

**PSYCHOSOCIAL AND CANCER SUPPORT
SERVICES**

SEPTEMBER 1999

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FOREWORD

The Eastern Health Board's Department of Public Health was commissioned by The Department of Health and Children to undertake the first *National Review of Support Services for Patients with Cancer*. This document is the result of the review.

Cancer is one of the most important health problems in Ireland. Each year there are 20,000 new cases diagnosed and 7,500 people die from cancer. It is the second leading cause of death in Ireland. Surgical, medical and radiation oncology specialists constantly strive to ensure patients receive the very best treatment and that survival improves. The psychological impact of the diagnosis on health has been recognised. It is now evident that psychological ill health in cancer patients is a serious problem requiring a holistic and comprehensive approach to management.

A diagnosis of cancer can have an immense negative psychological impact on patients and families. Many people have difficulty in coming to terms with the illness and in living with cancer. At least 25% of patients develop depression and anxiety. This may lead to poor quality of life and contribute to reduced life expectancy. The prevention and management of psychological ill health due to cancer must, therefore, be an essential element of cancer treatment. In preparing this report the Working Party became aware of many distressing and serious psychosocial problems which patients with cancer endure.

The purpose of this document is to review current psychosocial support services for people effected by cancer and to propose a framework for the provision of an all-inclusive service. It highlights the psychological impact of cancer on people's lives by examining clinical evidence and by making known the views of patients and families, health service personnel and members of support and self-help groups. Recommendations are made for the development of a multidisciplinary service as part of a patient's cancer care plan. These recommendations should be implemented as a matter of urgency as it is now clear that immediate attention needs to be given to supporting patients in an organised and realistic manner.

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EXECUTIVE SUMMARY

Most patients and their families worry when diagnosed with cancer. This is normal and understandable. However at least 25% of patients develop psychological ill health, usually depression and anxiety. Psychological and social (psychosocial) problems can have a negative effect on a patient's quality of life and possibly on longevity. Untreated psychosocial morbidity can lead to impaired response to treatment and adverse clinical outcomes. Treating these disorders may improve disease outcomes.

The aim of this review is to make recommendations on the development and provision of cancer support services. The terms of reference are to:

1. Outline available evidence from published national and international literature on the types and value of different forms of cancer support
2. Identify best practice regarding cancer support
3. Describe the availability, delivery and type of cancer support services in Ireland, both statutory and voluntary
4. Identify gaps in this service
5. Make recommendations on the development and provision of cancer support.
6. Recommend training required by agencies to be effective in their role of providing support services

The report is divided into five sections.

Section one gives the evidence from the scientific literature of the impact of psychosocial ill health on patients and families, the necessary components of a comprehensive support service and the benefits of providing this service.

Section two describes the methodology used to conduct the review. Wide ranging consultation took place. The views of consumers, health service providers, support groups and self-help groups were obtained by conducting specific research and by analysing submissions received from placing advertisements in the national press.

Section three gives the results. The most notable finding is that our health service does not generally provide psychosocial support services for cancer patients in a structured and holistic manner.

An attempt was made to quantify the level of support services currently being provided. This proved to be an almost impossible task as responses were heavily influenced by individual views.

The main findings of the review were:

- Adequate formal psychosocial support services are not provided by the health service. Even within the hospital setting, support services were described as being haphazard and unstructured
- Psychosocial problems, though common, are under recognised and under treated
- Patients may not wish to report psychosocial symptoms due to the negative attitudes and stigma associated with them
- The needs of families are not being addressed in a coherent manner
- The current provision of psychosocial support services depends on a number of factors including, cancer type, place of treatment, degree of involvement by the oncology team with mental health personnel and support groups, the ability of the patient to ask for help and the availability of psycho-oncology services
- People have real anxiety when awaiting a diagnosis and diagnoses are sometimes given in an insensitive manner
- Adolescents have specific needs, including hospital accommodation
- Patients want full and timely information on all aspects of their disease, its treatment and their entitlements
- There is a high degree of satisfaction with palliative care services. However, waiting lists exist
- Bereavement support is usually not provided to families
- Self-help and support groups can provide important support to patients. However some groups do not use good-practice guidelines and training of volunteers is sometimes inadequate
- The provision of complementary and alternative cancer therapies is uncontrolled
- Patients regularly face practical difficulties when diagnosed with cancer, including financial, transport and accommodation costs.

Section four discusses the results and draws the following general conclusions:

- There is a lack of formal psychosocial support services for patients and families with cancer in Ireland
- Some patients do not have the opportunity of being treated by cancer specialists. This reported deficiency in the provision of oncology services contributes to patient distress
- Patients, health care providers, support and self-help groups recognise that psychosocial support should be an essential component of cancer treatment

- Psychosocial support services should be multidisciplinary; developed within existing health structures; available to all patients; at all stages of care and take account of the needs of the patient's family
- Adequately trained and skilled health personnel are needed to recognise distress and refer patients to appropriate services
- Health personnel who provide intensive treatment for patients with cancer require their own support system
- Good communication across disciplines, between hospitals and with community health services is needed to ensure continuity of care
- Lack of psychosocial support has led patients to seek support from other sources, including independent counsellors, some of whom have very limited or no links with the health service; this provision of counselling is uncontrolled
- Complementary and alternative therapies used in conjunction with conventional medical care can help to improve quality of life and are used by many patients.
- Unproven remedies that have no scientific basis are also being used. They are usually provided by unqualified persons who sometimes claim to cure cancer. Such remedies can be dangerous and have no place in cancer treatment.

Section five outlines the recommendations.

Recommendations

Key Recommendations

1. Every patient should have access to a cancer specialist, as appropriate, for diagnosis and treatment.
2. The management of a patient's psychological state should be an integral part of cancer care.
3. Each health board should provide multidisciplinary psycho-oncology services to manage distress in patients with cancer.
4. Each health board should ensure there is effective communication between all Programmes for individuals and care groups.
5. Information booklets, describing different cancers, their diagnoses and treatments should be widely available i.e. "A Directory of Cancer Illness and Care". They should describe recognised treatment regimes, social supports and entitlements for services.
6. Best practice criteria for providing cancer counselling should be developed and followed.

7. **Cancer self-help and support groups should subscribe to a “Declaration of Good Practice”. Where this happens and where groups show that they assist patients, health personnel (health board and voluntary hospitals) should collaborate.**
8. **Complementary cancer therapies may be beneficial and can be considered an integral part of care. All therapists, by whatever name, providing complementary cancer therapies should be registered and accredited by a professional organisation. Patients should be protected, if necessary through legislation, from unproven remedies which are sometimes advocated by non-health professionals.**
9. **Assistance towards accommodation and travel costs should be considered for patients, where appropriate, who must travel long distances for treatment.**

Development of psychosocial support services

1. Each health board, in consultation with regional cancer directors, should develop psychosocial cancer services in their area. Their proposals for developing these services should set out the necessary structures, systems, resources and implementation measures.
2. Health personnel should be trained and skilled in the recognition, screening, preliminary management and appropriate referral of patients suffering from distress.
3. Relevant health personnel both in hospital and in the community should receive training in communication skills.
4. Support structures should be put in place for staff who treat cancer patients intensively.
5. Health personnel including those in training should be made aware of the psychosocial impact of cancer on health.
6. Each health board should ensure there is effective communication between hospitals, general practitioners (GPs) and other community health services and patients. The role of the multi-disciplinary team approach should be enhanced and supported.
7. Best practice criteria for providing counselling to patients with cancer should be developed and followed. These criteria should include the necessary training and accreditation for counsellors.
8. Health boards and the National Cancer Forum should address the special needs of adolescents with cancer.
9. Bereavement support should be offered to all people who are bereaved by cancer.

Information

1. Comprehensive, high quality information booklets describing different cancers and their treatments should be readily available to patients at treatment centres: “A Directory of Cancer Illness and Care”. These should also include details of support networks and service entitlements.

2. A national expert agency should take responsibility for producing information booklets, with input from key professions. The Irish Cancer Society has a role in this regard.
3. The agency should also develop a web site for supplying information.

Self-help and support groups

1. Each cancer self-help and support group should subscribe to a “Declaration of Good Practice” that outlines its aims, objectives, and plans.
2. Guidelines should be developed to inform groups how best to deal with patients and their families in relation to cancer and in relation to professionals in the hospital and community setting.
3. Groups should source training for volunteers on a planned basis with national expert agencies and with health boards.
4. Patients should have the option to be referred to self-help and support groups that maintain high standards.
5. Self-help and support groups should remain autonomous but work in co-operation with the health service.
6. Health boards should co-operate with groups that adopt and implement good practice guidelines, where high standards are maintained and where there is evidence that patients benefit from involvement with the group.

Complementary and alternative cancer care

1. Complementary cancer therapies may be beneficial to patients and can be considered as an integral part of cancer care.
2. All therapists, by whatever name, providing complementary cancer therapies should be registered and accredited by a professional organisation. Monitoring of services should be undertaken together with procedures for dealing with patient complaints.
3. Unproven remedies are sometimes advocated. These are to be discouraged.
4. Patients, who may be vulnerable because of their illness or lack of insight, should be protected, if necessary through legislation, from such unproven remedies. In relation to alternative medicines, the Irish Medicine Board’s guidelines should be followed.

Practical aspects

1. Information leaflets describing all the various health and social welfare schemes and their eligibility criteria should be visibly available in all treatment centres, GP surgeries and health centres.

2. Supra-regional cancer centres should organise special B&B type accommodation for patients who must travel long distances for treatment. The Irish Cancer Society may have a role in this area. The proprietors of such B&B accommodation should be sensitive to the needs of their clients (and their special needs); it would be beneficial if they had some understanding of ‘cancer’ and some training in support.
3. Financial assistance towards the cost of transport should be considered in special cases for patients who travel long distances for treatment.

LITERATURE REVIEW

1.1 INTRODUCTION

It has long been accepted that patients may experience problems in rehabilitation following the surgical and medical management of cancer. More recently the psychological and social impact of a diagnosis of cancer on health has been recognised. It is now known that psychological and social ill health have a negative effect on quality of life (Presant 1984).

Research indicates that there is a link between providing support for patients with cancer and some positive outcomes including physical and psychological well being and social functioning (Caplin 1974, Kaplan *et al.* 1977, Bloom 1982, Broadhead *et al.* 1983). Health researchers, therefore, now regard the provision of support as an important part of cancer treatment and they emphasise the need for support systems to be developed within the care setting.

1.2 THE PSYCHOSOCIAL IMPACT OF CANCER ON THE PATIENT

The term “psychosocial” is commonly used to describe the psychological and social consequences of cancer. Psychosocial factors have a role to play in understanding cancer, not only in terms of behaviours which may be related its onset, but also in terms of the psychological consequences, the treatment of symptoms, improving quality of life and longevity.

Many of the psychological consequences of cancer can be understood as reactions to loss or threat of loss. A patient can react to the diagnosis with a variety of emotions including despair, fear, shock, anger, guilt or even acceptance. It can bring social isolation, role changes and financial insecurity (Freidenbergs *et al.* 1980, Reeley 1994, Jary and Franklin 1996).

Elisabeth Kubler-Ross outlined the sequences of emotional stages. These include:

1. Shock, denial, numbness and or disbelief
2. Anxiety, anger, bargaining and protest
3. Sadness and despair
4. Gradual acceptance

There can be considerable differences between people in the sequence of these reactions and the length of time they spend in any phase. This is influenced by a variety of factors, including the type of cancer, personality of the individual, the way the diagnosis is explained, the degree of delay in diagnosing the cancer, the individual's coping style, current life circumstances and religious beliefs.

Diagnosis is often accompanied by an immediate crisis situation. The time following diagnosis is a period of adaptation (Marchioro *et al.* 1996). The patient tries to adjust to the uncertainty and anxiety surrounding the illness and attempts to cope with possible alteration in bodily function and role.

Though many patients cope well, psychological problems are common. Depression is the psychiatric disorder most commonly found in patients with cancer (Craig and Abeloff 1974(a), Levine *et al.* 1978, Krouse 1982, Derogatis *et al.* 1983). Levine *et al.* (1978) reviewed 100 consecutive hospitalised cancer patients referred for psychiatric consultation. They found that 56 per cent were depressed. Craig and Abeloff (1974) reviewed 30 consecutive patients admitted to an oncology unit and found that 53 per cent suffered from moderate to high levels of depression.

Psychological disturbances are common following a diagnosis of breast cancer and its treatment. Between 24 to 38 per cent of patients were found to suffer from clinical levels of anxiety and/or depression with high rates of referral to psychiatrists (Schottenfeld and Robbins 1970, Craig *et al.* 1974, Winick and Robbins 1977, Levine *et al.* 1978, Fallowfield 1986, Payne 1989). Between 20 and 30 per cent of women with breast cancer experience a decline in their quality of life due to psychosocial consequences such as loss of role or role change, loss of functional abilities and problems with social relationships (Irvine *et al.* 1991). Some researchers found that women diagnosed with breast cancer experience more stress than other cancer patients (Liang *et al.* 1990). Women who have undergone a mastectomy are recognised as being in need of specific support interventions.

The type of support required by patients depends on a number of factors, including the type of cancer and the family situation. For example, young families with a child diagnosed with cancer are particularly in need of support (Monaco 1986). Although the type and level of support needed may differ between patients the psychosocial problems associated with a diagnosis of cancer are generally common to all patients (Holland 1999).

The stigma associated with the terms 'psychosocial', 'psychological' or 'psychiatric' may act as a deterrent to patients seeking help. For this reason personnel at the Memorial Sloan-Kettering Cancer Center, New York, recommend the more neutral term *distress* to describe a broad range of psychosocial conditions

(Holland 1997). This is in an effort to overcome the stigma and to encourage patients and families to discuss their situation in order to obtain appropriate diagnosis and be directed towards suitable treatment.

Distress is defined as:

“The range of feelings and emotions expressed by people with cancer as they face personal and illness related problems varying from the common normal feelings of vulnerability, sadness and fears related to the illness itself to more severe reactions that constitute discrete psychiatric disorders.”

The term, **distress**, implies a wide range of emotions from normal to severe; it is less associated with embarrassment and is more widely acceptable than the term depression or anxiety.

1.3 THE PSYCHOSOCIAL IMPACT OF CANCER ON FAMILY MEMBERS

A diagnosis of cancer in a family member is stressful for families. It can cause psychological and social problems for them and diminish their quality of life especially for a spouse or partner (Hinton 1994). Families, too, need support. (Muzzin et al. 1994).

While caring for the patient, caregivers may also be called upon to provide support to other family members which places additional strain on their own coping capabilities (Harrison *et al.* 1995). Harrison and co-workers found significant levels of psychological distress among key relatives of patients with newly diagnosed cancer. A study of breast cancer patients and their husbands found that husbands experienced the same amount of psychological morbidity as the cancer patient (Northouse 1988). Other studies have reported higher rates of psychological distress (Oberst *et al.* 1989), anxiety and depression among relatives than those found in the patients themselves (Hinton 1994).

Parents of children with cancer suffer high levels of emotional distress, (Eiser 1993, Sloper 1996) anxiety and depression (Mott 1990) particularly following diagnosis (Kupst 1992). They may also experience problems allocating their time between caring for their sick child and maintaining the family unit (Spinetta and Spinetta 1986, Sloper 1996).

Siblings of children with cancer are vulnerable to difficulties in adjustment following the diagnosis (Kramer and Moore 1983). Siblings may experience a similar level of stress to that of the sick child including high levels of anxiety, depression, fear of death and separation (Spinetta 1981, Kramer and Moore 1983). They may also experience loss of personal support and attention they need.

The risk of psychological morbidity increases when children are excluded from caring for patients, while children who are encouraged to participate in caring for a sick relative adjust more positively (Breyer *et al.* 1993, Lauer *et al.* 1985). Yet siblings are often overlooked while health professionals focus on the sick child and their parents (Laker 1988). Attention must be given to siblings, playmates and extended family, such as grandparents (Schuler *et al.* 1985).

By learning to cope with life threatening illness, families can maximise their role in caring for the family member with cancer (Spiegel *et al.* 1981, Nethercott 1993). In cases of breast cancer, spouses' reactions may be of fundamental importance to the patient's recovery (Souhami and Tobias 1987). Therefore, interventions cannot ignore the needs of the patient's family (Harding 1996). Caring for family's psychosocial needs can improve quality of life as caregivers with high levels of anxiety and depression are unlikely to be able to provide effective support to the patient.

1.4 PSYCHOSOCIAL SUPPORT AND THE CANCER PATIENT

Patients' ability to deal with the demands placed on them at a time of crisis is dependent on the availability and utilisation of support services (Lazarus and Folkman 1984). Supportive care and interventions aimed at minimising the psychosocial impact of cancer improves quality of life and is an essential part of cancer treatment (Montazeri *et al.* 1997).

In broad terms 'social support' can be defined as the resources provided by others (Cohen and Syme 1985). 'Social support' can be divided into four main components. These components overlap and are often difficult to distinguish from each other (Wortman 1984, Broadhead and Kaplan 1991, Galbraith 1995, Bottomley 1997):

- **Emotional support**, such as listening to the patient and expressing concern
- **Informational support**, providing information or advice (e.g. about prognosis and treatment)
- **Instrumental support**, tangible support such as caring for the patient's physical needs
- **Appraisal**, acknowledging the appropriateness of a patient's feelings or beliefs and giving feedback to the patient.

Most research has focused on emotional and instrumental support.

A number of outcomes have been associated with the utilisation of psychosocial support services including positive adjustment to a diagnosis of cancer (Northouse 1988, Vernon and Jackson 1989, Breitbart 1995),

less emotional distress and longer life (Spiegel *et al.* 1989, Suominen *et al.* 1995) and improved coping methods (Marchioro *et al.* 1996).

Supportive interventions cover a wide range of services:

- Information
- Support from health professionals such as stress management and relaxation techniques
- Psychological and psychiatric interventions such as individual psychotherapy, psychoanalysis, cognitive therapy and family therapy
- Counselling
- Support and self-help groups
- Complementary therapies such as massage and aromatherapy.

When first diagnosed cancer patients require support to deal with the fear and uncertainty surrounding their situation (Bottomley 1995). Family support can play a crucial role at this time although there may be a fear, on the part of cancer patients themselves, that their illness is communicable which leads them to avoid family and friends (Wortman 1984, Peters-Golden 1992). Hospital and community based support services can become an important resource to patients and help them overcome feelings of isolation and fear especially at stressful times, for example, prior to surgery.

There is a wide variation in the literature regarding the type of interventions which should be offered to cancer patients. For example, Stuart and Lieberman (1986) argued that all cancer patients, regardless of whether or not they appear to be in distress, should undergo some form of psychiatric assessment. Krouse *et al.* (1982) emphasised the need for crisis intervention at the time of the initial or terminal diagnosis, while other authors have called for continued intervention as individuals learn to live with the disease (Lewandowski and Jones 1988). Harrison *et al.* (1995) suggest that relatives should also be screened for psychiatric disorders.

The use of self-rating questionnaires or scales may prove to be a simple and effective way to identify cancer patients in need of additional support services (Roth *et al.* 1998). One tool for screening distress was developed by Holland (1997), 'the distress thermometer'. This allows patients to identify their level of distress on a scale of 1 to 10. Patients are screened using this tool at various stages of treatment and referred to appropriate support services.

The varying degrees of psychosocial distress make it essential that patients are able to access different types of support. The level of support necessary is dependent on each patient's needs (Northouse 1989)

and the type of cancer from which they are suffering. It is important to identify the problems specific to certain types of cancer and incorporate relevant interventions into specialist cancer treatment units (Perkins 1993).

1.4.1 Information

Information is a basic form of support. It is often cited by patients as a necessary but unmet need (Montazeri *et al.* 1996). Information relating to diagnosis, treatment and follow-up policies are important to patients' adaptation to the disease, allowing lifestyle changes and developing methods of self-care (Cassileth *et al.* 1980, Fredette 1990). Satisfying a patient's information needs helps them to take control of their illness (Fredette 1990).

A patient's information requirement must be satisfied before other forms of support can be properly utilised (Lewanowski and Jones 1988, Perkins 1993). Studies suggest that patients who receive good information are more satisfied with their care and show lower levels of anxiety and depression (Fallowfield *et al.* 1986). Lewanowski and Jones (1988) ranked information as one of the highest needs of patients, yet studies have found that patients received less information than they require about their illness and treatment (Suominen *et al.* 1995). This may be due to health professionals underestimating patients' need and desire for information (Suominen 1995 *et al.*, Strull *et al.* 1984).

The timing of information is important. At the time of diagnosis patients may find it difficult to absorb the information given to them (Fallowfield *et al.* 1990, Bottomley and Jones 1997). Therefore it is vital that patients can access information at all stages of their disease following diagnosis (Conkling 1989).

Providing information to the patient is an essential part of the patient's ability to adjust to the diagnosis and deal with the stress and anxiety that accompanies it. The key to success is to provide information at a rate with which the patient can cope.

Health professionals should also be clear on which members of the multidisciplinary team are responsible for providing information in order to avoid 'information gaps' or the giving of contradictory information (Van Wersch *et al.* 1997).

Treatment and procedures, which may seem routine to medical staff, are frequently cited by patients as being a major source of anxiety. Bottomley and Jones (1997) reported that patients would welcome the use

of video information on treatments and procedures and audio recordings of commonly asked questions in order to alleviate some of their anxiety.

1.4.2 Health professionals and support

Cancer treatment is multidisciplinary. Patients come into contact with a range of health professionals while undergoing treatment. All professionals involved have the opportunity to provide support. However, health professionals may be unfamiliar with the psychosocial needs of the patients in their care (Van Wersch *et al.* 1997).

Holland (1999) recommended that information on the psychosocial needs of patients with cancer should be given to all health professionals involved in the care of cancer patients. Health professionals also require training to recognise high levels of anxiety and depression, to be aware of the possibilities for referral and to identify the specific support services which may be of benefit to patients (Broadhead and Kaplan 1991).

1.4.3 The role of the physician in cancer support

The physician plays a central role in a cancer patient's treatment and recovery. The physician is the professional that most patients look to for both comfort and information (Northouse 1988). The quality of the time that physicians spend with their patient is of great importance. Patients need to know that their physician is interested in them and in their progress (Silberfarb 1988).

By providing uninterrupted time the physician can build a rapport with the patient while offering support. It also allows the physician to identify patients at risk from psychological problems and to assess the need for referral to other professionals or groups. Referrals to other professionals complement the physician's care and support of their patient by creating a network of psychosocial support between the physician, the hospital and the local community (Stuart and Lieberman 1986, Gates 1988, *a*).

While caring for a cancer patient the physician must also direct attention at the patient's family. Becoming acquainted with the patient's family circumstances will allow the physician to evaluate the amount of support available. Family members may also be suffering psychologically as a result of the diagnosis and may need referral to support services.

Identifying the needs of family members is important not only in their own interest but for the patient's wellbeing and recovery. For example, the inability of a spouse or partner to adjust to a mastectomy may

seriously inhibit a patient's recovery (Gates 1998 b, Schain 1988). Physicians need to initiate contact with the patient's spouse or partner and direct them to services which can offer practical support (Gates 1988 a, Silberfarb 1988). Physicians should receive training in counselling and communication to allow them to deliver support to patients in their care (Maguire *et al.* 1980).

Stuart and Lieberman (1986) suggest that all physicians, whether oncologists or general practitioners, should initiate the following consultation with a cancer patient on each visit.

- Obtain information relating to the patient's problem and what has transpired in their lives since the last visit
- Enquire about how the patient feels about what is happening
- Determine what is troubling them about an event or situation
- Ascertain how they are handling problems
- Empathise with the patient, therefore legitimising their feelings.

Silberfarb (1988) outlined a number of psychotherapeutic techniques that can be used by physicians when treating the psychosocial needs of cancer patients.

- See patients at regular intervals
- Listen to what the patient is saying, avoid premature reassurance
- Correct misconceptions about the disease, its treatment, and its pathophysiology
- Be realistic and straightforward with both patient and family, but allow them to maintain hope
- Assess the family's needs and offer preventive treatment
- Allow denial and regression within reasonable bounds
- Be aggressive in attempting to relieve physical discomfort
- Treat anxiety, depression, and insomnia pharmacologically, if necessary
- Keep staff conflicts away from patients.

1.4.4 The Role of the Nurse in Cancer Support

The nurse-patient relationship is frequently reported as being of great importance to patients. Patients regard nurses as a key source of information and support (Northouse 1988, Bottomley and Jones 1997). Galbraith (1995) found that patient satisfaction with nursing was significantly related to the perceived level of support received.

Nurses agree that psychological interventions are an important part of caring for the cancer patient (Frost *et al.* 1997). However many nurses are often reluctant to enquire about a patient's concerns and feelings, because they do not feel they have adequate training or the necessary skills (Maguire *et al.* 1995). Some nurses and other health professionals, may distance themselves from patients because they may lack the skills to handle the difficult problems and the strong emotions that may emerge if get into detailed discussion with patients and relatives (Maguire and Faulkner 1988). This suggestion is supported by Galbraith (1995) who found that nurses provide more instrumental and informational support than emotional support to patients.

Nurses are often in a key position to offer support but without the necessary training may not recognise psychosocial distress and, therefore, may not respond appropriately. Nurses should receive training in counselling and communication skills to allow them to help patients disclose their concerns (Broadhead and Kaplan 1991).

Jary and Franklin (1996) described the breast-care specialist nurse as a 'hospital based professional providing support and advice to the patient at an acute stage of breast cancer'. The aim of the breast-care specialist nurse is to help the patient adjust to her situation. By meeting with the patient on a one-to-one basis the specialist nurse can identify patients' specific needs and concerns. The specialist nurse can then offer support aimed at raising the patient's self-esteem and ultimately reduce anxiety.

A number of studies have been carried out to assess the effectiveness of a specialist nurse providing psychosocial support to patients with breast cancer (Maguire *et al.* 1980, Watson *et al.* 1988). One such study was carried out in a Manchester Hospital by Maguire *et al.* (1980). A specialist nurse was appointed and trained in counselling methods. The role of the specialist nurse counsellor was to counsel patients before and after surgery, to monitor their progress by visiting them at home and in follow-up clinics and to refer vulnerable patients for psychiatric evaluation.

Maguire *et al.* (1980) found that although counselling did not prevent psychosocial problems, nurse monitoring of patients' progress allowed her to identify patients in need of psychiatric help. As a result of the nurses' recognition and referral of patients, 12 to 18 months after mastectomy there was significantly less psychiatric morbidity in the counselled group.

Maguire *et al.* (1982) found that counselling schemes using a specialist nurse are necessary and effective and may be implemented at little extra cost. The costs to the NHS of employing a specialist nurse to help women with breast cancer were almost wholly offset by the long-term savings made.

1.4.5 Psychological and Psychiatric Intervention

Various psychological and psychiatric interventions have been used to improve patients coping behaviour during the course of their illness (Worden and Wiseman 1984).

Individual therapy, namely psychotherapy, has been shown to be effective in helping patients overcome psychological problems associated with cancer (Moray *et al.* 1994, Spiegel 1992) and to adjust to their diagnosis (Greyer *et al.* 1992). It has been shown to be useful in reducing patient distress, anxiety and depression (Forester *et al.* 1985).

A number of studies examined the role of cognitive behavioural therapy in the treatment of cancer patients. The aim of cognitive behavioural therapy is to enable patients bring about desired change in their lives by assisting them in dealing with the effect of their illness on their self-esteem and self-image, coping ability, physical limitations, control of pain, and the effects of therapy. Cognitive behavioural therapy is an effective way of dealing with negative attitudes to the illness while improving self-confidence and control (Farmington 1994, Moray *et al.* 1994) and reducing long-term psychiatric morbidity (Greer *et al.* 1992).

Marchioro *et al.* (1996) examined the effect of cognitive psychotherapy on quality of life in non-metastatic breast cancer. The intervention which consisted of weekly individual cognitive psychotherapy sessions with a psychologist was aimed at improving quality of life and coping methods. The intervention helped patients deal with major problems experienced as a result of their diagnosis and treatment including resultant anxiety and depression and poor coping. Cognitive strategies have also been shown to improve patients' self-worth and their ability to be close to others (Taylor 1983).

There is substantial evidence on the effectiveness of group interventions (Spiegel 1981 *et al.*). This approach has been associated with improvements in self-esteem and psychological adjustment to cancer (Ferlic *et al.* 1979), in levels of depression and anxiety and in coping skills (Vachon and Lyall 1976). One advantage of group interventions as opposed to individual interventions is that patients benefit from meeting other patients experiencing similar problems.

A small number of studies examined the effectiveness of group cognitive behaviour therapy interventions (Telch and Telch 1986, Fawzy *et al.* 1990, Fawzy *et al.* 1993, Bottomley 1996). Studies have reported reduced psychological distress (Fawzy *et al.* 1993), reduced levels of depression and anxiety (Telch and

Telch 1986, Bottomley *et al.* 1996), higher levels of vigour (Telch and Telch 1986, Fawzy *et al.* 1993) and improved coping skills (Bottomley 1996).

Fawzy *et al.* (1990) examined the effect of a six-week, broad based, structured cognitive behavioural therapy group intervention for post-surgical patients with malignant melanoma. Intervention included health education, problem solving skills, stress management and psychological support. At six-month follow-up the intervention group showed significantly lower depression, fatigue, confusion, and total mood disturbance as well as higher vigour.

Spiegel and Bloom (1989) carried out a prospective study to assess the benefits of a one-year group intervention on patients with metastatic breast cancer. Weekly psychological support groups for patients were facilitated by a psychiatrist or social worker and a therapist who herself had breast cancer in remission. Physical problems such as the side-effects of chemotherapy or radiotherapy were discussed along with self-hypnosis strategies for pain management. After one year the intervention group had lower mood disturbances, fewer maladaptive coping responses and were less phobic than the control group. At 10-year follow-up, the survival time for the intervention group was significantly longer than those in the control group, on average 18 months longer. Spiegel and Bloom (1989) suggested that the support group allowed patients to mobilise support systems available to them and as a consequence patients were more able to comply with medical treatments and reduce depression.

1.4.6 Counselling

Burkhalter (1978) described counselling as a dynamic process of problem solving directed at maintaining or improving the patient's quality of life. The role of the counsellor is to establish a therapeutic relationship in a supportive environment while seeking to achieve the goals of counselling.

In a general hospital the work of counselling patients with cancer and their families is made easier where much of the inpatient treatment is in a specialised unit. There is also a great benefit in having medical social workers who specialise in cancer working within the unit (Souhami and Tobias 1987).

Counselling has been shown to be effective in helping patients' cope with psychosocial problems associated with their illness (Watson *et al.* 1988). It can reduce depression following initial diagnosis, however it must be continued to maintain its effectiveness.

Other studies have reported no such benefits from counselling. Reece (1994) carried out a study to examine the effect of counselling on the quality of life of cancer patients and their families. No significant difference was found between patients who received counselling in addition to support groups and patients who only attended support groups.

Some authors argue that counselling is a neglected area in cancer care (Montazeri 1996, Sloper 1996). Montazeri *et al.* (1997) found that only a minority of cancer patients participating in support groups had received any counselling. Maguire and Faulkner (1985) suggests that patients do not receive adequate counselling because health professionals lack the training necessary to counsel patients in their care.

In the United States, Sorensen and Liu (1995) established a psychosocial support service for breast cancer patients. The model is based on the use of a 'patient counsellor' who provides psychosocial care in the oncology unit. The development of this type of service was based on criticisms that separating the oncologist from psychosocial care placed additional hardship on patients. Key elements of the service include:

- A 'patient counsellor', trained in clinical social work and psychotherapy, was placed within the oncology unit and integrated with the physician's service
- The patient commences consultation with the 'patient counsellor' prior to attending the physician
- The counsellor is included in the patient's initial oncology visit in order to assess the patient's emotional state and their interaction with the oncologist
- The counsellor may have further consultations with patients between scheduled clinic visits, during chemotherapy treatment or on scheduled clinic visits while the patient is awaiting consultation with the physician
- The counsellor's meeting with patients are designed to:
 - Assess the patient and family's psychosocial history, their social support structures and their current concerns
 - Provide the patient and family with information on the illness, the treatment process and how to access educational and financial resources
 - Refer patients to other hospital or community based programmes
 - Refer vulnerable clients to a psychiatrist for further evaluation.
- Important information is communicated to physicians and nurses to encourage careful approaches to personally sensitive issues
- The patient counsellor frequently follows up patients by telephone
- The counsellor may arrange meetings between patients
- The counsellor can assess the need for other hospital and community based programmes.

Eighteen months into the service Sorensen and Liu (1995) reported increased awareness among physicians and nurses of the specific psychosocial needs of patients and greater patient satisfaction with all aspects of their care.

Counselling can be undertaken by a wide variety of health professionals depending on the aim of the counselling (e.g. nurses, social workers, doctors, psychologists, and psychiatrists).

1.4.7 Support Groups

Support groups are facilitated by trained health professionals (Lieberman 1988). The role of the facilitator is to promote open discussion among patients about emotional, practical and physical problems they have encountered and on how to cope with illness.

A large number of studies suggest that many problems experienced by cancer patients can be reduced through their participation in support groups (Young 1986, Lieberman 1988, Mott 1990, Montazeri *et al.* 1997). A diagnosis of cancer can create a sense of alienation for both patient and family members. Support groups, comprising of people who share a common experience or condition, provide an opportunity for patients to discuss their problems with fellow sufferers (Souhami and Tobias 1987, Bauman *et al.* 1992). Spiegel (1992) suggests that support groups help patients to take control of their own lives. It allows them to establish social networks, express anger, and avail of other social supports available.

Participation in support groups has been associated with improved methods of coping and adjustment (Maisiak *et al.* 1981, Spiegel *et al.* 1981). Studies found that support group participants had lower mood disturbances, lower maladaptive coping responses and less psychiatric morbidity (Spiegel *et al.* 1981, Cella and Yellen 1993). Few studies have found support groups to be ineffective (Welch 1981, Jacobs 1983).

Lieberman and Borman (1979) found that patients attending support groups did so with a desire to share common experiences and learn specific processes that would lead to help. Unlike psychological intervention groups, support groups are largely unstructured. Patients play a lead role in deciding the content of meetings. This distinguishes them from psychiatric or psychological intervention groups whose structure is more formal and based on defined methods of therapy.

1.4.8 Self-help Groups

Self-help groups are generally formed by former patients who found that their psychosocial needs were not being met within the formal care setting. Self-help groups have only limited facilitation by a fellow patient and are often under the direct control of the members themselves. They are self-governing and self-regulating, they decide on what services are offered and the techniques employed. Lieberman and Borman (1979) found that for patients in self-help groups the emphasis was on participating in the group as opposed to how they would benefit from that intervention.

Although self-help groups thrive on autonomy and self-rule they do not always exist outside the realm of the health profession. Health professionals are often involved in the establishment of such services and continue to be involved while the service is in operation, offering advice, support and delivering talks to members (Lieberman and Borman 1979, Muzzin *et al.* 1994).

Self-help groups may benefit from health care professionals referring patients to the group (Lieberman 1988). Patients' willingness to participate in such groups has been found to be significantly associated with their referral to the group by a health professional. Fears that participation in self-help groups may lead to negative attitudes towards medical personnel are unfounded (Monaco 1986, Chesler and Barbarian 1984, Lieberman 1988). Chesler and Barbarian (1984) found that parents of children with cancer attending self-help groups had a more positive attitude towards the medical staff caring for their child. For these reasons a number of authors consider that health professionals must support, encourage and help maintain existing self-help groups (Lieberman 1988, Monaco 1988, Muzzin *et al.* 1994, Montazeri *et al.* 1997).

1.4.9 Complementary and alternative therapies

Complementary and alternative therapies are those which generally lie outside the realm of conventional, mainstream care (Downer *et al.* 1994). Studies estimate that between 7-72% of cancer patients use complementary or alternative cancer therapies (Ernst and Cassileth 1998, Oneschuk *et al.* 1998, Adler 1999). Some of the variation in the number of patients found to be using such therapies can be attributed to the way in which different studies define what constitutes alternative or complementary therapy and patients' understanding of what is meant by these terms (Gray 1998).

Cassileth (1999) suggests that a distinction must be made between treatments or therapies used instead of conventional medicine and therapies which are applied in conjunction with conventional medicine. He defines **complementary cancer therapies** as those which are applied in conjunction with conventional medicine. They aim to improve quality of life and to improve symptom control. They may include

complementary and alternative therapies when provided in association with mainstream medical care. On the other hand Cassileth (1999) suggests that **alternative cancer therapies** be defined as products and regimens promoted for use instead of mainstream cancer care. Such therapies may claim to cure cancer. They are unproven and are often invasive and costly.

Studies suggest that the use of complementary cancer therapies has increased in popularity among cancer patients however only a small percentage of cancer patients reject conventional medicine for alternative cancer therapies (Oneschunk *et al.* 1998, Cassileth 1999, Fitch *et al.* 1999).

Complementary cancer therapies can be of benefit to patients when used in conjunction with routine oncology care (Cassileth 1999). Therapies, such as aromatherapy and massage, have been associated with a number of positive outcomes including reducing stress, anxiety, improving symptom control and improving quality of life (Kite *et al.* 1998, Cassileth 1999). For this reason some researchers have advocated the development of a more integrated system of care where the use of complementary therapies is accepted and encouraged (Milton 1998, Wyatt *et al.* 1999).

Patients are often reluctant to disclose their use of complementary cancer therapies to health professionals fearing a negative response (Downer *et al.* 1994, Adler *et al.* 1999). Patients reported thinking that their physician would be disinterested in their use of complementary cancer therapies or that their physician would be unable or unwilling to provide any useful information (Adler *et al.* 1999).

Health care professionals need to be aware that some patients use complementary cancer therapies in conjunction with conventional care (Gray 1998, Wyatt *et al.* 1999). However, patients need to be educated about the safety and efficacy of some therapies so that they can make informed choice and minimise any associated risks (Gray 1998). Studies have shown that nurses and physicians recognise the need for more information on complementary cancer therapies to be given to both patients and health professionals (Gray 1998, Fitch *et al.* 1999).

1.5 SUMMARY

The psychosocial problems associated with a cancer diagnosis have a dramatic effect on patients' quality of life. Support services must be recognised as an important part of the care of cancer patients and incorporated into routine care (Bottomley and Jones 1997).

The psychosocial problems associated with a cancer diagnosis can be experienced by all cancer patients at all stages of their illness – at the time of diagnosis, during treatment, after discharge, during follow-up and on recurrence (Holland 1999).

A diagnosis of cancer can also have serious psychosocial consequences for the patient's family. Addressing family needs can improve the patient's and family's quality of life. Caregivers suffering from high levels of anxiety and depression are unlikely to be able to provide support to the patient. Therefore, supportive measures must also be directed towards the family.

Patients and their families must be educated on the importance of informing health professionals about any emotional and social problems they encounter (Holland 1999).

The stigma associated with psychosocial problems may prevent patients from informing health professionals about problems experienced. Psychosocial problems associated with a cancer diagnosis should be referred to as 'distress' rather than other words such as 'emotional', 'psychological' or 'psychosocial'.

Information is an important form of support. Information relating to diagnosis, treatment, follow-up policies and preventive strategies are vital to patients' adaptation to the disease.

As the treatment of cancer is multidisciplinary Support systems must also be multidisciplinary in nature. All health professionals involved in the care of cancer patients have the opportunity to provide support. Health professionals should receive information and training on how to recognise patients experiencing high levels of distress and the possibilities for referral. The use of self-rating questionnaires or scales may prove to be a simple and effective way to identify cancer patients with high levels of anxiety or depression (Roth *et al.* 1998, Holland 1999).

Varying degrees of psychosocial distress require that a wide range of support services are available including psychological/psychiatric services, counselling, information, complementary cancer therapies, self-help and support groups.

METHODOLOGY

2.1 INTRODUCTION

This chapter gives details of the aims, terms of reference and the methodology employed.

2.2 AIM

The aim of this review is to make recommendations on the development and provision of cancer support services. The terms of reference are to:

- Outline available evidence from published national and international literature on the types and value of different forms of cancer support
- Identify best practice regarding cancer support
- Describe the availability, delivery and type of cancer support services in Ireland, both statutory and voluntary
- Identify gaps in this service
- Make recommendations on the development and provision of cancer support
- Recommend training required by agencies to be effective in their role in providing support services.

2.3 DEFINITION OF TERMS

The term **‘support’** includes services such as information, support from health professionals, psychological therapy, self-help and support groups and complementary cancer therapies. It also describes practical support such as information on entitlements, financial advice and domestic support.

A cancer patient can receive support from a wide variety of sources including physicians, nurses, social workers, psychologists, psychiatrists, support groups, self-help groups, family and friends.

2.4 METHODOLOGY

At the outset a number of organisations in the United Kingdom, Canada and United States were consulted to obtain information on how cancer support services were organised and delivered in their respective countries. Senior health service managers in hospitals and health boards in Ireland were informed that a review of cancer support services was being undertaken and their views on current services were sought.

On identifying the broad areas to be addressed the following steps were taken to document current psychosocial support services available and to ascertain the views of key persons on the development of future services.

- (1) Submissions were sought from interested persons and organisations
- (2) Voluntary support and self-help groups were interviewed
- (3) Health boards and voluntary hospitals were surveyed
- (4) GP units in each health board were surveyed.

2.4.1 Submissions from interested persons, groups and organisations

An advertisement was placed in two national newspapers (*Appendix I*). Interested persons and groups, both statutory and voluntary, were invited to make submissions on their views of current cancer support services and the development of services within hospital and community settings.

People who had availed of any cancer support service were asked to describe

- their experience of using support services including their availability, diversity and value both to themselves and their family
- their views on what services are needed
- how the services they identified should be provided to achieve a comprehensive cancer support service.

Service providers were asked to provide information on:

- the availability and adequacy of support services in their region and profession
- their views on what services are needed
- how the services they identified should be provided to achieve a comprehensive cancer support service.

2.4.2 Survey of voluntary support and self-help groups

A survey of all known voluntary support and self-help groups in Ireland was carried out using a semi-structured interviewer administered questionnaire (*Appendix 2*). Each group was first informed of the purpose of the review.

2.4.3 Survey of Health Boards and Voluntary Hospitals

A survey of health boards and voluntary hospitals was carried out using a structured self-administered questionnaire (*Appendix 3*). Its purpose was to document current hospital based cancer support services and to seek the views of hospital personnel on the development of cancer support services. The Chief Executive Officer of each health board and voluntary hospital was contacted and asked to nominate a person to take responsibility for ensuring that questionnaires were completed by all relevant personnel.

The questionnaire was made up of 10 sections.

- General information was sought on the type of services available in the hospital.
- Surgeons, physicians, nurses and members of the palliative care team were asked to describe their role in providing support, the need for support services, the strengths and weaknesses of existing hospital and community based support services and their views on the development of cancer support services.
- Social workers, psychologists and psychiatrists were asked to detail the number of cancer patients referred to them, the main sources and reasons for referral and the strengths and weaknesses of existing hospital and community support services and their views on the development of cancer support services.
- Public health nurses and community social workers were asked to outline their role in the care of cancer patients and developments they would like to make to the service. They were also asked to state what they regarded as the strengths and weaknesses of existing hospital and community support services and their views on the development of cancer support services.
- General Practice Units of each health board were asked for their views on the strengths and weaknesses of current hospital and community support services and on the development of cancer support services.

RESULTS

3.1 SUBMISSIONS AND SURVEYS

3.1.1 Submissions from interested persons and organisations

One hundred and sixty-two submissions were received in response to advertisements placed in the national press. These included 116 submissions from individuals and 46 from groups or organisations (*Appendix IV*).

3.1.2 Survey of voluntary self-help and support groups

Thirty-one voluntary support and self-help groups were identified nationally (*Appendix VI*). Twenty-eight agreed to take part in the survey. One group refused, giving the reason that they had made a submission, and two groups could not be contacted during the study period.

3.1.3 Survey of health boards and voluntary hospitals

All health boards participated in the study. At least one major hospital in each health board and all hospitals designated as regional cancer centres took part. In addition some general hospitals also participated.

Not all hospitals completed all ten parts of the questionnaire (*Appendix III*). There were 121 responses. Responses to the following sections were received: General information (12); Surgery (9); Medicine (11); Nursing (32); Palliative care (13); Social work (9); Psychology (10); Psychiatry (6); Public health nursing (13); Community social work (6).

Though one of the objectives of this research was to quantify the level of psychosocial support currently being provided by the health service and other agencies, this proved to be an almost impossible task. Many responses were heavily influenced by individual views on the adequacy of their own service rather than reflecting objective descriptions of available services. Quantitative data on services were gathered but as they are incomplete and unrepresentative, they are therefore not presented in this report. Consequently these results are qualitative in presentation. All the major themes raised by contributors to the review are presented.

3.2 AVAILABILITY OF PSYCHOSOCIAL SUPPORT SERVICES

It was stated that formal support services cannot be mobilised until psychosocial services are first recognised as an integral part of the care given to cancer patients. Lack of formal psychosocial support was felt to be due, in part, to the fact that such services are not perceived as being an essential part of cancer care.

"For a comprehensive cancer service it is first necessary to recognise that with physical illness comes psychological distress. This concept underpins the provision of a patient-focused service."

Health professional

"There is a deficiency in our psychosocial support of patients with this devastating disease. The diagnosis of cancer of any type is devastating for most people and I find people take much longer to come to terms with their disease than they do to get over surgical or chemotherapy treatment".

Health professional

Patients stated that their support requirements, ranged from companionship with people who had undergone a similar experience to treatment for anxiety or depression. This support was considered to be lacking in hospitals and in the community. Most patients felt that this conveyed a lack of interest or understanding of the 'holistic' dimension of their condition.

3.3 THE DEVELOPMENT OF PSYCHOSOCIAL SUPPORT SERVICES

All respondents considered it essential to develop structured psychosocial support services to enhance patients' quality of life and to help them adapt to the diagnosis.

"Men and women are so fearful of cancer that they are afraid to even think about it, even when there are obvious signs and symptoms present. Despite the developments in cancer treatments and better symptom control, patients still encounter great difficulties. Surely some of the fears could be addressed through better psychological care."

Health professional

Many suggestions were made on the development of psychosocial support services and most respondents agreed that services should take account of the following points:

Psychosocial support services should be:

- multidisciplinary
- developed within existing health structures
- available to all patients.
- available throughout all stages of a patient's care and
- take into account the support needs of the patient's family.

- **Psychosocial support services should be multidisciplinary in nature.**

"Patients with cancer need care delivered in a structured manner by a multi-professional team."
Health professional

Respondents urge a team approach to psychosocial support. Members of the team may include: oncologists, radiotherapists, surgeons, oncology nurses, other nurses, psychologists, psychiatrists, social workers, pastoral care workers, pharmacists, general practitioners, public health nurses, dentists, physiotherapists, radiographers, occupational therapists, speech and language therapists and phlebotomists.

- **Psychosocial support services should be developed within existing health structures.**

"The hospital setting has many advantages which would facilitate the development of support services. Hospitals have multidisciplinary teams, the medical knowledge, the professional input and specialist nurses."
Voluntary group

The basic structures required to enhance psychosocial supports are already in existence, both within the hospital and the community.

- **Psychosocial support services must be made available to all patients.**

Continuity of care and quality of service was emphasised for all patients regardless of their address. Cancer treatment centres should have access to a wide range of support services.

- **Psychosocial support services should be available throughout all stages of a patient's care.**

"Care has to be provided at all stages of the cancer journey. Areas that require support are the pre-diagnostic, diagnostic, remission, relapse and end of life phases. The development of cancer support must consider these critical events"
Health professional

Support should be available to patients while awaiting diagnosis, at the time of diagnosis, during treatment, on discharge from hospital, at relapse and at the terminal stage of the disease, through to bereavement aftercare.

- **Psychosocial support service must take into account the support needs of the patient's family**

Many respondents felt that the psychological and social needs of family members are often neglected and that the special needs of children should also be addressed.

“As well as taking into account the needs of the patient a cancer support plan should consider the family's needs. Patients' families often experience distress. It is also accepted that care of a family's psychological and sociological needs can reduce the demand on a patient at the time of treatment and improve their treatment experience.”

Health professional

“Siblings are a group presently very hidden and not receiving an adequate service. Cancer is recognised for its effects on all family members and social work input for this group is long overdue”

Health professional

3.4 HOSPITAL BASED CANCER SUPPORT SERVICES

3.4.1 Awaiting the diagnosis

Awaiting diagnosis was described as a stressful time. Waiting in a busy clinic, queuing for appointments and investigations and anticipating bad news are worrying times. A number of respondents suggested that patients should be given some form of support while awaiting their diagnosis.

“I was given a letter from my GP to go to the breast clinic. However when I rang the breast clinic to make an appointment I was told by a nurse that they were booked up for a month.”

Patient

“I was horrified to see over a hundred patients sitting in a number of waiting rooms and corridors, with no information or support available to them. I was seen after a few hours.”

Patient

“There are women and men who don't want to tell anyone about their health worries and who are particularly unwilling to talk to doctors about them. Where symptoms are present a fear of diagnosis may be the driving force behind a person's unwillingness to communicate with health care professionals. The development of organised professional support for people may encourage people to come forward sooner”.

Voluntary group

3.4.2 Giving the diagnosis

The need for patient and family support at the time of diagnosis was emphasised. Most respondents were dissatisfied with the level of support provided at this time and the manner in which patients were told about their diagnosis.

"At 8.30am one morning in April...my late husband was diagnosed with terminal cancer. There was no family member present, and the doctor left him on his own to try and deal with this in whatever way he could. When I came in to visit by chance, at 9.15am I found him sitting alone in the corridor. He then had to tell me the diagnosis and ask me to try and find the doctor to get further information".

Family member

"Situations where a cancer diagnosis is given while standing in a busy corridor or where a patient is given a diagnosis and then left alone to deal with the devastating news are all too common".

Voluntary group

"We want patients to be given their diagnosis in a gentler way, in private and with time given to them. It is hit and run a lot of the time with patients questions left unanswered".

Voluntary group

"Support is needed at the time you are told you have cancer, what a traumatic time it was for myself and my family, to say nothing about the time waiting to hear how far the cancer had spread."

Patient

Respondents felt that physicians should be more aware of the distress of a cancer diagnosis and consequently be more sensitive when informing patients of their diagnosis. It was suggested that physicians should receive training in communication skills as part of their overall training.

"It is the experience of the Medical Social Work Department that communication with patients and families needs to be improved. Junior hospital doctors have acknowledged to social work colleagues that they are not adequately trained in the area of giving bad news to patients and their families."

Health professional

It was suggested that physicians should ensure patients are informed of their diagnosis in a suitable and private environment with a family member present. Respondents also advocated that a professional be made available to patients and their families at the time of diagnosis to offer support and advice.

"Hospitals should recognise the benefits accruing from the provision of an on-site professional who is available, where there is a need, to give specialist support to patients and their families directly after diagnosis has been given."

Voluntary group

“Support is needed at the time you are told you have cancer. The doctors try their best to explain everything but believe me you don’t take in a word they say, as you are so traumatised”.

Patient

3.4.2 Access to psychosocial support services during treatment

Most respondents regarded current psychosocial support services within hospitals as ‘haphazard’ and without structure. Consequently only those patients visibly in need of support are presently receiving a service.

“It is accepted that 30-40% of cancer patients need the services of a psychologist or psychiatrist. However only those visibly distressed and/or those who ask for help are treated.”

Health professional

Even existing supports within the hospital are not readily available to patients and their families. Support from professionals is usually provided when patients specifically request it but is not offered to them as a matter of course.

“During my diagnosis and treatment I was not aware or made aware of any services available to me”.

Patient

A number of respondents illustrated this point when discussing the role of social workers within the hospital. While patients are often aware that social workers were available in most hospitals, their role in providing emotional support is not widely known. As a result only a small percentage of patients are offered or avail of this form of psychosocial support. Patients should be made aware of all support services available from the various professions.

Increasing the awareness among patients and health professionals of psychosocial problems may increase the use of existing support services. It was suggested that information campaigns could increase awareness and also de-stigmatise psychosocial problems.

3.4.3 The Role of Health Professionals in Providing Support

Health professionals were regarded as being in a key position to offer support to patients. While patients praised the support given by health professionals many felt they do not appear to have the time to provide the level of support required.

“Nursing and medical care cannot be faulted, but in each instance I would say that emotional and psychological care was minimal to put it mildly. I do not feel that it is an unwillingness to help in this regard, but nursing and medical time is very limited.”

Patient

"To date psychological support has been provided mainly by nurses who often have no formal counselling background or experience."

Health professional

"All health care professionals who come into contact with cancer patients should, as appropriate to their level of contact, provide support to patients."

Voluntary group

It was suggested that all health professionals responsible for the day-to-day care of cancer patients should receive information and training on the psychosocial needs of patients. This would enable them to recognise distress, provide a basic level of support, when and where appropriate, and ensure that all patients in need of further support are identified and referred.

"If a patient needs further psychological help I must be observant enough to recognise this".

Health professional

A number of health professionals suggested that the development of a simple screening procedure would assist them in assessing the psychosocial needs of patients. This screening tool or procedure could be used at the time of diagnosis, during and at the end of treatment. This would enable patients with psychosocial problems to be identified and referred to other professions or support groups thus increasing the network of support between key personnel, the hospital and the community.

The need for a suitably qualified '*contact person*' to be allocated to each cancer patient on their admission to hospital was emphasised. It was suggested that this person could clarify any questions patients had relating to their condition, treatment and care. It was envisaged that this person would provide on-going support and advice and inform the patient of other support services and groups. While offering patients continued support throughout their illness this '*contact person*' would develop a rapport with patients allowing them to identify those in need of additional psychosocial support. Patients themselves emphasised the importance of having some person who is '*a constant*' throughout their treatment to liaise with general practitioners and other community health professionals.

Respondents diverged in their views on a suitable '*contact person*'. Some argued that social workers were in a key position to address these needs while others thought that specialist or liaison nurses should fulfil this role.

Health professionals considered that the co-ordination of the multidisciplinary team members needs to be improved to facilitate their role in psychosocial support. They made several references to the lack of structure and co-ordination between members of multidisciplinary teams caring for oncology patients. They also considered that insufficient time is given to discussing patient care plans and for receiving input from all team members. They also recommended a more structured and co-ordinated approach to cancer care and support between the various professions and agencies involved in the delivery of cancer care (i.e. between hospitals, community and voluntary agencies).

Some respondents suggested that oncology units should have an area where patients and their families can drop in and receive counselling or just chat in a welcoming environment. Trained staff should provide such services, with hours of opening and services offered posted clearly in oncology wards.

Counselling services available within hospitals was considered inadequate, including access to psychologists and psychiatrists. Health professionals recommended that such services should be available in all cancer centres. Respondents considered that counselling be available to patients while awaiting diagnosis, at the time of diagnosis, throughout their treatment, during relapse and during the terminal phases of the disease.

“We feel there is a need for a counselling service for spouses and families of patients. This should be available from the point of diagnosis. Such services should be available even after hospital discharge”.
Health professional

3.4.4 Support for Health Professionals

Health professionals believe that in order to provide patients with the necessary emotional and practical support they require a support system.

“There is no support for nursing staff working with cancer patients. We need debriefing sessions, coping skills and personal development. If this area is ignored it will affect how dedicated staff provide a quality service in the future.”
Health professional

“It is fundamental that the increasing demand placed on health care professionals be accompanied by a support and debriefing service”.
Health professional

“Psychological support for health care professionals is essential to the provision of a comprehensive cancer support system”.
Health professional

A support system for staff could include clinical supervision, support from colleagues, counselling and debriefing sessions. Health professionals felt that this would enable professional development and prevent burnout.

3.4.5 Adolescent Cancer Services

Adolescents with cancer were considered to be a distinct group of patients who can be highly vulnerable. They have specific needs. Child or adult units were not regarded as equipped to address these needs. Respondents strongly advised the development of a haematology and oncology unit for adolescents in a national centre with out-reach facilities to regional units.

“(Some teenagers) have been treated in children’s hospitals and others in adult units as there is no specialist adolescent centre in this country at present. Teenagers have distinctive and different needs and these should be recognised and provided”.

Voluntary group

“At the moment teenagers receive their treatment in an adult unit. The cure rate for children is better than adults and it can be very upsetting for teenagers to see people dying. A unit attached to a children’s ward would be better”.

Voluntary group

“ At present children as young as thirteen are being treated in adult hospitals and 17 year olds in paediatric units.”

Health professional

3.5 COMMUNITY PSYCHOSOCIAL SUPPORT SERVICES

3.5.1 Discharge from hospital

Post hospital discharge was described as a difficult time for patients when they often feel isolated and vulnerable as contact with health professionals diminishes. Lack of continuity of care causes distress and prolongs a patients adjustment after treatment.

“Once all my treatment was over I was relieved and expected to get back to normality and routine. However this was not the case ... I became quite depressed and the shock of what happened to me and the treatment I had to go through only started to hit me. Nothing or no-one can prepare you for the after-effects of the treatments.”

Patient

“ We felt isolated when we were away from the hospital as we knew that in the event of a temperature or something else...that the people close to us were unaware of the situation – this feeling of isolation is underestimated by professionals. To go from living within an oncology unit to returning home with a child who could get very ill is a daunting prospect”.

Family member

“When a patient is discharged from hospital everyone expects him/her to get on with things as normal, but things aren't normal anymore. But all the support given to patients in the hospital by the nurses is gone and they have nobody to talk to”.

Voluntary group

Disappointment was expressed regarding the transfer of information from hospital to community. Support services were considered essential within the primary care setting in order to improve continuity of care. A hospital co-ordinator was considered as necessary to liaise with general practitioners and other community health professionals.

3.5.2 The role of community health professionals

It was suggested that community health professionals such as, primary care physicians, public health nurses, community social workers, occupational therapists, physiotherapists and psychologists should become more involved in the care of cancer patients following their discharge from hospital. A multi-disciplinary team approach was considered as important as was the particular role of the GP and of the key worker (who may be the GP). GPs were seen as being well placed to recognise psychosocial distress; however they were considered under-utilised in their role of providing support. Some respondents suggested that patient held records and GP training may increase GP input and assist continuity of care on discharge.

It was argued that few community health professionals are trained in the care and support of cancer patients. Respondents suggested that community health professionals trained in the care of cancer patients should make contact with patients after their discharge from hospital in order to assess their needs.

“Social workers are needed to visit children who have come off acute treatment. Parents and children feel very isolated when they leave the hospital”.

Voluntary group

Some respondents felt patients should be given the name of an organisation close to their home where they could avail of support once discharged from hospital.

A number of respondents also advocated the establishment of cancer support facilities attached to regional cancer centres where people can access support.

3.6 INFORMATION

Information was considered to be a basic form of support but it is an unmet need. Respondents highlighted the importance of having sufficient information on diagnosis, treatment, follow-up policies and preventive strategies.

“Information relating to diagnosis, treatment, short and long term follow-up policies and preventive strategies are vital to patients’ adaptation to the diagnosis”.

Voluntary group

A number of patients noted that they were unable to absorb all the information given during consultations.

“The nurses explained everything but I couldn’t take it in”.

Patient

It was suggested that relevant hospital staff should spend more time discussing patient concerns at each stage of their treatment in order to alleviate concerns.

“It would seem that in the absence of adequate communication training and a lack of measured standards in relation to information transfer, consultants tend to give the patient less information than more.”

Health professional

“From my experience, patients do not receive adequate information on their illness, side-effects, how they can help themselves, how they can cope”.

Patient

“Time was taken by the surgeon to explain the reasons for further surgery, both to me and my partner, on several occasions and I found this very supportive”.

Patient

Comments were made about the absence of comprehensive literature both within the hospital and the community. Information on cancer should be readily available in written form so that patients can absorb it at their own pace.

“The breast cancer nurse came in to talk to me, but I was too much in shock to think. I asked if they had a booklet or any information available on breast cancer – they had none.”

Patient

"The nurses explained everything verbally (before receiving chemotherapy) but it was hard to remember all the medicines that would be given and their side effects and precautions. When I asked for something written down, they had to search and eventually came up with a guide to chemotherapy, with a torn cover."
Patient

"I had to resort to the Internet to get information from the American Cancer Society, which was excellent, and this gave me a list of questions to ask the doctor at each stage but I wondered how other women managed".

Patient

Comprehensive information on all aspects of cancer should be developed. This should be widely available, consistent and appropriate. This would ensure that patients can access all relevant information at one point rather than in a random and fragmented way, thus greatly enhancing their choices and decision-making.

Information was requested on a number of subjects including:

The disease itself	Role of different staff members
Treatment	Benefits
Hospitals services	Transport
Drugs and their side-effects	Financial entitlements
Community services	Relevant contact numbers.

A number of patients said they were not satisfied with the support provided by cancer help-lines, arguing that they were frustrated and dissatisfied with answers to queries while others were very pleased to have such help provided.

3.7 PALLIATIVE CARE

Participants who had experience of the palliative care services were of the view that high standards of care exist. The supporting and co-ordinating role of the palliative care team was highly valued.

"I find the home care team very much on the ball. Knowing they're behind you and that you can contact them at any time of the day or night if you need them, it's a great support and it gives you more confidence knowing there's someone there for you".

Issues raised that may require attention include:

- Waiting times for service. Accounts were given of patients waiting between one to three weeks for service
- Greater attention to the psychosocial needs of patients and families is needed

- Greater collaboration between all palliative care service providers is needed as is a
- Greater role for GPs in providing palliative services.

3.8 BEREAVEMENT COUNSELLING

Respondents commented on the lack of bereavement support services available for the families of cancer patients. Bereavement and pre-bereavement counselling is necessary, especially when children are involved. It was suggested that bereavement services need to be available locally. All families who lose a family member due to cancer should be offered bereavement services.

"I was shocked recently to respond to a family's request for advice as to how to prepare young children to view the body of their recently deceased mother. A relative contacted me on her mobile phone, outside the mortuary of one of our most prestigious hospitals. I spoke to her only minutes before she walked with them into say goodbye to their mum. They received no follow-up service."

Health professional

"If we fail to recognise family bereavement need, we may be storing up mental health issues for the future."

Health professional

3.9 VOLUNTARY SELF-HELP AND SUPPORT GROUPS

A number of patients mentioned the valuable work carried out by self-help and support groups.

"For me it was the combination of knowledge, counselling, caring attitudes, variety of supports, reading matter, music and voice tapes which made all the difference".

Patient

"It was very helpful and informative because I met women who had gone through chemotherapy and they could tell me that I would be O.K; and other women who had survived cancer and were years behind their diagnosis and were well again. This was so important and gave me so much hope."

Patient

Most groups commented that the existence of many voluntary cancer support groups is not widely known. They suggested that information on voluntary groups be made widely available and called for list of all voluntary self-help and support groups to be developed and maintained. It was suggested that such a list could be posted in a prominent position in health centres, GP surgeries and hospital units.

Groups suggested that hospital personnel be made aware of their existence and purpose. They can, in turn, inform patients of groups thereby giving the patient an opportunity to talk to someone who has recovered from cancer.

“Volunteers who are themselves recovered cancer patients can provide hope and friendship as well as practical and information support in a way that is not possible from health care professionals”.

Voluntary group

Some health professionals were disappointed by the lack of recognition and support given to voluntary self-help groups. Others were concerned that they did not have enough information on voluntary self-help groups to confidently refer patients on to them.

A number of health professionals queried if volunteers really had the appropriate training to deal with distressed cancer patients and their families and recommended that all volunteers be trained. Voluntary groups also outlined their need for training programmes, which at present is often not available.

Training volunteers was seen as a way to ensure a more effective support. The work of the Irish Cancer Society in providing advice and training to support groups was acknowledged. Concern was expressed about groups independent of the Irish Cancer Society who are responsible for their own training.

Health professionals suggested that evaluation and supervision of voluntary self-help services is essential to ensure patients receive high standards of support and referrals from oncology staff. The development of guidelines for support groups and self-help groups was encouraged. All voluntary agencies interviewed during this study agreed that they should be monitored.

Most groups indicated that they would welcome increased contact with other groups providing support to cancer patients and their families. A number of voluntary groups stressed the need for a nation-wide umbrella group for all cancer support groups and self-help groups. Groups suggested that this would provide a forum in which voluntary groups could meet, share experiences, exchange ideas and provide support to one another.

“(We) need to be linked up with other local cancer support groups and exchange ideas and well as inter-group support”.

Voluntary group

3.10 COMPLEMENTARY AND ALTERNATIVE THERAPIES

A number of respondents encouraged the use of complementary therapies, such as massage, aromatherapy and reflexology.

“I believe that cancer patients need more than medical treatment for the body. Complementary medicines complete the recovery of the entire person.”

Patient

“Other therapies, such as visualisation and massage, should be made widely available and information about these therapies widely disseminated.”

Patient

“Complementary therapies are appreciated by patients. They also appear to be beneficial in reducing stress and anxiety.”

Health professional

Some concerns were raised about the use of non-professional ‘unproven’ therapies. A number of respondents highlight the fact that patients with cancer are vulnerable and susceptible to anyone offering support. Concern was raised about distressed patients seeking help from various non-professional ‘therapists’ whose therapy has no sound basis and no clinical efficacy. Such ‘therapists’ were described as “quacks” or “cancer chancers”.

“Such “therapists” be treated cautiously”.

Health Professional

The ad hoc provision of unproven therapies by any individual was regarded as a serious cause for concern that requires regulation.

3.11 PRACTICAL ISSUES

3.11.1 Financial Strains

Many patients highlighted the financial burden associated with cancer. Respondents stated that patients and family members may need to give up work during illness. This places a severe strain on family finances. Strains due to loss of earnings for leave from work range from career breaks to intermittent ‘days off’ during treatment, relapse and impending death.

Many hidden costs were highlighted. These included extra out of pocket expenses for small appliances, clothes as people may gain or loose weight, colostomy care products and wigs. People travelling long distances for treatment face the added burden of accommodation costs, meals and travelling expenses.

It was suggested that special consideration be given to each cancer patient in relation to a general medical services card (GMS) and that special procedures should be put in place to help families who encounter financial difficulties. Access to a discretionary fund would be useful to relieve the pressure of those in need.

“No-one will tell you about the Domiciliary Care Allowance, how to approach the health board, how to deal with the V.H.I., how to get a medical card or just how to get through the next day....”

Patient

An information booklet advising cancer patients of possible financial entitlements was encouraged as a method to alleviate unnecessary stress associated with the costs of cancer care.

Although there are guidelines relating to the granting of a GMS card, long term illness card and domiciliary care allowance respondents perceived an inequity and were unclear of eligibility criteria for allowances, services and social welfare grants.

“The major recommendation I would make, having gone through the system, is to try to organise a single, transparent system of entitlements so that the social worker in the oncology unit can offer a parent or patient valid and accurate information pertaining to all health boards”.

Family member

“Leukaemia is the only cancer included in the (Long Term Illness) scheme. It should be extended to include all cancers”

Health professional

3.11.2 Transport Issues

The distressing situation of patients travelling long distances to and from hospital was a recurring theme. Cancer patients reported experiencing transport problems including inconvenient public transport, scarcity of car parking, expensive car parking at hospitals and inefficient and uncomfortable health board transport.

“Many of my patients have recounted tales of being eight hours on the return journey with frequent stops, where patients who were nauseated and vomiting following treatment, had to be allowed to vacate the vehicle and literally “get sick” on the roadside”.

Health professional

“I see parents... very distressed at the thought of having to travel to and from Dublin with sick children. They dread the journey there and back.”

Health professional

"I had the misfortune to avail of ... health board transport one Friday...What a nightmare! Three hours waiting in the lobby and then four hours travelling around the city of Dublin from one hospital to another, never again!"

Patient

Health board transport services were considered to be in need of improvement. It was felt that patients who are returning home following treatment in oncology units should be guaranteed an efficient and comfortable journey.

The provision of temporary accommodation for day patients attending oncology day units and radiotherapy centres was also suggested. Cancer centres offering intensive treatment should have a facility for B&B accommodation for patients who travel long distances.

"We need a house close to the hospital where the family can stay while the child is having treatment".

Voluntary group

DISCUSSION

4.1 GENERAL

This is the first national review of cancer support services to be conducted in Ireland. The views of consumers, health service providers, support groups and self-help groups were obtained by conducting research and by analysing submissions arising from advertisements placed in the national press. Wide ranging consultation was undertaken to ensure that the views of all individuals and interested groups were properly considered. The key issues in relation to psychosocial cancer support in Ireland are outlined.

There are 20,000 new cases of cancer diagnosed and treated in Ireland every year and approximately 50,000 hospital admissions overall. The development of psychosocial support services should take account of the diverse needs of patients and the ability of health services to respond to those needs. There is strong evidence that distress is common among people with cancer. Depression and severe psychological problems occur in at least 25% of patients.

It has been shown that untreated psychosocial morbidity leads to adverse outcomes including reduced quality of life, more frequent clinic visits, extended hospital stay, reduced compliance with treatment and increased cost. It may also result in poorer disease outcome or impaired response to treatment. It may lead to stress, anger and frustration among families. However, treating distress may impact positively on disease outcome.

Contributors to this review clearly identified deficiencies in current psychosocial support services. Suggestions for the development of a comprehensive service were provided. Suggestions on ways to develop psychosocial support services greatly depended on respondents' own experience and their areas of special interest.

The review produced the following general conclusions:

- There is an absence of adequate formal psychosocial support services for patients with cancer in Ireland
- Psychosocial problems, though common, are under-recognised and under treated
- Patients may not wish to report psychosocial symptoms due to associated negative attitudes and stigma

- Psychosocial care was found to depend on a number of factors including, cancer type, place of treatment, degree of involvement of the oncology team with mental health personnel, the ability of the patient to ask for help and the availability of psycho-oncology services
- Patients, health care providers and support group personnel recognise that psychological health should be an essential component of cancer care.

Concern was also expressed that:

- Some patients do not have the opportunity to be treated by a cancer specialist. This reported deficiency in the provision of oncology services contributes to patient distress
- Adolescents have specific needs
- Hospital accommodation is limited for patients and families
- Waiting lists for palliative care should not exist
- Bereavement support is often not provided
- There are wide variations in the provision of oncology services in different parts of the country.

It is recommended that all patients with cancer receive comprehensive treatment with input from relevant specialists and that psychosocial care becomes an integral part of the care plan.

4.2 THE DEVELOPMENT OF PSYCHOSOCIAL SUPPORT SERVICES

The following principles should underlie the development of a quality based psychosocial support service for patients with cancer:

- Sensitive to the wide ranging nature of patient distress
- Continuous, dynamic and responsive
- Co-ordination across all disciplines in hospitals and in the community
- Provided by personnel who have appropriate skills
- Recognition of the roles of different health personnel
- Patient focused and empowerment of patients
- Treatment of patient holistically rather than merely his /her illness.

Awareness and detection of distress can be improved by:

1. Educating health personnel including those in training of the psychosocial impact of cancer
2. Encouraging a positive attitude among health personnel towards dealing with distress
3. Providing health personnel, especially nurses, with the skills to manage distress and to refer appropriately

4. Developing guidelines for referral to multidisciplinary psychosocial services
5. Introducing publicity campaigns alerting patients and the public to the prevalence of distress and the treatment options available.

Management of distress can be improved by:

1. Providing psycho-oncology services in regional cancer centres
2. Developing a screening tool for use by specific health personnel, especially nurses, to identify distress.
3. Incorporating psychological and psychiatric care in the treatment programme.
4. Enhancing communication between hospitals, community health services, GPs and consumers and further strengthening of the multi-disciplinary team concept in the community.
5. Improving doctors' communication skills especially in the way a diagnosis is given.
6. Encouraging research into the modalities of treatment.

Counselling services

Counselling can be a component of psychosocial care. The understanding of the role and value of counselling varies greatly. Health personnel, who are aware of patients' mental health needs should advise on the necessity for psychological interventions, as well as whether counselling is required. At present the provision of counselling is uncontrolled and unregulated. It can be provided by people with limited knowledge of the health service and little understanding of patients' pathology, treatment or prognosis. For patients with cancer it is essential that counsellors are highly skilled. They should be appropriately trained, have a background in health care and be accredited by a professional organisation.

It is recommended that regional cancer centres develop psycho-oncology services. Relevant health personnel should be trained and skilled in the recognition and management of distress.

Communication with patients, hospitals and community health services needs to be improved. The particular needs of adolescents in relation to hospital care requires consideration and redress.

Professional standards and registration of counsellors involved in counselling cancer patients and their family requires urgent attention. Support structures for staff who are involved in intensive programmes with cancer patients need to be put in place.

4.3 INFORMATION SUPPORT

Information is a basic and necessary form of support. It is an unmet need in most instances. Comprehensive information can lead to greater satisfaction with health care. It helps families to deal with distress and

anxiety. Information compliments and supports other ‘support’ services. The timing of information is important, as some patients may not be able to absorb many details at the time of diagnosis.

Patients want high quality written information at various stages of the disease process. Information is required on the particular diagnosis, possible treatment options and side effects, support networks and practical issues. It is essential that all information be evidence based and kept up to date in order to maintain confidence.

It is recommended that full and timely information on all aspects of their cancer is available to patients. A national expert agency should be given this responsibility in association with the key professions.

4.4 SELF-HELP AND SUPPORT GROUPS

Self-help groups and support groups can help patients cope with distress. There are currently 31 groups in Ireland. Self-help groups are generally self-regulated, unstructured and run by former patients. Group members support each other through sharing common experiences and establishing social networks. In contrast support groups are linked to professional services or health professionals.

Patients gave many examples of how self-help and support groups helped them to cope with their illness. Some health professionals were also positive. Other health professionals were sometimes reluctant to refer patients to such groups particularly if they were unsure of their activities and operation. Though all groups have a stated and definite purpose, many need to develop a “Declaration of Good Practice” that outlines aims and objectives and describes their activities. They also need to show that the group is run in a clear and accountable manner and volunteers are appropriately trained. Access to training is a difficulty experienced by many groups. All groups advocate greater links with the health service.

Many patients would like the option of being referred to self-help or support groups. This should occur when groups have produced acceptable aims and objectives, their role and functioning is clear to the health service and their volunteers are trained.

One of strengths of groups is that they are autonomous of the health service. However, they cannot work successfully in isolation from it. In particular groups should be known to the regional cancer directors, cancer co-ordinators, specialist nurses and oncology teams.

The Irish Cancer Society has an existing role in this area and is likely to continue to participate in initiatives in this regard.

It is recommended that best practice guidelines be developed to inform groups how best to deal with patients and their family in relation to cancer and on how to deal with the various professionals in the hospital and community setting. Of particular importance is the self-empowerment of patients and the promotion of positive health. Guidelines should be drawn up by a group representing health care professionals and representatives of self help and support groups. Training should be provided to such groups on a planned basis.

4.5 COMPLEMENTARY CANCER THERAPY AND ALTERNATIVE CANCER THERAPY

In this review a definite distinction is made between **complementary cancer therapy** and **alternative cancer therapy**.

Therapies, which are provided in association with conventional cancer treatment, were considered to be **complementary cancer therapies**. Therapies that meet those criteria may be of benefit to patients, improve quality of life and are recommended by some medical specialists. Therapies often used in conjunction with cancer care include massage, aromatherapy, relaxation and reflexology.

Alternative cancer therapies were defined as those that are provided to the exclusion of conventional medical care. It is of concern that a small number of individuals, generally non-health professionals, recommend and provide unproven therapies that exclude and reject conventional health care. Various colloquial terms were used to describe such people, including “quack” and “cancer chancer”. Patients may even be told that these remedies will effect a complete cure. Such approaches, involving an unrecognised approach, are dangerous and seriously damage patients’ health; these have no clinical basis and have no place in the provision of a modern cancer service.

It is recommended that legislation be introduced to regulate the provision of unproven remedies that reject best medical practice. All therapists, by whatever name, providing complementary cancer therapies should be registered and accredited by a professional organisation.

4.6 PRACTICAL ISSUES

Patients described many examples of the practical difficulties they regularly encounter in accessing care for cancer. These include:

- Financial worries possibly due to loss or curtailment of employment opportunities
- Transport difficulties to major centres of treatment from more remote areas
- Overnight accommodation concerns when required to travel long distances for treatment
- Difficulties in obtaining information on entitlements
- Perceived inequity between different parts of the country regarding entitlement to various schemes including *GMS card*, *Long Term Illness Scheme* and the children's *Domiciliary Care Allowance*.

It is recommended that the unnecessary hardship endured by some patients who must travel very long distances for treatment be minimized. In these special cases assistance towards B&B type accommodation and transport costs should be offered. Every patient should be aware of their entitlements to service.

RECOMMENDATIONS

5.1 Key Recommendations

1. Every patient should have access to a cancer specialist, as appropriate, for diagnosis and treatment.
2. The management of a patient's psychological state should be an integral part of cancer care.
3. Each health board should provide multidisciplinary psycho-oncology services to manage distress in patients with cancer.
4. Each health board should ensure there is effective communication between all Programmes for individuals and care groups.
5. Information booklets, describing different cancers, their diagnoses and treatments should be widely available i.e. "A Directory of Cancer Illness and Care". They should describe recognised treatment regimes, social supports and entitlements for services.
6. Best practice criteria for providing cancer counselling should be developed and followed.
7. Cancer self-help and support groups should subscribe to a "Declaration of Good Practice". Where this happens and where groups show that they assist patients, health personnel (health board and voluntary hospitals) should collaborate.
8. Complementary cancer therapies may be beneficial and can be considered an integral part of care. All therapists, by whatever name, providing complementary cancer therapies should be registered and accredited by a professional organisation. Patients should be protected, if necessary through legislation, from unproven remedies which are sometimes advocated by non-health professionals.
9. Assistance towards accommodation and travel costs should be considered for patients, where appropriate, who must travel long distances for treatment.

5.2 Development of psychosocial support services

1. Each health board, in consultation with regional cancer directors, should develop psychosocial cancer services in their area. Their proposals for developing these services should set out the necessary structures, systems, resources and implementation measures.

2. Health personnel should be trained and skilled in the recognition, screening, preliminary management and appropriate referral of patients suffering from distress.
3. Relevant health personnel both in hospital and in the community should receive training in communication skills.
4. Support structures should be put in place for staff who treat cancer patients intensively.
5. Health personnel including those in training should be made aware of the psychosocial impact of cancer on health.
6. Each health board should ensure there is effective communication between hospitals, general practitioners (GPs) and other community health services and patients. The role of the multi-disciplinary team approach should be enhanced and supported.
7. Best practice criteria for providing counselling to patients with cancer should be developed and followed. These criteria should include the necessary training and accreditation for counsellors.
8. Health boards and the National Cancer Forum should address the special needs of adolescents with cancer.
9. Bereavement support should be offered to all people who are bereaved by cancer.

5.3 Information

1. Comprehensive, high quality information booklets describing different cancers and their treatments should be readily available to patients at treatment centres: “A Directory of Cancer Illness and Care”. These should also include details of support networks and service entitlements.
2. A national expert agency should take responsibility for producing information booklets, with input from key professions. The Irish Cancer Society has a role in this regard.
3. The agency should also develop a web site for supplying information.

5.4 Self-help and support groups

1. Each cancer self-help and support group should subscribe to a “Declaration of Good Practice” that outlines its aims, objectives, and plans.
2. Guidelines should be developed to inform groups how best to deal with patients and their families in relation to cancer and in relation to professionals in the hospital and community setting.
3. Groups should source training for volunteers on a planned basis with national expert agencies and with health boards.
4. Patients should have the option to be referred to self-help and support groups that maintain high standards.

5. Self-help and support groups should remain autonomous but work in co-operation with the health service.
6. Health boards should co-operate with groups that adopt and implement good practice guidelines, where high standards are maintained and where there is evidence that patients benefit from involvement with the group.

5.5 Complementary and alternative cancer care

1. Complementary cancer therapies may be beneficial to patients and can be considered as an integral part of cancer care.
2. All therapists, by whatever name, providing complementary cancer therapies should be registered and accredited by a professional organisation. Monitoring of services should be undertaken together with procedures for dealing with patient complaints.
3. Unproven remedies are sometimes advocated. These are to be discouraged.
4. Patients, who may be vulnerable because of their illness or lack of insight, should be protected, if necessary through legislation, from such unproven remedies. In relation to alternative medicines, the Irish Medicine Board's guidelines should be followed.

5.6 Practical aspects

1. Information leaflets describing all the various health and social welfare schemes and their eligibility criteria should be visibly available in all treatment centres, GP surgeries and health centres.
2. Supra-regional cancer centres should organise special B&B type accommodation for patients who must travel long distances for treatment. The Irish Cancer Society may have a role in this area. The proprietors of such B&B accommodation should be sensitive to the needs of their clients (and their special needs); it would be beneficial if they had some understanding of 'cancer' and some training in support.
3. Financial assistance towards the cost of transport should be considered in special cases for patients who travel long distances for treatment.

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APPENDIX I

ADVERTISEMENT FOR SUBMISSIONS

(placed in January 1999)

CANCER SUPPORT SERVICES

The Department of Health and Children has commissioned a review of cancer support services and a Working Group has been established. Submissions are now being sought from interested persons or groups.

Information is being sought from people who have availed of any cancer support service on:

- *Your experience of using support services and*
- *Your views on what services are needed and how they should be provided to achieve a comprehensive cancer support service.*

Information is being sought from service providers on:

- *The availability and adequacy of cancer support services in your region and in your profession*
- *Your views on what is required to provide a comprehensive cancer support service*

The deadline for receipt of submissions is ***Friday 12th February at 5pm.*** Written submissions should be sent to:

**The Project Director
Cancer Support Services
Room G29
Dr. Steeven's Hospital
Dublin 8**

Under the Freedom of Information Act, submissions could be subject to Freedom of Information request.

APPENDIX II

SELF-HELP AND SUPPORT GROUP QUESTIONNAIRE

SECTION A: ORGANISATION DETAILS

Q1. Name of organisation _____

Q2. How would you describe your service/organisation? (e.g. support group).

Q3. When was this organisation/group established? _____

SECTION B: CLIENT PROFILE AND REFERRAL

Q4. Approximately how many cancer patients came into contact with your service in 1997? _____

Q5. How many of these people were newly diagnosed (< one year)?

Q6. What type of cancers affect the people coming into contact with your service?

Q7. What proportion of people are affected by the type of cancers you have specified?

Q8.	What proportion are male and female?	Male	Female

Q9. In general, how do people hear about your service? _____

Q10. What organisation/persons, if any, refer people to your service?

Q11. Do you advertise your service? Yes No

If yes... How do you advertise your service? _____

Q12. Do the majority of people coming into contact with your service live in the immediate area?

Yes No

If no ... Do people come from different parts of the county, different parts of your health board or from all over the country?

County	Health Board	Country
--------	--------------	---------

SECTION C: SERVICE PROVISION

- Q13. Do you provide people with information leaflets?** Yes No
 If yes.... Who developed the material you distribute? _____
- Q14a. Do you offer one-to-one counselling?** Yes No
- Q14b. Who facilitates these one-to-one counselling sessions?** _____
- Q14c. How are facilitators recruited?** _____
- Q14d. What training do facilitators have?** _____
- Q14e. Do facilitators receive on-going training?** Yes No
 If yes... please specify _____
- Q14e. Please specify the days/times this service is available.** _____
- Q14f. On average how many counselling sessions do attenders receive?**

- Q15a. Do you run support groups?** Yes No
- Q15b. What type of support groups are they?**
 Phone-ins Social nights/outings
 Group meetings Conferences
 Other, please specify _____
- Q15c. Are these groups cancer specific?** Yes No
 If yes...please specify the type of groups held. _____
- Q15d. How many support groups are held each week/month?** _____
- Q15e. On average, how many people attend each meeting?** _____
- Q15f. Who facilitates these groups?** _____
- Q15g. How are facilitators recruited?** _____
- Q15h. What training do facilitators have?** _____
- Q15i. Do facilitators receive on-going training?** Yes No
 If yes...please specify the type of training facilitators receive.

- 16. Do you offer complementary therapies?** Yes No

If yes... What type of therapies are offered?

17. Do you offer alternative therapies? Yes No
If yes... Please specify.

Q18a. Do you provide support over the phone? Yes No

Q18b. Who provides support over the phone? _____

Q18c. How are they recruited? _____

Q18d. What training do they have? _____

Q18e. Do they receive on-going training? Yes No
If yes... please specify the type of training received.

Q18f. Please specify at what days/times this service is available? _____

Q18g. What type of advice is sought by people over the phone?

Q19. What services are offered to people with a terminal diagnosis?

Q20. What other facilities or services are offered?

Q21. Do family members come into contact with the service? Yes No

Q22a. Do you offer support to family members? Yes No

Q22b. What type of support is offered to families, including children and adolescents?

Q22c. What type of support is offered to families, including children and adolescents, after a family member has died?

Q23. What do you see as the strengths and weaknesses of the service you provide?
Strength

Weaknesses

Q24. What improvements would you like to make to your service?

Q25. What would you require to carry out these improvements?

Q26. In what way do you monitor the service you provide? (e.g. patient satisfaction, complaints, advice given).

Q27a. Do you think voluntary / non-statutory organisations offering support to people affected by cancer should be monitored?

Yes

No

Q27b. How should organisations be monitored?

Q27c. Who should monitor voluntary/non-statutory organisations?

SECTION D: STAFF AND FUNDING

Q28. How many staff/volunteers do you have working with you at present (not including administrative staff)?

*Full-time paid
Part-time paid*

*Full-time volunteer
Part-time volunteer*

Q29. What qualifications does your staff have?

Paid staff

Volunteers

Q30. Do you offer/arrange training for volunteers? Yes No

If yes... Please specify the type of training offered.

Q31. Do you have any administrative staff? Yes No

If yes... how many administrative staff do you have? _____

Full-time paid
Part-time paid

Full-time volunteer
Part-time volunteer

Q32. Do you receive funding from the Department of Health, Health Board, E.U. or other agency? Yes No

Q33. Are people charged for any services they receive? Yes No

If yes... please specify costs.

Q34. Are people asked to make a financial contribution to the service? Yes No

SECTION E: LINKS WITH OTHER ORGANISATIONS

Q35. What links do you have with the health services (e.g. GPs, nurses, hospitals)?

Q36. What links do you have of other organisations/persons working within the cancer area (e.g. voluntary organisations, hospices)?

Q37. Would you like to see increased links with other services?

If yes... Why? _____

If no... Why not? _____

SECTION F: SATISFACTION WITH CANCER SUPPORT SERVICES

Q38. What do you regard as the strengths and weaknesses of current hospital based cancer support services?

[in terms of Availability, Access, Service Provision, Quality, The way it runs]

Strengths

Weaknesses

Q39. What do you regard as the strengths and weaknesses of current cancer support services within the community (both community health services, GP services and voluntary agencies)?

[in terms of Availability, Access, Service Provision, Quality, Organisation]

Strengths

Weaknesses

Q40. What do you consider to be the priorities in providing good cancer support services?

1. _____

2. _____

3. _____

Q41. What are your views regarding the development of cancer support services?

APPENDIX III

HEALTH BOARD AND VOLUNTARY HOSPITAL QUESTIONNAIRE

Administration Questionnaire

Q1. Patient Discharges

Please state the number of discharges from your hospital in 1997 for each of the following:

- a. Number of in-patient discharges (all cases). _____
- b. Number of day cases discharged (all cases). _____
- c. Number of in-patient discharges with a diagnosis of cancer. _____
- d. Number of day cases discharged with a diagnosis of cancer. _____

Q2. Hospital Services

Please tick ✓ which services the hospital provides for patients with cancer.

- | | | | |
|----|---------------------------|-----|----|
| a. | General Surgery | Yes | No |
| b. | Specialist Surgery | Yes | No |

Please detail the type of specialist surgery, e.g. breast, urological.

- | | | | |
|----|----------------------------|-----|----|
| c. | General medicine | Yes | No |
| d. | Specialist medicine | Yes | No |

Please detail the type of specialist medicine, e.g. Gastroenterology, Respiratory.

- | | | | |
|----|-----------------------------------|-----|----|
| e. | Medical Oncology | Yes | No |
| c. | Radiotherapy | Yes | No |
| d. | Specialist Palliative Care | Yes | No |
| e. | Specialist nursing | Yes | No |

Please detail the type of specialist nursing, e.g. Breast, urological.

- | | | | |
|----|--------------------|-----|----|
| f. | Social Work | Yes | No |
| g. | Counselling | Yes | No |

REVIEW OF CANCER SUPPORT SERVICES

h.	Psychological Services	Yes	No
i.	Psychiatric Service	Yes	No
j.	Complementary Services	Yes	No
k.	Bereavement Support	Yes	No
L.	Voluntary Groups availing of hospital facilities.	Yes	No

Please specify the name of the support group or groups.

I. Please specify any other services your hospital provides for patients with cancer.

Sample Questionnaire: Surgical, Medical, Nursing and Palliative Care

Support Services may include: Information, Self-help, Support groups, Specialist nursing, Social workers, Counselling, Psychological therapy, Psychiatric therapy.

- Q1. Please state the number of surgeons employed in your hospital? _____
- Q2. How many surgeons specialise in the treatment of cancer? _____
- Q3. Approximately how many cancer patients were treated by surgical teams in 1997. _____
- Q4. In your opinion what proportion of cancer patients are in need of support services? _____
- Q5a. Are cancer patients usually referred by surgical teams to support services?
Yes No
- Q5b. Approximately what proportion of cancer patients are referred by surgical teams to support services? _____
- Q5c. What are the main types of services patients are referred to?

- Q5d. Please state the main reasons for referral.

- Q6. In your opinion whose responsibility is it to refer cancer patients to support services?
Please rank in order, 1=Discipline with the greatest responsibility.
- | | |
|-----------------------|-----------------------------|
| General Practitioners | Radiotherapists |
| Medical teams | Nurses |
| Surgical teams | Other, please specify _____ |
- Q7. What do you regard as the strengths and weaknesses of current hospital based cancer support services?

[in terms of Availability, Access, Service Provision, Quality, How it runs]

Strengths

Weaknesses

Q8. What do you regard as the strengths and weaknesses of current cancer support services within the community (both community health services, GP services and voluntary agencies)?

[in terms of Availability, Access, Service Provision, Quality, How it runs]

Strengths

Weaknesses

Q9. What do you consider to be the priorities in providing a good cancer support services?

Q10. What are your views regarding the development of cancer support services?

Any other comments

Sample Questionnaire Social Worker, Psychology and Psychiatry

Support Services may include: Information, Self-help, Support groups, Specialist nursing, Social workers, Counselling, Psychological therapy, Psychiatric therapy.

- Q1. Please state the number of social workers employed in your hospital? _____
- Q2. How many members of the social work team have special responsibility for the care of cancer patients? _____
- Q3. How many members of the social work team have specialist training in the care of cancer patients? _____

Q4. PATIENT REFERRALS

- a. Please state the number patients (all causes) referred to your service 1997. _____
- b. Please state the number patients with a diagnosis of cancer referred to your service in 1997. _____
- c. For patients with cancer, please tick ✓ the main sources of referral to your service.

Surgery	Psychiatric Services
Medicine	Social work service
Oncology	Counsellor/therapist
Radiotherapy	Public health nurse
Palliative care	Self/family
Nursing	General Practitioner
Psychological services	Self-help groups

- d. Please state the proportion of patients with cancer, referred to your service by the main sources of referral you specified above.

Surgery	_____	Psychiatric Services	_____
Medicine	_____	Social work service	_____
Oncology	_____	Counsellor/therapist	_____
Radiotherapy	_____	Public health nurse	_____
Palliative care	_____	Self/family	_____
Nursing	_____	General Practitioner	_____
Psychological services	_____	Self-help groups	_____

- e. Please state the main reasons given for referral to your service?

1. _____
2. _____
3. _____
4. _____

- Q5. In your experience what are the main type of problems experienced by cancer patients referred to your service?

1. _____
2. _____
3. _____
4. _____

Q6. What additional support services/persons, in any, have you referred patients to?

Q7. What do you regard as the strengths and weaknesses of current cancer support services within the community (both community health services, GP services and voluntary agencies)?

[in terms of Availability, Access, Service Provision, Quality, How it runs]

Strengths

Weaknesses

Q8. What do you consider to be the priorities in providing a good cancer support services?

Q9. What are your views regarding the development of cancer support services?

Any other comments

Public Health Nursing Questionnaire

Support Services may include: Information, Self-help, Support groups, Specialist nursing, Social workers, Counselling, Psychological therapy, Psychiatric therapy.

Q1. Approximately how many public health nurses work as part of the community care team in your health board? (Whole time equivalent). _____

Q2. Approximately how many registered general nurses work as part of the community care team in your health board? (Whole time equivalent). _____

Q3. Approximately what proportion of nurses time is spent on prevention and what proportion is spent on treatment and cure.

PREVENTION _____ TREATMENT AND CURE _____

Q4. Please state the main types of conditions treated by nurses in the community.

1. _____
2. _____
3. _____
4. _____

Q5. Please outline the main duties and activities undertaken by PHNs and RGNs in caring for people with cancer.

1. _____
2. _____
3. _____
4. _____

Q6. What do you see as the strengths and weaknesses of the service provided by PHNs and RGNs in relation to cancer care?

Strengths

Weaknesses

Q7. What improvements would you like to make to the service provided by PHNs and RGNs for people with cancer?

Q8. What do you regard as the strengths and weaknesses of current cancer support services within the community (both community health services, GP services and voluntary agencies)?

[in terms of Availability, Access, Service Provision, Quality, How it runs]

Strengths

Weaknesses

Q9. What do you consider to be the priorities in providing a good cancer support services?

Q10. What are your views regarding the future development of cancer support services?

Any other comments

Community Social Worker Questionnaire

Support Services may include: Information, Self-help, Support groups, Specialist nursing, Social workers, Counselling, Psychological therapy, Psychiatric therapy.

Q1. Approximately how many community social workers are there in your health board? (Whole time equivalent). _____

Q2. Approximately how many clients did community social workers see in 1997. _____

Q3. Please state the main types of duties carried out by social workers in the community.

1. _____
2. _____
3. _____
4. _____

Q4. Approximately what proportion of clients seen by the social work service are cancer patients? _____

Q5. Please outline the main duties undertaken by social workers in caring for people with cancer.

1. _____
2. _____
3. _____
4. _____

Q6. What do you see as the strengths and weaknesses of the service provided by social workers caring for people with cancer?

Strengths

Weaknesses

Q7. What improvements would you like to make to the service provided by community social workers for people with cancer?

Q8. What do you regard as the strengths and weaknesses of current cancer support services within the community (both community health services, GP services and voluntary agencies)?

[in terms of Availability, Access, Service Provision, Quality, How it runs]

Strengths

Weaknesses

Q9. What do you consider to be the priorities in providing a good cancer support services?

Q10. What are your views regarding the development of cancer support services?

Any other comments

APPENDIX IV

SUBMISSIONS FROM INTERESTED PERSONS

Breda Baker	Darragh Hammond
Helen Behan	Kay Harrington
Anne Marie Beirne	Helen Hennessy
Terence D. Boyle	Maureen Horgan
Elizabeth Brady	Valerie Horgan
Dermot Brady	Rossa Hurley
Kay Brennan	N. Kenny
Paul Browne	Seamus Kearns
Mairin Bruen	Margaret Keating
Eoghan Cahill	Orla Keegan
Trudi Carberry	Freda Keenan
Denis Carroll	Ann Kenny
Siobhan Carroll	M John Kennedy
Verona Connolly	Mary Keohane
Heather Connor	Eileen Kehoe
Vera Coogan	Marie Kidney
Bride Counihan	Mary King
Kar Courtney	Ms. Brid Laffan
Pauline Cowell	Joan Lahiff
Dr. Rachael Cullivan	Caelinn Largey
Betty Cummins	Anne Lerrins
Maura Curran	Anne Linnane
Catherine Daly	Sharon Lowry
Marie Daly	Mrs Anne McCaul
Olive Delaney	M. T. Maguire
Roy and Helen Devine	Catherine and Liam Malone
Thomas Myles Dodd	Maxell Meane
Declan Doyle	Bridie Mulqueen
Michael Dowling	Marie Murphy
Peter Doyle	Lilo Murphy
Dr. Ita Durkin	Mai Murphy
Pauline Eccles	Tom and Mary Murray
Dr. Micheal Fay	John Molloy
Anna Farmer	Kerri Moloney
Maureen Feely	Anne Mooney
Olive Fleetwood	Mairead Moymhen
Liz Franklin	Tom Mulqueen
Eileen Furlong	Nancy Murphy
Ms. Pauline Gilbert	Clara Ni Ghiolla
Maureen Glynn	David O' Bonne
Alice Gormley	Patricia (Tierney) O' Callaghan
David Hanlon,	Anita O' Connell
Joan Hamilton	John O' Connell
Adelaide Hanlon	Maureen O' Connell
Michael Hanlon	John O' Dowd
Dr. Tom Houlihan	

B O' Keefe
Denis O' Shea
Jim O' Sullivan
Sinead O' Toole
Maria Parall
Elizabeth Pollard
Catherine Quinlan
Karen J Reck
M. Rhemisch
Julie Rhind
Margaret Shanley
Anne Staunton
Dr Michael W. H. Timms
Chris Tully
Alison Vines
Sara Whelan
Sheila Wright

7 ANONYMOUS SUBMISSIONS

Appendix V

SUBMISSIONS FROM INTERESTED GROUPS AND ORGANISATIONS

ARC Cancer Support Centre
Ardagh Clinic
Association of General Practitioners
Barretstown Gang Camp
Bray Cancer Support & Information Centre
Cancer Nurse Specialists in Ireland
Cancer Plus
Canteen, Young Peoples Cancer Support Group
Caring About Women and Cancer
Caring for Carers Ireland
Cavan Cancer Hospice Association
Comfort for Cancer Cork
Complementary and Supportive Services, Ours Lady's Hospice Harold's Cross
County Meath Vocational Education Committee Cancer Support Group
Department of Nursing, St Luke's and St Anne's Hospital
Europa Donna Ireland
Greystones Cancer Support
Head Medical Social Workers Group
Helpful Hands
Irish Association for Nurses in Oncology (IANO)
Irish Breast Care Nurses Association (IBCNA)
Irish Cancer Society
Irish Lymphoedema Support Network
Irish Nutrition and Dietetic Institute
Irish Society of Medical Oncology
M.A.C Men Against Cancer
Medical Social Work Department, Cork University Hospital
Medical Social Work Department, Our Lady's Hospice Harold's Cross
Mna na hEireann,
National Centre for Medical Genetics
National Women's Council of Ireland
North West Hospice
Nurses Working in Cancer Services
Nutrition and Dietetic Department, Cork University Hospital
Oncology Team, Our Lady's Hospital for Sick Children
Slanu Dublin Support Group
Sligo Cancer Support Group
Social work Department, James Connolly Memorial Hospital
Social Work Department, Our Lady's Hospital for Sick Children
Speech and Language Therapists, Mater Misericordiae Hospital and Community Care Area 6
St. Francis Hospice, Raheny
Stillorgan & District Cancer Support Group.
Turning Point Positive Health Centre
Unity Counselling
Women's Health Council

APPENDIX VI

SELF-HELP AND SUPPORT GROUPS

ARC Trust – Cancer Support Centre
Beaumont Hospital Laryngectomy Support Group
Bone Marrow Transplant Support Group
Brain Tumour Support Group
Bray cancer support and information centre
Cancer Plus (National Association for Parents of Children with Cancer)
CanTeen Ireland (Teenage Cancer Support Group)
Charleville and District Cancer Support Group
Colostomy and Ileostomy Welfare Support Group
Comfort for Cancer Cork
Donegal Town Cancer Support Group
Greystones Cancer Support Group
HUG - Hodgkin's United Group
IA - Ileostomy and Internal Pouch Support Group.
Irish Lymphoedema Support Network
Killybegs Cancer Support Group
Laryngectomy Association of Ireland
Limerick Cancer Support Group
Listowel Cancer Support Group
MAC (Men Against Cancer)
Meath Support Group
Portlaoise Breast Cancer Support Group
Reach to Recovery
Slanu Galway Cancer Help Service
Slanu, Dublin
Slanu, Newbridge
Sligo Womanise Cancer Support Group
Stillorgan and District Cancer Support Group
St. Luke's Support Group for Newly Diagnosed Breast Cancer Patients.
Tuam Cancer Care Group
West Clare Cancer Support Group