



Pathway for Bereavement Care



PATIENT INFORMATION

Name: **Pal Care No:**
Address: **Patients Tel. No:**

DOB: **Date of Death:**
Date of Funeral:
**Main Carers/
 Relatives Name:**
Address:
Other significant others:

Place of death:
Who present:
Time receiving care:

RISK ASSESSMENT

The Death

Did the death occur without adequate warning?	YES	NO	
Was the death particularly distressing for the bereaved?	YES	NO	
Was the death suicide?	YES	NO	UNSURE
Has the death resulted in the loss of the primary care giver/ primary emotional support?	YES	NO	
Is this the death of a child/sibling?	YES	NO	
Was the death preceded by a long-term illness or required intensive care?	YES	NO	

The Bereaved

Had the deceased and family failed to reach an acceptance relating to the prognosis?	YES	NO	
Is the bereaved the primary care giver for a dependent family?	YES	NO	
Did the deceased die in a place or manner unacceptable to the bereaved?	YES	NO	
Does the bereaved have a past history of mental illness?	YES	NO	UNSURE
Is there a past history, or suspicion of alcohol/drug dependency?	YES	NO	UNSURE
Do you feel the bereaved is at risk of committing suicide?	YES	NO	UNSURE
Does the bereaved appear to experience high levels of stress?	YES	NO	
Does the bereaved appear to experience low self esteem?	YES	NO	

Did the bereaved have an ambivalent relationship with the deceased?	YES	NO
Was the bereaved totally dependent on the deceased?	YES	NO
Is the bereaved unable to care for self adequately?	YES	NO
Have there been other significant losses in past years?	YES	NO
Are there other known additional stress factors? Redundancy, moving, financial difficulties? (Please specify)	YES	NO
Is there chronic illness present in the home of the bereaved?	YES	NO
Is there a poor social support system?	YES	NO
Is there inadequate emotional support network – unable to express grief?	YES	NO
Is there poor marital/family communication?	YES	NO

SCORING: YES = 2 NO = 0 Suspicion/Unsure = 1
Low risk = 0-10 Medium Risk = 11-15 High Risk = 16+

ADDITIONAL INFORMATION:

What coping strategies does the bereaved have?

Does the bereaved have a meaningful believe system?	YES	NO
Does the bereaved have access to spiritual/religious support?	YES	NO

How does the bereaved feel they are coping?

Assessors professional view including intuition:

Choose pathway and documentation:

Set date for review:

Are there young children in the immediate family?	YES	NO
---------------------------------------------------	-----	----

If YES plan their follow up

Are there other family members requiring support?	YES	NO
---------------------------------------------------	-----	----

If YES complete separate risk assessment

Signature of Assessor:

Date completed:.....

Appendix 3

DIRECTORY

BEREAVEMENT SERVICES IN NORTH CUMBRIA

Cruse Bereavement Care Cumbria

P.O.Box 51
Cockermouth
Cumbria CA13 OWU

Helpline: 07071 780761
Office: 01900 828446

Eden Valley Hospice

Counselling and Bereavement Support

Durdar Road
Carlisle CA2 4SD

Tel No: 01228 810801

The Samaritans

Tel No: 01228 544444
Tel No: 08457 909090

Bereavement Services East Cumbria

North Lakeland Hospice at Home

Tel No: 01768 210755

Bereavement Coordinator

Maternity and Family Services

Cumberland Infirmary
Carlisle CA2 7HY

Tel No: 01228 523444

Bereavement Services West Cumbria

West Cumbria Hospice at Home

Tel No: 01900 705200

Bereavement Counsellor Maternity Services

Tel No: 01946 693181
Extn: 4250

Many **General Practitioners** have access to a **Counsellor** and may be able to refer to them or to other professionals (**CPN** or **Psychologist**) where this is appropriate.

Other organisations locally offer bereavement support to people with whom they have links.

OutReach Cumbria: Aims to offer advice and support to members of the lesbian, gay and bisexual community.

Tel: 01228 603075

14, Portland Square, Carlisle CA1 1PT

Tuesday-Thursday 10am – 4pm

Age Concern Northwest Cumbria

Tel: 01946 66669

Old Customs House, West Strand, Whitehaven, Cumbria CA28 7LR

Age Concern Carlisle & District

Tel: 01228 536673

20, Spencer Street, Carlisle, Cumbria CA1 1BG

Age Concern Eden

Tel: 01768 863618

Resource Centre, Sandgate, Penrith, Cumbria CA11 7TP

Alzheimer's Society (Carlisle Branch)

Tel: 01228 819299

1, Rydal Street, Carlisle, Cumbria CA1 1SQ

Alzheimer's Society (West Cumbria)

Tel: 01900 607280

Ann Burrows Health Centre, Workington

Alzheimer's Society (Penrith Branch)

Tel: 01768 899633

32, Tynfield Drive, Penrith, Cumbria CA11 8HZ

Carlisle Carers Association

Tel: 01228 542156

Suite 2, Chapel Court, 44, Cecil Street, Carlisle, Cumbria CA1 1NT

West Cumbria Carers

Tel: 01946 592223

133, Queen Street, Whitehaven, CA28 7QF

To access information about other organisations that may be a source of support, try the North Cumbria Health website:

www.northcumbriahealth.nhs.uk/vologs

Many people locally will offer bereavement support as part of their work. E.g Macmillan nurses, Diana Nurses, Rainbow Trust, Mental Health Teams for adults and children, and also specialist units within the hospitals such as Intensive Care, Renal Unit and Accident and Emergency.

To access information about diversity:

www.cumbria.uk/diversity

To access support from the church try Places of Worship or Religious Organisations in the Phone Directory.

To contact the Chaplains, phone the local hospital.

Cumberland Infirmary

01228 523444

West Cumberland Hospital

01946 693181

Numbers of Community Hospitals in the Phone Directory.

To obtain information about other religions, contact the Equalities Officer, Cumbria County Council

01228 606060

National Organisations

Many national organisations will be able to put you in touch with someone local or with someone who has experienced a similar loss. There are difficulties maintaining up to date information about local groups, so phoning the national office first is often the best way to ensure you are able to speak to someone who understands why you are phoning and who is able to give you appropriate information.

Age Concern: A national organisation with local branches that offers support for older people in various circumstances, including those bereaved.

Tel: 020 8679 8000

www.ageconcern.org.uk

Astral House, 1268. London Road. London SW16 4ER

Arc: (Antenatal Research & Choices) information and support to parents who are making decisions during the antenatal testing process and having to make difficult decisions about continuing or ending the pregnancy. Also aims to use improve professional practice.

Tel: **020 7631 0285** (Helpline)

020 7631 0280 (Office)

www.arc-uk.org

73, Charlotte St, London W1T 4PN

Child Death Helpline: Befriending and emotional support for anyone affected by the death of a child, teenager or young adult.

Tel: **0800 282 986** (Helpline, not 24 hours)

020 7813 8551 (Office)

www.childdeathhelpline.org.uk

The Bereavement Services Department, Great Ormond Street Hospital, Great Ormond Street, London WC1N 3JH

Childhood Bereavement Network: Co-ordinating body which aims to improve bereavement services for children and young people, their families, and other caregivers throughout UK, and to increase access to information, guidance and support services.

Tel: 020 7843 6309

www.ncb.org.uk/cbn

8 Wakley Street, London EC1V 7QE

Compassionate Friends: Support for parents, grandparents and their families following the death of a child at any age.

Tel: **0117 953 9639** (Helpline)

0117 966 5202 (Office)

www.tcf.org.uk

53 North Street, Bristol, BS3 1EN

Cruse Bereavement Care: National charity set up to offer free confidential help to bereaved people.

Tel: **0870 167 1677** (Helpline)
020 8939 9530 (Office)

www.crusebereavementcare.org.uk

Cruse House, 126, Sheen Road, Richmond, Surrey TW9 1UR

Rd4u: The youth branch of Cruse set up to help young people after the death of someone close.

Tel: **0808 808 1677** (Helpline, answered by trained volunteers aged between 16-25. 4-7pm, Mon-Wed.)

www.rd4u.org.uk

Cruse Bereavement Care, Cruse House, 126, Sheen Road, Richmond, Surrey TW9 1UR

Foundation for The Study of Infant Deaths : Support for families of babies who die suddenly or unexpectedly.

Tel: **0870 787 0554** (Helpline 9am-11pm Mon-Fri, 6pm-11pm Weekends and public holidays)

0870 787 0885 (Office)

www.sids.org.uk/fsid

Artillery House, 11-19 Artillery Row, London, SW1P 1RT

Jewish Bereavement Counselling Service: offers support to any member of the Jewish Community.

Tel: 020 8385 1874 Fax: 020 8385 1856

www.jvisit.org.uk/jbcs

8-10, Forty Avenue, Wembley, Middlesex, HA9 8JW

Lesbian and Gay Bereavement Project: offers support and advice to lesbians and gay men bereaved by the death of a same-sex life partner.

Tel: **020 7403 5969** (Helpline)

020 7407 3550 (Office)

Healthy Gay Living Counselling, 24, Sothwark St, London SE1 1TY

National Association of Widows: offers support and advice to all widows.

Tel: 024 7663 4848 (Mon – Thurs 10am-4pm)

48 Queens Road, Coventry, CV1 3ER

RoadPeace: dedicated to supporting bereaved and injured road crash victims.

Tel: **0845 4500 355** (Helpline 9am-9pm daily)

www.roadpeace.org

PO Box 2579, London NW10 3PW

SOBS (Survivors of Bereavement by Suicide): offers support to those bereaved by suicide. Many of those helping have themselves been bereaved by suicide.

Tel: 0870 241 3337

www.uk-sobs.org.uk

Centre 88, Saner Street, Hull HU3 2TR

Stillbirth and Neonatal Death Society: Offers support for bereaved parents and their families when their baby dies before, during or soon after birth.

Tel: **020 7436 5881** (Helpline)

020 7436 7940

www.uk-sands.org.uk

23, Portland Place, London, W1N 3DE

Sudden Death Support Association: Offers support to relatives and close friends of people who die suddenly.

Tel: **01189 889997** (24 hour answer phone)

www.suddendeathsupport.co.uk

Dolphin House, Park Lane, Swallowfield, Reading, Berkshire, RG7 1BB

Support After Murder and Manslaughter (SAMM): Support and a confidential helpline offering support and information to anyone affected by murder or manslaughter.

Tel: 0207 735 3838 (Mon-Fri, 9am-5pm)

www.samm.org.uk

Cranmer House, 39, Brixton Road, London SW9 6DZ

The Miscarriage Association: offers support and information on all aspects of pregnancy loss (miscarriage up to 24 weeks and ectopic pregnancy).

Tel: 01924 200799

C/o Clayton Hospital, Northgate, Wakefield, West Yorkshire, WF1 3JS

The Child Bereavement Trust: provides resources and information for bereaved families and the professionals who care for them.

Tel: **0845 357 1000** (Information and Support Line for Professionals 09h00-17h00)

01494 446648(Office)

www.childbereavement.org.uk

The Child Bereavement Trust, Aston House, West Wycombe, High Wycombe, Buckinghamshire, HP14 3AG

Winston's Wish: Charity that offers support to young people who have experienced bereavement.

Tel: **0845 20 30 40 5** (Helpline 9.30am-5pm, Mon-Fri. 9.30am-1pm Sat)

01452 394377 (Office)

www.winstonswish.org.uk

Winston's Wish, The Clara Burgess Centre, Gloucestershire Royal Hospital, Great Western Road, Gloucester, GL1 3NN.

The WAY (Widowed and Young) Foundation: Provides a self-help social and support network for men and women widowed up to the age of 50 and for their children.

Tel: 0870 011 3450

www.wayfoundation.org.uk

The WAY Foundation, PO POX 6767, Brackley, NN13 6YW

Youth Access: Can tell you about local counselling, advice and befriending services for young people who have been bereaved.

Tel: 020 8772 9900 (Not 24 hour)

1-2 Taylors Yard, 67, Alderbrook Road, London, SW12 8AD

One of the most comprehensive lists of support available nationally is the **BBC website.**

www.bbc.co.uk/health/bereavement/links

For young people the **Radio 1** site is worth looking at:

www.bbc.co.uk/radio1/onelife/personal/bereavement

There is a website called **If I Should Die** which is dedicated to providing as much practical information and support as possible in one place. It has information for those writing a will or planning a funeral as well as for those bereaved.

www.ifishoulddie.co.uk