THE ROLE OF THE SOCIAL WORKER FOR CANCER PATIENTS

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INTRODUCTION

A social work service for people with cancer and their families in the Lancaster district was established in 1990 when I was appointed to this post. The service extends to people at the terminal stage of any illness, but in practice most of my work is with cancer patients. The service is jointly funded and managed by Social Services on the provider side of the department. Prior to Social Services' restructuring, referrals came from various sources but are now channelled through the purchasing arm of the department via three local assessment teams. My post is unusual in that most social workers in the area of palliative and terminal care are hospice or hospital-based, rather than community, but I have developed a strong liaison role and good working relationships with the multi-disciplinary team at St John's Hospice, Ward 3 Annexe, and Cancer Care.

FOCUS OF SOCIAL WORK SERVICES

The importance of addressing the psychosocial needs of the person diagnosed with cancer and the impact on the family is paramount. This encompasses social, psychological, practical and financial problems arising from a cancer diagnosis. The repercussions of the diagnosis, particularly if the condition is terminal, resonate throughout the family and create and compound difficulties which are often present in family situations and relationships. Social work support and sensitive counselling can explore both individual and family strengths and coping mechanisms, and elicit the main problems for that particular individual or family. This may not only be the cancer diagnosis, but also existing problems or problems arising as a result of the illness.

METHOD OF WORKING AND INTERVENTION LEVELS

On referral an introductory visit is made to evaluate the situation. Typical levels of intervention are:

- Specialist assessment of need.
- High input of support around diagnosis/initial referral period to deal with immediate problems and build counselling relationship.
- Medium input through treatment stage to support and monitor the situation.
- Low input or case closure if remission appears constant with an offer of renewed support if needed.
- Intense input again on recurrence of disease or treatment failure.

- Terminal stage, again requiring more intensive support.
- Bereavement work where necessary.

In the specialist assessment, the use of the theoretical background in social work training helps to provide holistic evaluation of the client and family needs. The presence of a social worker, alongside health colleagues, outlining the available support and help, is often an intense relief to newly diagnosed people. An outside acknowledgement of their particular situation and a review of all the help available locally can reduce feelings of isolation and is sometimes sufficient to enable a family to cope. Skills required in palliative and terminal care are similar to those required in other areas of social work or counselling, with the possible additional skill of coping with close contact with dying and death. Inherent in this skill is the need to face one's own mortality. Issues which arise where social work skills and knowledge are of particular use are:-

- 1 Where there are complex emotional and relationship problems.
- 2 Where there are family members particularly vulnerable because of dependency, eg children, adolescents, elderly relatives people with learning difficulties or psychiatric illness. In all these cases, a social worker has the knowledge and skills to give information and support or to arrange the necessary help. As a result of changing family composition, there is a need for planning future care, particularly in the case of children from single parent families where the parent is dying. Experience in working with distressed children and liaison with relevant agencies is often necessary.
- 3 Where there are financial and practical stresses which need information and advocacy to maximise benefits, obtain grants and support rehousing needs. The benefits system is increasingly complex and guidance is also needed regarding eligibility for help from Social Services as well as care options from the private and voluntary sectors.
- 4 Where there are issues of multiple losses, either existing or unresolved within a client or family. Coping with loss is an intrinsic element of social work irrespective of the client group involved.
- 5 Where a perspective from a non-medical background can give people the opportunity to explore feelings and make choices from a different vantage point.

When people have a life-threatening illness, they confront not only the existential uncertainties about the meaning of life and death, but also fears about how ill they are, what to do about family and work responsibilities, the likely course of

their illness, possible pain and how it will be relieved and decisions about treatment options. There is no contradiction between trying to lessen these uncertainties whenever possible, yet acknowledging that some uncertainty is inevitable. People often experience a time of great uncertainty on the shifting sand between hope and despair. I attempt to build a counselling relationship where a balance can be achieved between being alongside my client in this ambivalence and encouraging them to maintain some control over their situation. It is important to find out where the person is in relation to their understanding of their illness. Rather than ask questions, I encourage people to tell me the story of their illness and in recounting this, verbal and non-verbal clues appear which indicate their level of awareness, what people know about their illness and what they want to know or deny. People vary in the amount of reality they can bear and at some stage and for some people, denial serves a useful function. For example, denial can provide a break to assimilate painful facts. For others, the information and support to remain in control are crucial. Information is a vital part of remaining in control.

SUPPORT AT KEY STAGES

Diagnosis

At the diagnosis stage, medical information is obviously needed as well as information about practical and financial support available locally. Throughout the illness, different questions arise all the time and new information is needed. Problems which arise often divide into those which require practical information to make a concrete decision and those which concern feelings about dealing with the illness.

Later in the illness and facing death

As the illness progresses, the need to monitor what further help is needed and to assist both client and carer to make informed choices about future care is important in terms of pain control. Pain control can relate to physical, social, emotional and spiritual pain and the ability to assess which pain is uppermost is important.

Many of my clients who are terminally ill are able to remain at home for most of the time in the care of their GP and primary care team. This is often augmented by symptom control, day and respite care at St John's Hospice, other support services provided by CancerCare, the McMillan nurses and domiciliary care as assessed by social services.

At the centre of this network of care is the client who should always be centre stage but never more so than towards the end of life. Although it is almost impossible to predict when people will die, there are choices for those who are dying and their carers which should be made on the basis of information rather than advice. People often wish to remain

at home and sometimes there is a balance to be drawn between the person who wishes to remain at home and their carer who may be opposed. By talking through feelings

and fears and offering sufficient support, families often feel able to try.

Over the past five years, people have remained at home with excellent support from their GP and primary care team

working in conjunction with other cancer services. The crucial element is the main carer who often needs

intense emotional support. An important part of my social work role is to give the carer time and space to talk through the bewildering maelstrom of emotions, including love, anxiety, resentment, anger, fear and exhaustion.

Other people, particularly those with a poor support system, choose to have hospice care at the extreme terminal stage of illness and some people leave the decision as to what happens in the hands of their family and health professionals. However, this is still a choice. In a similar way, some people wish to go home from St John's for a short period and families need encouragement and support for this to happen. A joint assessment and a co-ordinated discharge can mean a final period at home is possible. Whether these choices have been given and fulfilled make an immense difference in bereavement.

BEREAVEMENT

This leads to the final social work role of bereavement counselling. As part of ongoing assessment and monitoring during the illness, issues of family dynamics, coping strategies and support networks regarding bereavement are noted. Feelings of grief may start long before death, for both the dying person and the family. It is possible to predict to some degree where a difficult bereavement is likely to occur and to offer bereavement support. The fact that a relationship is already established with the main carer and other vulnerable family members, provides a foundation for useful bereavement support.

CONCLUSION

The role of social work in a health-related setting often overlaps and complements the work of health colleagues. However, overlapping is preferable to leaving a gap in the fabric of care and it is suggested that social work can offer a particular expertise as part of the multi-disciplinary approach to people with cancer and their families. The accent is on multi-disciplinary work as no single person can provide total support. During the life of a person with cancer, there is available locally a wide range of professional and voluntary support. Often at different points in the illness, different elements of this support system will predominate as new needs arise. Knowledge of different roles, mutual respect for each other's expertise and joint working all contribute to effective and life-enhancing support.

Death is about loss and endings and bringing things to a close. We all know something about the art of dying because we experience and practice this art by our losses throughout our lives. One of the tasks for social work in palliative and terminal care, in common with all other services in these settings, is to help people acknowledge their ability to cope with impending and actual loss. I once read somewhere that the three essential qualities which distinguish any work of art are the expression of emotion, control and inner balance and these could also be said to distinguish the end of a well-lived life and a well-supported death.

“The crucial element is the main carer”

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