Irish Cancer Society

Guidelines for **CANCER SUPPORT SERVICES** in Ireland

Contents

- Recruiting and selecting staff and volunteers
- Garda vetting
- Inducting and initial training for staff and volunteers
- Ongoing training for staff and volunteers
- Working with trainees and students
- Supporting and supervising staff and volunteers
- Exit planning
- Preventing and dealing with workplace bullying and harassment
- Good employment practices

Section 6: Confidentiality and Data Protection

- What is confidentiality?
- Information policy
- Managing information
- Gathering personal data from members/ clients
- Direct marketing
- Right to access
- Recording information
- Storing information
- Using computers
- Using external researchers

Section 7: Providing Support

- Types of support
- Developing a self-help group
- The process of providing support
- Family support
- Emotional support
- Survivorship programmes
- Providing support to terminally ill members/clients
- Home and hospital visiting
- Providing practical support
- Providing telephone support
- Providing email support
- Providing a drop-in centre
- Providing therapies or counselling on-site
- Providing a transport service
- Respite as a source of support
- Dealing with disclosure
- Working with professionals – doctors, nurses, therapists, counsellors and others
- Self-care, support and supervision for support workers

Section 8: Facilitation

- What is facilitation?
- How is facilitation different from co-ordination?
- Managing group meetings
- What are the competencies of effective facilitators?
- Boundaries of the facilitation role
- Facilitation tool kit
- Troubleshooting for facilitators
- Support and supervision for facilitators
- Training for facilitators

Acknowledgements

Section 1: Introduction

What this section covers

This section covers the following topics:

- The Irish Cancer Society
- Cancer support services
- What is psychosocial support?
- What is good practice?
- How were these Guidelines developed?
- What is the purpose of these Guidelines?
- Who are these Guidelines for?
- How to get the best use out of these Guidelines
- How the Irish Cancer Society can help

The Irish Cancer Society

The Irish Cancer Society is the national charity for cancer care. It was established in 1963. The mission of the Irish Cancer Society is to play a vital role in achieving world-class cancer services in Ireland, to ensure fewer people get cancer and those that do have better outcomes. Its goals are focussed around prevention, survival and quality of life. The Irish Cancer Society achieves these goals through advocacy, cancer services and research. It believes that high quality psychosocial support is an integral part of a comprehensive world-class national cancer service.

In fulfilling its mission, and in response to a recommendation from *A Strategy For Cancer Control in Ireland (2006),* the Irish Cancer Society has embarked on a project to improve the effectiveness of cancer support services. Part of this process includes promoting good practice guidelines.

Cancer support services

The main types of cancer support services provided in Ireland are as follows:

Cancer Support and Self-Help Groups: These are mainly voluntary local organisations that are facilitated by a person who has experienced cancer. A small number of groups are facilitated by health professionals. Most groups cater for the broad spectrum of people experiencing cancer. A small number specialise in certain types of cancer or are gender-specific. Many offer interventions such as information and access to complementary therapies. See the Irish Cancer Society website, www.cancer.ie, for more information.

Cancer Support Centres: These are mainly community-based centres. They are open to all and have drop-in facilities. A small number are based in hospitals. The centres offer a range of services and activities, including complementary therapies and counselling. Most of the centres employ salaried staff. Centres also use volunteers and some centres are directed and managed exclusively by volunteers. See the Irish Cancer Society website, www.cancer.ie, for more information.

National Peer Support Programme: This programme offers confidential emotional and practical support on a one-to-one basis to those with cancer and their families. Volunteers are all recovered cancer survivors who have been trained by the Irish Cancer Society to provide this type of support. Volunteers are also available to address public meetings with regard to their own personal experience of cancer. On request, representatives of the programme can meet with support groups and centres. See the Irish Cancer Society website, www.cancer.ie, for more information.

Cancer Support Services for Young People: There are a number of cancer support services for young people. These include a national service dedicated to those aged 12 to 25 that provides information and organises recreational and social events; regional services in the west that provide practical support to families and a camp in the east that provides holidays, weekend breaks and psychosocial support. All of these services use trained volunteers and some also have salaried staff. See the Irish Cancer Society website, www.cancer.ie, for more information.

Educational programmes: There are a number of educational programmes for women, men and mixed groups, some of which focus on specific cancers such as breast cancer. These are short programmes, for example six weeks, which aim to inform and educate those with cancer about their condition and how to manage it. Many of these programmes operate in hospital settings.

Residential programmes: There is one cancer support service that currently provides a range of residential programmes. These programmes support clients in relaxation, reflection and recovery by skilled therapists, nurses and counsellors. Clients are provided with an opportunity to discuss issues in a relaxed environment with staff and other participants. See the Lakelands Area Retreat & Cancer Support Centre website, www.larcc.ie, for more information.

What is psychosocial support?

Cancer can affect people in many ways and pose emotional, physical, financial and psychological challenges. These include:

- Denial
- A sense of loss or grief
- Changes in ability to engage in 'normal' activities
- Uncertainty about the future
- Fears over survival and/or recurrence
- Anxiety and/or depression
- Feeling overwhelmed
- Feeling disconnected from everyday life and social activities

- Feeling isolated
- Loss of earnings
- Loss of networks due to unemployment
- Feeling loss of control over everyday life, e.g. no longer being able to do domestic tasks
- Anger, grief, guilt and/or resentment over having to rely on others
- Financial costs associated with treatment (e.g. transport)
- Dealing with pain
- Dealing with tiredness and/or lack of energy
- Physical issues such as eating, swallowing, changes in sense of taste, touch or smell
- Altered body image
- Changes in self-confidence and self-esteem
- Distress over actual or potential loss of fertility or sexual function

Through all stages of cancer, access to psychosocial support is a critical factor in helping the cancer patient to cope, make necessary adjustments in their lives and to develop a positive outlook. Sometimes it is not possible to get this support from family or friends. There may be conflict in a family or friends may feel inadequate or incapable of responding. Sometimes there is a belief that emotional distress in someone with cancer is normal and does not require treatment. The emotional distress that accompanies cancer is significant. Heightened anxiety and depression can be a consequence and this can be further debilitating if left untreated.

Family members are also affected by cancer and can suffer levels of distress comparable to or even exceeding those of the patient. They can feel helpless, left out, guilty, or

unable to cope with new tasks arising from the family member's cancer (e.g. family chores like shopping, cooking, cleaning and washing). Young children can feel guilt when something bad happens to their parents and need to be informed and reassured. Older children need to feel informed, included and able to contribute as well as being able to participate in normal childhood activities.

Along with hospital-based psycho-oncology services, psychosocial supports that can help[1] include:

- Effective communication
- Information, especially if it is tailored to meet the needs of the individual
- Emotional support
- Empathy and active listening
- Practical assistance
- Continuity of care
- Identifying and responding appropriately to specific concerns
- Spiritual support
- Peer support
- Counselling
- Educational programmes
- Cancer support helplines

What is good practice?

Good practice is a term that is used to describe a way of working or 'practising' that is mindful of the best way to do things. In the context of cancer support, it means working in a way that is deemed best, based on a shared understanding of what works well for cancer support services in terms of meeting the needs of members/clients. Good practice means aiming to have high standards in all that you do.

Good practice is flexible, to a degree, and can evolve as services[2] evaluate their work, share ideas and learning amongst each other. Over time, systematic evaluation will build a body of evidence to further inform and strengthen guidelines for good practice.

How were these guidelines developed?

The Irish Cancer Society undertook a scoping study during which participants (drawn from existing cancer support services in Ireland and other experts) were asked for their input regarding good practice guidelines for cancer support in Ireland. The Irish Cancer Society and the researchers identified other good practice guidelines (both cancer-specific and broader supports) to inform the drafting of these guidelines. A briefing document was sent to all cancer support services in July 2010 informing them about the development of the guidelines and how they could contribute to the process. All cancer support services on the Irish Cancer Support database were sent an outline of the core topics and invited to comment on their usefulness as a resource for their work. They were also invited to add other topics that should be considered for inclusion in the guidelines. Fifteen organisations returned a completed

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1   Sources include: *Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer, 2003; Moderator's Guide. Clinical Practice Guidelines for the psychosocial care of adults, 2006.*

2   The term 'service' is used to encompass all types of cancer support groups, cancer support centres, and peer programmes.

matrix giving their input into the content of the guidelines. This represents a response rate of 29% based on a total of 52 cancer support services that were invited to respond. This feedback informed the development of the guidelines.

The researchers drafted a first set of guidelines which were discussed with the Irish Cancer Society in July and August 2010. The draft then went to the Steering Committee that oversaw the research and was discussed by the Committee on the 16th of September 2010.

A consultation process followed with cancer support services consisting of three regional meetings. These meetings were held in Dublin, Cork and Sligo. The researchers facilitated these regional workshops. Each cancer support service on the Irish Cancer Society database was invited to send two representatives to the regional meeting most convenient for them.

Nineteen representatives of cancer support services attended the Dublin meeting, ten representatives attended in Cork and 17 attended in Sligo. In addition, the Manager of Patient Support Services and the Programme Co-ordinator from the Irish Cancer Society attended each of the regional meetings to inform those attending about the Irish Cancer Society's plans for the affiliation process.

The meetings lasted for five hours during which participants gave their views on the Table of Contents for the guidelines and identified any gaps. They were then divided into smaller groups to discuss chapters of the report in more detail. They were requested to review each chapter in terms of its content, style and language and to identify any additional topics that they felt should be included.

The feedback obtained from the regional meetings and the Steering Committee informed the re-drafting of the guidelines. A final version was published by the Irish Cancer Society. The guidelines were updated by the researchers in 2013, based on feedback received and requests for new information.

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What is the purpose of these guidelines?

The mission or purpose of these guidelines is:

> *To inspire and encourage cancer support services to provide and manage their services in the best way possible.*

Guidelines set out principles or criteria as a resource to inform and guide the ethos and actions of a service. These guidelines serve to articulate what good practice means in the context of cancer support so that all cancer support services have an opportunity to learn and apply them in the course of their work.

The potential benefits of guidelines are many. These include:

- Enhancing the support offered to people who are living with cancer and their families
- Bringing consistency to practice across cancer support services
- Ensuring that all those using cancer support services, irrespective of location, will receive an equal standard of care

- Helping cancer support services become more effective where it really counts by providing supports and services of verifiable high quality for people experiencing cancer

- Giving an opportunity to build credibility across the sector and with health professionals and to underpin the importance of community-based psychosocial support for people with cancer

- Helping cancer support services keep pace with change

- Helping cancer support services fulfil their legal obligations

- Helping cancer support services ensure good governance is in place

These guidelines provide guidance on a range of topics including how to set up a new cancer support service, how to manage and maintain a service, the involvement of volunteers and paid personnel, confidentiality and data protection, the process of providing support, facilitation, advocacy and meeting responsibilities (i.e. governance).

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Who are these guidelines for?

These guidelines are for cancer support groups, cancer support centres and national peer support programmes. For convenience, all of these are referred to as 'cancer support services' or 'services' throughout the guidelines.

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How to get the best use out of these guidelines

There are a number of specific ways that cancer support services may wish to use these guidelines to support them in their work.

Some cancer support services may be starting up and at the information gathering, planning and decision making stage. These guidelines will provide structure to their planning and generate ideas about how to get their service up and running.

Some cancer support services may wish to spend time browsing through these guidelines and discussing any response that the guidelines evoke amongst members.

Some cancer support services may choose to check their own systems, processes and procedures against these guidelines and review how they work.

Some cancer support services may encounter specific challenges (e.g. death of a member, conflict within a group) along the way and may dip into the guidelines to inform how best to respond to these challenges.

Some cancer support services may wish to talk with or visit other services who also use the guidelines to network and learn from different ways of working.

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How the Irish Cancer Society can help

The Irish Cancer Society can help your cancer support service in the following ways:

- By providing links for groups to connect with each other
- By holding a repository of up to date information and resources
- By providing training for managers and volunteers
- By providing technical assistance
- By creating opportunities for networking and resource sharing among groups
- By developing and maintaining regional and national statistics for cancer support services
- By advocating with health professionals and statutory bodies on behalf of cancer support services
- By providing financial assistance for programmes and services
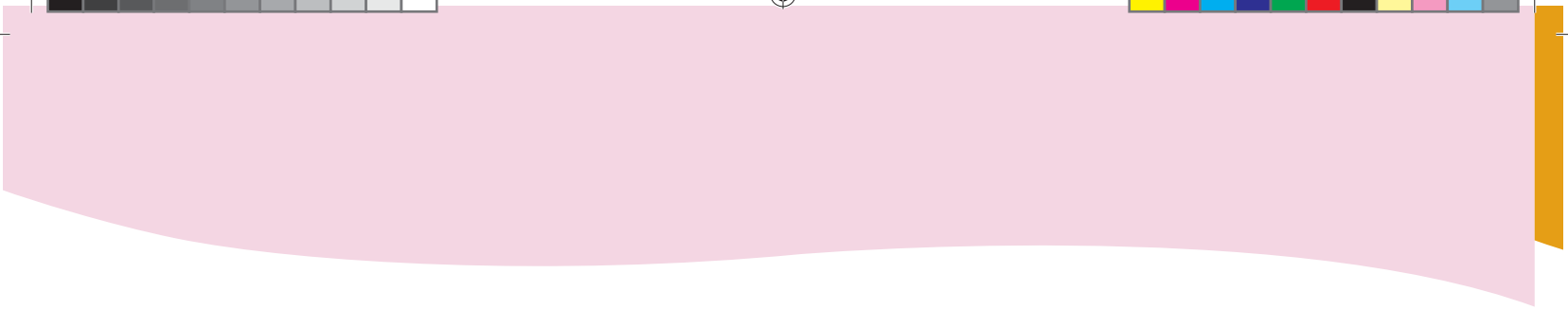
Section 2: Affiliation

What this section covers

In this section you will find information on the following:

- What is affiliation?
- Joining a network
- Irish Cancer Society plans for affiliation
- What will be the benefits?
- What will be the process?
- What are affiliates expected to do?
- How to apply?
- What will it cost?
- Statement of affiliation

What is affiliation?

Affiliation is where a group or cancer support service becomes part of a network (it can be local, regional or national). This can be a loose arrangement or it may involve a more formal affiliation process where the cancer support service has to meet certain criteria in order to become an affiliate.

Joining a network

Becoming linked to a network or joining a network can provide your cancer support service with access to information and support. It can give you contacts. It might be able to offer you some basic administration. You get to share information and learning with others.

Before joining a network you should be aware of the following:

- Any criteria that you need to meet in order to join and/or stay in a network
- Any additional administrative or financial burden joining might place on your service and budgeting and planning for this
- What the benefits of joining will be
- How your cancer support service will engage with the network and if this will impact on your existing workload
- How your cancer support service's voice will be heard in the network and how you will be informed about the network and its activities

Irish Cancer Society plans for affiliation

The goal of the Irish Cancer Society affiliation project is to increase access to and utilisation of cancer support services in Ireland using a proven model of practice and a network of support services. As part of the affiliation project, the Irish Cancer Society is developing a more structured approach to its provision of training, technical supports and grants. More training will be offered on a regional basis and affiliates will be invited to apply for specific grants to carry out measurable activities. The Irish Cancer Society will provide support to new cancer support services during their first year of development regardless of whether they affiliate or not.

Participation in the affiliation is completely voluntary.

In consultation with cancer support services, the Irish Cancer Society has created a Declaration of Good Practice. This Declaration states that the cancer support service is committed to the four principles set out in the Declaration. These principles are set out in the box opposite.

The Irish Cancer Society will provide all who wish to sign up to the affiliation a copy of the Declaration to display in their space.

The Irish Cancer Society undertakes to provide all who sign the Declaration with the technical support and training they require in order to adhere to the principles. It is understood that there is a spectrum of services in Ireland and that some will need more assistance than others.

Principles Underpinning the Declaration of Good Practice

Principles	What they mean in practice
1. Equity	• We promote equality, access and inclusiveness • We have respect for each other, our members and our clients
2. Governance	• We have a clear mission, management structure and reporting relationships • We document, organise and plan our work • We plan and evaluate all of our efforts • We comply with relevant legislation and ensure adherence to the agreed standard where no legislation applies
3. Service	• Our therapies are carried out professionally • We engage in a supervision process • Our practitioners are suitably qualified • We provide relevant vetting and training for all our staff and volunteers
4. Confidentiality	• We respect the dignity and privacy of our team and members/clients • We comply with the Data Protection Act • Our confidentiality policy is readily available and is shared with our members/clients

What will be the benefits?

The benefits of an affiliation to the Irish Cancer Society include:

- Increasing the collective strength of cancer support services in Ireland, which will ultimately benefit those people in Ireland who are on a cancer journey

- Participation in the development of guidelines for cancer support services

- Inclusion in directories published by the Irish Cancer Society and its agents

- Opportunities to apply for grants offered by the Irish Cancer Society to assist in the provision of psychosocial programmes

- Permission to use logo/trademark that clearly states the service is affiliated to the Irish Cancer Society

- Access to technical assistance

- Access to training programmes
- Access to national statistics and trends
- Increased public awareness and access to media
- Networking opportunities, both regional and national
- Participation in group applications for such things as indemnity insurance
- Brings credibility and assurance about your service to the public, Health Service Executive and health care professionals
- Inclusion in the network will enable collective lobbying at a national level
- Access to the Irish Cancer Society peer support programme
- An annual grant to assist services to attend training and technical assistance

What are affiliates expected to do?

Proposed and continuing affiliates will be expected to:

- Ensure on a regular basis that their contact information is up to date and correct and provided to the Irish Cancer Society
- Provide clear evidence of agreement with these good practice guidelines
- Show evidence of efforts to follow these good practice guidelines
- Share statistics as requested
- Participate in regional networks

How to apply

Cancer support services that wish to become affiliates should contact the Irish Cancer Society. They will be provided with an Affiliation Pack that will contain the following:

- A statement on the role and responsibilities of the Irish Cancer Society as umbrella body
- An outline of the benefits of affiliation
- A statement on the responsibilities of affiliates
- A copy of the Declaration of Good Practice
- An application form

The Irish Cancer Society will meet with new cancer support services to assist them through the application process.

Cancer support services that apply to be affiliates will be given the Declaration of Good Practice to sign and a copy of the *Guidelines for Cancer Support Services in Ireland*.

What will it cost?

Ultimately, the affiliation programme will benefit cancer patients in Ireland by ensuring they receive the best possible care from cancer support services, therefore there will be no financial cost to cancer support services.

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Statement of Affiliation

This cancer support service is affiliated to the Irish Cancer Society. We are committed to the following principles of best evidence-based practice:

EQUITY

We promote equality, access and inclusiveness.
We have respect for each other, our members and our clients.

GOVERNANCE

We have a clear mission, management structure and reporting relationships.
We document, organise and plan our work.
We plan and evaluate all of our efforts.
We comply with relevant legislation and ensure adherence to the agreed standard where no legislation applies.

SERVICE

We provide relevant vetting and training for all our staff and volunteers.
Our practitioners are suitably qualified.
Our therapies are carried out professionally.
We engage in a supervision process.

CONFIDENTIALITY

We respect the dignity and privacy of our team and service users.
We comply with the Data Protection Act.
Our confidentiality policy is readily available and is shared with our service users.

Signed:

/   /   Name and Title
                                    on behalf of the Board of Directors

Section 3: Getting Started

What this section covers

The topics that this section covers are as follows:

- About groups
- Forming a cancer support service
- The committee/board
- What makes an effective committee/board?
- Training for the committee/board
- Setting your intentions (aims and objectives)
- Doing your research
- Providing a safe place
- Promoting your cancer support service and drawing in members/clients
- Accessibility, equality, inclusion and diversity
  - *Accessibility*
  - *Equality legislation*
  - *Open or closed groups*
  - *Including people with a disability (physical, sensory, learning)*
  - *Including ethnic minorities*
  - *Gender*
- Code of conduct

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About groups

Research shows that groups, whether informal gatherings of people or more structured organisations, usually go through four stages in their development as depicted in the box below. These stages tend to occur sequentially and the time frame is open. It is also possible that groups may revisit stages as they encounter and respond to challenges, grow and develop over their lifecycle.

Stages of Group Development

Stage	What it is	Characteristics
'Forming'	When the group first comes together	• Building trust • Working out what is going to happen, when it will happen, how often it will happen • Working out who will be in the group and how the group will treat other members • Learning to work together
'Storming'	The group learns to deal with differences and different points of view	• People are more comfortable • Openness • Ideas flow • Willing to test each other's authority • Dealing with conflict • Skills and knowledge develop • Learning how to manage conflict
'Norming'	Patterns of behaviour develop and the sense of belonging and working together improves	• Identification with the group and its members • Learning how to carry out tasks • Dealing with issues • Managing conflict effectively • Making decisions • Resolving differences • Exchanging information freely • Skills and knowledge develop further • Norms for the group are established
'Performing'	The group is now able to focus on completing tasks and solving problems together	• Good communication • High morale • Things get done • Self-sufficiency • Trust • Commitment • Active engagement

A cancer support service is not a static entity; it changes and evolves over time. A group might go through many of the stages outlined above on more than one occasion, not always in sequence, and may even go back to the very start as circumstances or the status quo change.

Individual members of a group tend to take on different roles depending on their style, personality and preferred way of behaving, e.g. leading, planning, getting things done, creating a positive environment. Effective groups recognise that everyone has a role to play and each of these roles is valuable.

Forming a cancer support service

Before starting a cancer support service you need to ask yourself and your colleagues some basic questions:

- Why do you think a cancer support service is needed in your locality?
- Are there other cancer support services already in existence in the locality?
- If so, in what way will your service be different or complement them or will you work in partnership with them?
- What do you hope to achieve?
- What type of cancer support service do you want to provide?
- Who is the service for, e.g. cancer patients in general or those with particular types of cancer, family members?
- What will you need to realise this (e.g. premises, staff, volunteers, money?
- How much time and energy do you have to set up a cancer support service?
- Who else is willing to help you?
- What type of group structure may be needed?

The committee/board

A 'committee' is a structure that can help your cancer support service to get things done. Initially your committee might be an informal gathering of like-minded people who want to get a cancer support service off the ground. As your service develops, a more formal committee structure or board should be put in place.

The purpose of a committee/board is to facilitate the management and co-ordination of a service's activities. It also shares the burden amongst a number of people and can draw on the different experiences and expertise of its members. Where possible, it should include some professionals and people who have experienced cancer. It is important to recognise the strengths of committee/board members and use them to the best advantage of your cancer support service.

The committee/board is responsible for:

Strategy:

- Developing the cancer support service's principles and ethos
- Establishing the aims and objectives of the service (i.e. what it is trying to achieve and for whom)
- Developing the service's strategy (i.e. how it will achieve its aims and objectives, what resources will be needed and how they will be sourced, how its activities will be monitored and reviewed
- Making high-level decisions about the cancer support service, its activities and its future direction

Oversight:

- Determining policies and procedures for the service (e.g. human resources, financial, child protection
- Overseeing the performance of the service and its activities (i.e. is the service doing what it was set up to do, is it dealing with the client-group(s) it intended to deal with, is it adhering to good practice?)
- Appointing the manager/director of the cancer support service and monitoring their performance

Accountability:

- Being accountable to members/clients, funders and other stakeholders
- Responsibility in relation to and accountability for funding
- Compliance with legislative requirements

The sub-section on the role of the board and boundaries in *Section 10: Meeting Your Responsibilities* provides more guidance about boards. There are further sub-sections listed below on what makes an effective committee/board and developing aims and objectives.

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What makes an effective committee/board?

Committees/boards that function well have the following features:

- They understand what the job involves
- They have clearly defined roles and know where the boundaries lie between their role and responsibilities, that of management (if such exists) and that of staff or volunteers

- Meetings are chaired and run well, i.e. clear purpose with an agenda, to time, inclusive, focussed
- Adequate information is provided for the committee to make informed decisions
- Appropriate decisions are made and in a timely manner
- Conflict is resolved and not allowed to fester
- The members of the committee/board work as a team
- The members receive induction and training and are supported in their participation
- The committee/board sets aside time for strategic planning and review

Training for the committee/board

Obtaining some training for the members of the committee/board can be an important confidence booster and can clarify respective roles and responsibilities. Even when your cancer support service develops and perhaps even becomes professionalised with a professional management and staff team, revisiting training for the committee/board can help to refresh it and maintain focus on its role. New committee/board members should undergo some form of induction to make them aware of the cancer support services, the structures and issues the service is currently addressing.

Further information about training for committees/boards can be obtained from the Carmichael Centre's website (www.carmichaelcentre.ie).

Setting your intentions (aims and objectives)

Early on in the formation of your cancer support service, and before you seek funding, you should set out in writing what your service is planning to do, i.e. its aims and objectives, and how it plans to achieve these. At the very least, this will help to clarify your thinking and help you to assess the realism of your intentions.

The advantages of taking time out to think through your aims and objectives include:

- Developing clarity over who your service is for
- Deciding what range of services or supports you will offer. Remember you cannot do it all, nor should you try
- Thinking about what image you want to have for your cancer support service
- Organising your structure and deciding what tasks need to be done and who will do them
- Identifying the resources you need (money, people, venues, etc.)
- Deciding how the service will be provided and the role of volunteers or paid staff
- Giving your cancer support service credibility

Doing your research

Research will give you valuable information to guide the development of your cancer support service and to help you make decisions. To do research you need to set aside time and energy to seek out and gather information. Information can be obtained by:

- Visiting other cancer support services
- Talking to the Irish Cancer Society
- Talking to people with cancer and their families
- Talking to healthcare and other professionals
- Using the internet and searching websites
- Talking to community groups or other voluntary services
- Reading relevant material, e.g. fact sheets about cancer

The type of information that will be useful to you when you are considering setting up a cancer support service includes:

- Checking if there is a cancer support service already in the locality and if there is, finding out what type of services it provides and whether it is open to new members/clients
- Some sense of the number of people in your locality that might benefit from a cancer support service
- Some idea of the type of cancer support they would like, e.g. peer support, drop-in centre, home visiting, access to counselling
- Possible suitable venues in which to hold meetings or to provide services
- Possible links, supports and/or collaborative opportunities with other services locally, e.g. Health Service Executive, public health nurses, social workers, counsellors, therapists, General Practitioners
- Possible sources of funding and support
- The range and quality of other relevant services locally
- Working out what skills and resources you will need to get your cancer support service started
- Deciding what to call your cancer support service and checking there is not another service using this name

As your cancer support service grows and develops, you may need to carry out further research, e.g. into the needs of members/clients, to identify gaps in service provision, to obtain feedback on your service. Further guidance on using external researchers to carry out research is provided in *Section 6: Confidentiality and Data Protection*.

Providing a safe place

There are two aspects to providing a safe place: physical and atmospheric. Cancer support services in Ireland meet in a range of settings. These include purpose-built cancer support centres, local hotels, hospitals, local community halls, homes of members, rented rooms and Family Resource Centres. When selecting a venue be aware of any costs you may have to pay, e.g. room hire, insurance cover, refreshments. Agree amongst the members who will be responsible for booking, opening and closing the meeting space. Ensure that the venue can be found and is accessible.

It is important to find a neutral setting for your meetings. Meeting in people's homes is not ideal as it can present a risk to the homeowner and could create a barrier for people coming for the first time. If your cancer support service has no option but to meet in the home of one member or rotates around the homes of members, be conscious of the following:

- Accessibility for those who may have a physical impairment.
- Availability of parking
- Availability of adequate seating and seating arrangements
- Comfort levels of members to attend someone's home
- Safety and security. Only give out the address or home phone number to people you know and trust. You will need to think through how new members will be made aware of where meetings are held and who will bring them to their first meeting
- Insurance – check that the homeowner's insurance will cover people meeting in their home

Generating a positive atmosphere is also important:

- Members should be made to feel welcome and comfortable
- Rituals such as lighting candles, bringing flowers, having an opening reading at meetings, can help to create a positive and safe space
- Confidentiality must be honoured
- Make sure the meeting place is neither too hot nor too cold and is well ventilated
- Offer refreshments
- Have comfortable seating
- Build in hospitality time to meetings

Promoting your service and drawing in members/clients

Promoting your cancer support service requires some time and energy and it can often be a delicate process. Letting your community and potential members/clients know about your service has often to be balanced with conveying the important value that you place on confidentiality.

There are a number of ways in which you can raise awareness about your cancer support service. These include:

■ Briefing local community groups and services (e.g. General Practitioners, healthcare workers, counsellors, therapists, Citizens Information Centre, Family Support Centre, Community Development Projects) about your service and what it does; asking them to be aware of you and to spread the word as they go about their business

■ Producing a poster and leaflets to explain your service and putting these in selected vantage points, e.g. health centres, General Practitioners' surgeries, supermarkets, Family Resource Centres, pharmacies

■ Advertising in local press, community newsletters, community radio, Golden Pages or local telephone directories

■ Setting up a website or having your cancer support service included on the websites of others

■ Having calling cards

■ Sending out mailshots and flyers

■ Having a newsletter

■ Giving talks

Promotional material should contain information that:

■ Is honest and does not make unreasonable or unrealistic claims or promises

■ Has clear messages

■ Uses clear simple language

■ Contains relevant and accurate contact details

There is no set pattern to the way in which people are attracted to seek out the support of a cancer support service. They might see a poster, hear about it from a friend or get a referral from a healthcare professional.

The first direct contact a member/client has with your cancer support service is very important. They need to be:

■ Made welcome, e.g. with a warm greeting, offer of tea or coffee, showing them around your building if you have one

■ Made aware of the services you provide

■ Made aware of the times your service is open or available

■ Made aware of how to contact your service and book appointments, e.g. for therapies

■ Sign relevant consent forms, e.g. to avail of therapies your cancer support service might provide

Accessibility, equality, inclusion and diversity

Accessibility, equality, inclusion and diversity are terms that you will often see in guidelines and policy statements.

Accessibility means that members/clients are aware of your service, are able to find it, are able to get into it (e.g. if they use a wheelchair), feel comfortable to use it and feel warmly welcomed and included.

Equality is achieved when all members/clients, staff and volunteers are treated the same irrespective of their background, age (in the context of the cohort of members/clients your service provides support to), gender, nationality, or any other feature that might differentiate them.

Inclusion is where every effort is made to include all who need and want to use a service. Inclusive practice honours the diversity of humanity.

Diversity is where we recognise that people are different and, as far as possible, take this into consideration when planning our services, employing staff or taking on volunteers. Diversity includes people's religious and spiritual beliefs and cancer support services will recognise that there are many possibilities in this regard. It is therefore best to be neutral in the use of religious iconography or props such as symbols, statues, rituals, prayers, etc.

Cultural beliefs are many and varied and cancer support services should be open to accommodating different cultural norms and ensure that staff and volunteers are conscious of this. It is not possible to be fully aware of all cultural norms and beliefs, but asking the member/client about their preferences can go a long way to ensuring that offence is not caused. In addition, it may be necessary to provide access to language interpreters or translators in order to support some members/clients to access your cancer support service.

Having policies for each of these topics will help you to set the tone and image for your cancer support service, make fund raising easier and help your service to observe any legal requirements. It also helps you to consider how you will deal with breaches of these policies.

Accessibility

Accessibility is more than just physical access to a service, premises or event. Some key questions you might pose in checking the accessibility of your cancer support service are:

- Is the service open to all?
- How will members/clients know about your service?
- Where will you promote your service?
- Can your premises or events be reached by different types of transport?
- Are your premises or events clearly signposted?

- Can people with physical and sensory disabilities easily get into and around your premises, e.g. ramps, lifts, clear signage, good lighting?
- Are your premises or events welcoming?
- Are the opening times suitable for all members/clients?
- Could some of your procedures be simplified?
- How do you cater for members/clients with poor or no English?
- How do you communicate with members/clients who have sensory disabilities?
- How do you attract older and younger members/clients, men and women?
- How much do you charge (if anything) for services or events?

Equality legislation

No matter how small your cancer support service is you are subject to equality legislation.[1] The law prohibits discrimination on nine grounds: age, disability, family status, gender, marital status, race, religion, sexual orientation and being a member of the Traveller community. It covers employment, the provision of services and sale of goods and advertising, as well as the prevention of harassment and making 'reasonable accommodation' for people with disabilities.

Open or closed groups

Good practice is that a service or group should be as inclusive as possible and open to all. Occasionally small groups of people involved in self-help decide that their group has become large and cohesive enough that they deem it to have reached optimum membership. This is acceptable providing all members agree. However, it is important that groups practice being open, as the very nature of a group is that it is dynamic and ever changing. To maximise the natural dynamics of a group to best effect, it is useful to monitor membership, attendance and seek to grow and learn from a wide range of experiences.

Including people with a disability (physical, sensory, learning)

The equality legislation refers to making 'reasonable accommodation' for people with disabilities. Examples include adapting premises or equipment, or changing working times.

Regardless of the legislation, if you wish to be truly accessible to all persons with a disability you need to consider the following:

- Physical access to buildings and within buildings
- Transport for people with disabilities
- Use of Braille (e.g. door handles, lifts)

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1   The Employment Equality Acts (1998-2004) and the Equal Status Acts (2000-2004)

- Picture or audio or video alternatives to written text
- Disability-friendly websites
- Welcoming the personal assistants/carers of persons with disabilities (including assistance dogs)
- Providing access to signers
- Using large print in your publications
- Using email and SMS/text to communicate
- Providing staff and volunteers with disability awareness training
- Challenging discriminatory language, jokes, behaviour or literature

Including ethnic minorities

Ireland is now a multi-cultural society which includes many different nationalities and cultures. Members of our new communities and of the Traveller community can face particular difficulties in accessing services. These can include lack of awareness, limited or no knowledge of how to access and engage with services (public, private or voluntary), poor English language skills for some people coming from other countries and cultural differences to name but a few.

In order to ensure that your cancer support service is accessible to members of ethnic minorities you should consider the following:

- Translating leaflets, newsletters and fact sheets into common languages (e.g. Polish, Russian, French)
- Promoting your services in other services or places where ethnic minorities are likely to be, e.g. local General Practitioner's surgery, supermarket
- Providing access to translators and/or interpreters
- Using plain English in all communications (see www.nala.ie)
- Providing staff and volunteers with culturally appropriate training
- Challenging discriminatory language, jokes, behaviour or literature
- Ensuring that staff or volunteers do not make presumptions about religious beliefs

Gender

Women and men sometimes deal with similar situations in different ways. It is important that your cancer support service is open to the preferences of male and female members/clients. For example, men often deal with and discuss emotional issues in a different way to women and can feel uncomfortable in mixed groups, particularly if women make up the predominant membership. International literature suggests that men resist receiving help and prefer problem solving and receiving information. Some options include:

- Ensuring that discussions or topics are inclusive of the perspectives and experience of both genders

- Planning talks and giving information that will be of particular interest to men

- Having talks or discussions about practical matters, e.g. coping with no longer being able to work

- Providing 'cancer buddies' for men; other men in the group or support workers they feel comfortable with. Having a common interest can be an important success factor, e.g. soccer

- Providing access to the internet or information about useful websites for men (men often have a preference for accessing information in this way)

- Setting up a sub-group/'boys club' for the men to discuss and meet together as a group.

- Providing a telephone helpline answered by men

- Recognising that some people are more open about sharing their experiences and feelings than others and respecting those that choose to be silent

International literature suggests that women focus on receiving help and peer-based support. Women often have a preference for sharing experiences and information and discussion. For example, by having informal chats with trusted friends or through sharing a social event. Having time-out to sit quietly alone or with others is also important.

Increasingly, social networking and the internet are important sources of information and support for men, women and children. The sub-section on using the internet and assessing information from it in *Section 4: Maintaining and Growing an Effective Cancer Support Service* provides additional guidance.

Under equality legislation you cannot discriminate against potential employees or members/clients by virtue of their sexual orientation including lesbian, gay, bisexual, transgender (LGBT) individuals. Some important ground rules are:

- Publicise that all are welcome to your cancer support service

- Honour the fact that people may wish to remain private about their sexual orientation or marital status

- Use gender neutral language, e.g. 'how is your partner?'

- Be careful about assuming that everyone is heterosexual

- Encourage respect and challenge any inappropriate or discriminatory language, jokes, behaviour or literature

Code of conduct

Early in the formation of your cancer support service, it is important that you discuss and agree what values and principles will underpin your work and your service.

Some examples of the values the Irish Cancer Society suggests cancer support services should uphold are:

- Confidentiality
- Equality
- Empowerment
- Inclusion
- Honesty
- Respect
- Safety

Some examples of the principles the Irish Cancer Society suggests cancer support services should abide by are commitment to:

- Confidentiality
- Active listening
- Being non-judgemental
- Openness and sharing experience
- Supporting one and other
- Being constructive
- Including people from all sectors of society
- Quality service provision

A code of conduct should cover basic ground rules for all staff and volunteers. Examples of some of the items that the Irish Cancer Society would wish cancer support services to include are:

- Confidentiality
- Being non-judgemental
- Being aware of the changing needs of members/clients and responding accordingly
- Being aware of ones own limitations and seeking help and support when needed
- Respecting the beliefs of individual members/clients and resisting any urge to impose our beliefs on them
- Remaining neutral and not promoting outside interests within the service or to members/clients

- Ensuring that you do not give advice or answer questions when not qualified to do so

- Being open and encouraging members/clients to express their needs, preferences or wishes and not making hasty assumptions. Employ the principle of 'ask first'

- Not undermining the confidence of the members/clients in the medical treatment they receive or healthcare professionals they deal with

- Being honourable and transparent in any financial transactions

Section 4: Maintaining and Growing an Effective Cancer Support Service

What this section covers

This section provides guidance on the following topics:

- Planning ahead
- Developing policies and procedures
- Managing change and sustainability
- Ongoing communication
  - *Content*
  - *Keeping members/clients happy*
  - *Involving members/clients*
  - *Keeping in touch with donors and funders*
  - *Keeping in touch with health professionals*
  - *Public relations and working with the media*
  - *Website*
  - *Social media*
- Identifying information, self-development and training needs for members/clients
- Sourcing information, training and development
- Evaluating training and development
- Working with guest speakers
- Using the internet and evaluating information
- Complementary therapies and alternative therapies
- Developing a library
- Working with the pharmaceutical and other industries

Planning ahead

Whether your cancer support service is small or large, some degree of planning for its future is needed to maintain and grow it. At a minimum you will need to plan for your expenditure and sources of revenue to meet this expenditure. Planning gives your cancer support service focus and direction. Planning helps your cancer support service to review:

- The purpose of the service and if it continues to be relevant
- Continuing need for your services
- Potential opportunities for your service and whether or not the service should pursue these
- Potential threats or challenges for your service and how these might be overcome
- Key activities and actions that are needed to deliver your service(s)
- Resources that are needed (e.g. human, financial)
- Who else your service needs to engage with or work with (e.g. health services) and how best this will be achieved
- The progress your service is making

The sub-section on strategic planning in *Section 10: Meeting Your Responsibilities* provides more information about strategic planning. In addition, visiting the section on *Getting Started* and using it as a checklist might assist your planning process.

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Developing policies and procedures

As a service develops and grows it is important that it develops policies and procedures and that these are recorded and shared as appropriate. This will ensure continuity and consistency in how the service operates should members of staff or volunteers change. Policies set out the principles that govern particular activities of the service and which staff and volunteers are expected to follow. Procedures are clearly defined sets of action that must be followed in defined situations. They specify who does what, when and how. Policies and procedures also help to ensure that your service is conscious of and meeting its legal obligations.

Key areas that you should consider developing policies and procedures for include:

- Human resources (i.e. recruiting, selecting, inducting, training, supervising and supporting staff and volunteers)
- Financial management
- Health and safety
- Child protection
- Service provision
- Premises
- Confidentiality

Managing change and sustainability

Establishing and maintaining a cancer support service is both rewarding and challenging. Common challenges include those to do with organisations, finance, people and managing conflict. Prevention is often better than cure. Some examples are given below.

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Examples of Common Issues

Nature of problem	Some common issues	Some solutions
Organisational	• Not enough people to do the work • Membership/service usage is falling	• Be realistic about what can be done • Encourage those without roles to take up new responsibilities • Have a person dedicated to attracting new members/clients • Review how the group/service operates
Financial	• Not enough funding to do all that the service wants • Focus on funding distracts from the core mission	• Scale back your activities • Concentrate on core supports • Widen your sources of funding • Revisit your mission • Develop good systems
People	• People not getting on • Breaches in confidentiality • Dominating behaviour • Not working within 'rules'	• Deal with the issue informally first before moving onto a more formal process • Develop good systems • Provide training • Have re-election for key roles such as chairperson
Conflict	• People with different views	• Establish common values and goals • Try to resolve conflict internally first before calling in a third party • Seek the facts, discuss and negotiate • Be sensitive to people's feelings • Learn from rather than repeating mistakes

Sometimes a cancer support service needs to end. This can be for positive reasons or negative reasons. If ending is a possibility then important steps are:

■ Discussing all the options including closure

■ Making sure that closure is the right option and that all other alternatives that might work are considered, e.g. merging with other groups

■ Listing out the practical tasks that will be needed to close the service. These include engaging in democratic processes to close membership groups (there may be a set procedure in your constitution), obtaining professional help to close a company, closing bank accounts, selling assets, reallocating resources, letting volunteers or staff go, etc.

■ Putting in place alternatives to ensure continuing support for members/clients

■ Having a final meeting to acknowledge and express appreciation of the good work the service has done and to learn from the experience (some of those present may go on to form a new group)

The ending of a cancer support service can be the beginning of something new.

Ongoing communication

There are many different ways your organisation can communicate: newsletter, annual report, website, leaflets, fact sheets, magazine or newspaper articles, email, etc. The principles of good communication are:

■ Being open, honest and clear in all communication both written and oral

■ Reflecting on your audience(s) and tailoring your material to meet their needs, level and appetite

■ Having and maintaining a professional image (e.g. stationery, logo)

■ Having an external communications policy in place

■ Communicating in a meaningful way. This may mean presenting the same information in different formats for different audiences or stakeholders or it may mean gathering and presenting different information for different stakeholders or audiences

■ Keeping staff and volunteers informed of new developments or changes in the cancer support service or in areas that impact on the service

Content

Information that is provided in communications or written material (e.g. fact sheets) should be:

■ Clearly presented

■ Written in plain English (see www.nala.ie)

- Timely
- Up to date
- Honest and only contain promises and claims that are reasonable

Some tips for producing a newsletter include:

- Decide who will be the editor
- Look at the newsletters of other groups/services to get ideas and to see what you do and do not like about them
- Decide who your newsletter is targetting, but also be aware of other audiences it might appeal to
- Work out what type of news you want in the newsletter, e.g. news of events, personal stories, information about cancer, clinical articles
- Consider who will contribute to the newsletter and write articles and news pieces
- Decide what budget you have for printing and dissemination
- Decide if you are going to have an electronic version of the newsletter that can be downloaded from your website

Keeping members/clients happy

If your cancer support service is membership-based, you need to plan how you will keep in touch with members and how you will be accountable to them. There are many ways that you can communicate with members including newsletter, website, email, annual report, members' meetings, workshops, seminars and conferences.

The Annual General Meeting (see the sub-section on Annual General Meetings in *Section 10: Meeting Your Responsibilities*) is also an important forum for communicating with members and an opportunity for them to have their voice heard. Combining it with other activities, e.g. workshops or seminars, can help to keep it fresh and relevant and well attended.

Ask members/clients informally for their views about your cancer support service. Carry out short satisfaction surveys periodically (e.g. once a year) or feedback sheets at the end of training or workshops and other events.

The internet or text messaging are tools that can assist you to keep contact with your members/clients.

Involving members/clients

Your cancer support service is for its members/clients – they are its raison d'être, so it is important that you treat and respect service users as a critical stakeholder group in your organisation, particularly if they are not also the members. Their views are important in informing how well your service operates and if it meets their needs.

Ideally, members/clients should be involved in having input into all aspects of the service including service design, management, delivery and evaluation. This does not mean that they have to be actually working in the organisation. But their views are important and should be taken on board. You can achieve this through focus groups, questionnaires, suggestion boxes, meetings or inviting members/clients to sit on boards or management committees or working groups. Members/clients who sit on boards or committees or representative bodies (e.g. member/client forums) should be supported to acquire the skills to be an effective representative (e.g. assertiveness, making a case, communication, understanding meeting procedures).

Having a Charter of Rights for members/clients can be highly beneficial. It not only communicates your service's ethos and how it will treat its members/clients and their rights, but also serves to remind staff and volunteers of these things.

Having a well-publicised complaints procedure and a confidentiality policy is also important. See the sub-section on handling complaints in *Section 10: Meeting Your Responsibilities* and *Section 6: Confidentiality and Data Protection*.

If your cancer support service is membership-based, it is important to offer everyone an opportunity to contribute and be involved. This will also help to share the burden of work and decision-making and give your group access to the many skills that your members will have. Having a fixed term for key roles is a good way to share the workload and to ensure that the group remains fresh, has new ideas and does not become dominated by one or two people.

Keeping in touch with donors and funders

Wherever possible, you should make it clear who funds your cancer support service (this can be difficult if you get anonymous donations).

No matter where you receive your funding from (the general public, the State, etc.) you must be absolutely clear about what the money will be used for.

Always thank your funders and donors and report back to them on how the money they gave was spent and the benefits to your members/clients.

The internet or text messaging are tools that can assist you in keeping in contact with your donors/funders.

Keeping in touch with health professionals

You should take the initiative to keep health professionals informed about your service. Keeping in touch regularly will help allay any fears or concerns they may have and enable you to build an effective working relationship over time.

Invite health professionals to give talks or to meet with members/clients.

Include health professionals in evaluations of your service.

Give health professionals brochures, newsletters, leaflets or posters so these can be handed to or viewed by their patents.

If you receive grant aid (e.g. from a statutory body such as the Health Service Executive or a philanthropic organisation) you will probably be required to make regular progress reports and you may also have to take part in commissioned independent evaluations.

The internet or text messaging are tools that can assist you in keeping in contact with health professionals.

Public relations and working with the media

The media includes television, radio, newspapers, magazines and the internet. The media can help to raise the profile of your services, to get your message across to a wide audience, and to reach new members/clients or supporters. It can help you contribute to policy debate at local, regional or national level. It can also act as a tool for crisis management if your service receives unfavourable publicity.

Your cancer support service should develop a policy for working with the media and for responding to media enquiries. This should cover:

■ Confidentiality of members/clients

■ Identified person(s) that will act as spokesperson for your cancer support service

■ Areas that you will provide information on or respond to enquiries about and areas that you will not

Working with the media takes time and planning. You need to build and maintain relationships with relevant people in the media (e.g. journalists). You need to be able to distil what you want to say into clear, short messages.

It is important to clearly distinguish between your own personal views and those that represent your cancer support service when acting as a spokesperson. Media messages should pertain to your cancer support service and care should be taken to avoid commenting on wider public issues relating to politics, sex and religion.

The internet or text messaging are tools that can assist you in keeping in contact with your media partners.

Website

Many organisations now have a presence on the internet and a website can be an important tool to build awareness of your service, to keep people informed and up to date. Websites do not have to be complex to be effective. The rules that apply to good written communication also apply to websites:

- Keep it clear and simple
- Include basic contact details
- Invest some time in layout so that your website is easy to navigate
- Ensure that any research or information on it is reputable
- Keep information up to date
- Develop links to other relevant websites
- Keep your material attractive and interesting

You might consider having on-line registration or membership for members/clients. Other things you might include are your range of services, news items, information on upcoming events, how your service is structured, what its main policies are, your publications (including free downloads and/or options to purchase on-line), etc.

Social Media

Social media are tools that organisations are increasingly using to communicate with either specific or wider audiences. It involves the creation of content that is shared on the internet using freely available websites. The main social media outlets are as follows:

Facebook: This is used to connect people with friends and other individuals. It is used to keep in touch, upload photos, share links and videos. Organisations use it as a two-way communication channel with customers/service users or the general public.

Google+ is similar to Facebook but the user chooses which people to include in their circle of communication.

Twitter: This is used to post 140 character updates. Some people/organisations use it as a newsfeed by following prominent people or networks. Others use it as a 'chat room', yet others use it to update blogs or to share photos.

Instagram is similar to Twitter (and is often used in tandem with Twitter) with the key difference that it is focused exclusively on photos and images.

YouTube: This allows people to upload and share video content. Depending on privacy settings, others may comment and even upload their own video responses.

Flickr is similar to YouTube but with a focus on photos and images.

Linkedin: This allows professionals to connect to each other.

Blog: This is usually written by an individual about a specific topic and updated regularly.

Forum: Forums, sometimes called message boards, are online bulletin boards which allow the exchange of ideas and conversation on specific topics. Forums were very popular before the arrival of social networks such as Facebook and Twitter. While their usage has declined they still remain widely used. An example of a good forum is www.boards.ie.

App: This is a software application that is used in smartphones or other mobile devices to access content online.

Other forms of digital media include e-zines/online magazines, banner advertising, search engines and online directories.

Social media are public forums and instantaneous and can generate both positive and negative commentary. If your cancer support service plans to use social media you should appoint someone in your organisation to be responsible for managing social media accounts, including content, and appoint a spokesperson responsible for making posts. You should develop a privacy policy and display it on your sites. You should also include disclaimers to attach to online comments in order to protect your cancer support service from libel or legal liability.

Content of your social media should be relevant, interesting and useful to site users. It should be positive and constructive, open and honest.

Remember, what goes on the internet is there forever – only post that which will uphold the reputation of your cancer support service. Postings must respect copyright, privacy, fair use, data protection and any other applicable law. You should not disclose confidential information and photos of others should not be posted without their permission. Only have links to outside web sites that you trust.

Correct mistakes immediately and post that you have done so. Your manager or chairperson should be alerted to serious mistakes so that they can develop an appropriate response to minimise the impact on the organisation.

Most social media involve a 'conversation'. It is important therefore that if you use social media you are available and responsive. It would be considered rude to leave a face to face conversation mid-way – the same applies to social media. Respond calmly and constructively to negative comment or criticism and consider providing links to private communication channels such as telephone numbers or email addresses in order to deal with sensitive issues.

You should develop a social media policy for employees and volunteers. Areas it should cover include in what circumstances, if any, accessing social media while at work is permitted, who can act as spokesperson for the organisation, how feedback or commentary will be handled and by whom.

Identifying information, self-development and training needs for members/clients

Points to bear in mind when identifying information, self-development or training needs for members/clients are:

■ Encouraging members/clients to identify what training and/or information needs they have

■ Helping members/clients to prioritise this list of needs so that the most urgent need is addressed first

■ Seeking feedback from members/clients who take part in training

■ Seeking feedback about guest speakers

■ Keeping a note of what members/clients found useful or otherwise for future reference

When accessing information or training, points to be aware of are:

■ Use reputable trainers

■ Be sure that information is accurate and up to date

■ Be open to learning from other services and sharing with other services

It is useful to:

■ Have a list of reputable local counsellors and other professional supports that members/clients can be referred to

■ Have a list of useful local sources of information or websites to share with existing and new members/clients

Similarly, when identifying training needs for your staff and volunteers you should carry out a needs assessment, prioritise the training needs and seek feedback from the participants after the training.

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Sourcing information, training and development

There are many places where you could source information and training for your members/clients and for your staff and volunteers. Sources of information include the Irish Cancer Society, Citizens Information Centres, MABS, the Wheel, Volunteer Ireland, Community Development Projects, Family Resource Centres, Local Employment Service and the Health Service Executive. These organisations may also be able to direct you to quality training.

When sourcing training and development for your cancer support service or for members/clients bear in mind the following:

■ Check the credentials of trainers, e.g. by asking for curriculum vitae, asking for and checking references, checking if the trainer is a member of a professional body

- Check if the style of the trainer will suit the needs of those taking part in the training
- Meet with the trainer to brief them about the needs of those taking part in the training
- Check what accreditation or certification, if any, will be provided to those taking part in the training

Evaluating training and development

Reflecting on training, information sessions or development activities that members/clients take part in helps you to know what works well and to build up a bank of such events for future use that are worth investing in. Important things to know include:

- What went well?
- What did participants like and enjoy?
- What would participants have liked more or less of?
- What benefits did the participants get?
- What could be improved?

Working with guest speakers

Using guest speakers can be a useful way to provide information and training for your members/clients, staff and volunteers. It is important that you choose wisely. You should assess the appropriateness of what the guest speaker will be saying/presenting and any materials they plan to use. You should check out the experience of the guest speaker by asking for and checking references.

In order to get the best from a speaker you need to give them some guidance.
This should cover:

- The needs of the group
- How long the speaker has to talk
- The topics to be covered and particular angles that are of interest to the group
- The length of time they will speak for
- The format – will it be a formal presentation or a facilitated discussion?
- What tools are needed, will you supply them or should the speaker bring them along (e.g. laptop, projectors, flipcharts, handouts)?
- Whether or not you want the speaker to stay on after their speech

- Agree beforehand whether the speaker needs to be paid or not or if their expenses need to be covered. Your cancer support service may decide that all speakers are offered a nominal fee. If this is your policy it is important to let speakers know in advance before booking them
- Always thank the speaker

Finally, you need to decide if there will be a charge/fee for those attending and if so, you need to notify members/clients and any other people who may wish to attend.

If you are paying a speaker, it is good practice to carry out an evaluation afterwards to determine if the speaker met expectations and was good value for money. Even if you did not have to pay the speaker, it is still useful to get feedback from those attending as this will inform any future decisions you might make.

Using the internet and evaluating information from it

There is a lot of information about cancer on the internet, some of which is true but also some of which is incorrect or misleading. Choosing websites that provide reliable and high quality information is important. Signs of good quality include:

- The reputation of the organisation that runs the website. Is it a nationally recognised body, e.g. the Health Service Executive, or a registered charity that specialises in cancer, e.g. Irish Cancer Society?
- Names and references for medical professionals and experts who have written or checked articles
- A recent date (e.g. within last two years) on the information provided, especially medical information
- Information based on evidence from published medical research
- Balanced reporting which gives both sides of the issue
- Language which is not hyped or sensational
- No extreme claims that seem too good to be true
- Disclosure of conflicts of interest

Complementary therapies and alternative therapies

It is important to distinguish between complementary therapies and alternative therapies.

Alternative therapies are often promoted as a substitute for medical treatment. They are used instead of conventional treatment and some are dangerous. Some claim these therapies can cure cancer, but they have not been scientifically tested and proven and their side effects are unknown.

Complementary therapies are treatments that can help people with cancer deal with the emotional and physical symptoms and after-effects of cancer. Some can help with the side-effects of medical treatment. They 'complement' or work alongside conventional medicine but are not a substitute for medical treatment. They include Reiki, massage, bio-energy, aroma-therapy, Alexander technique, reflexology, acupuncture, art therapy, music therapy, yoga, etc.

Some cancer support services provide complementary therapies on-site as part of their service. For further guidance go to the sub-section on providing complementary therapies and counselling on-site in *Section 7: Providing Support*. Other cancer support services might refer members/clients to such therapies.

When discussing complementary or alternative therapies with a member/client:

- Respect their right to explore both complementary and alternative therapies
- Explain and provide support to help them make an informed decision
- Encourage them to tell their doctor if they want to use complementary or alternative therapies in case they interfere with conventional treatments
- Make sure therapists you recommend are qualified and competent (currently the sector is not regulated in Ireland)

Developing a library

People using your cancer support service will want information. Over time, it can be useful to build a library to hold all the information that you source in one place and to provide members/clients who prefer to do their own information searches with a place and source materials to do so.

Keep a record of resource materials in the library and have a system in place to keep track of borrowed material.

Working with the pharmaceutical and other industries

It is important that your cancer support service remains independent and true to its mission, values and objectives. The following guidance is based on the *Code of Practice between Patients' Organisations and the Healthcare Industry* (www.ecpc-online.org/advocacy-toolbox/code-of-practice). The code is equally applicable to working with any industry, not just pharmaceutical companies.

- Only accept funding from the industry for activities that are consistent with your service's values, mission, aims and objectives

- When you do receive funding, from whatever source, but particularly from industry, ensure that you are transparent and open about this (e.g. by referencing sources of funding in your annual report or newsletter)

- While it is important and good manners to acknowledge the organisation which provides funding for your service, it is also important to make sure that in so doing you are not naming or endorsing a specific product or project

- Advertising or promoting or endorsing prescription medicines is prohibited under EU legislation. Your service should develop a policy on the type of activities that might be considered promotional and communicate this to staff and volunteers. Some examples of these activities are provided in the box below

Examples of Promotional Activities

- Information about your service being used to promote, advertise or endorse a product or business

- Your service being quoted in a company's press release about a product

- Taking part as a speaker or participant at the launch of a company's product

- Providing unbalanced or unvalidated or incomplete information about a company's product to your members/clients

- Allowing your service's material, e.g. leaflets, magazines, newsletters, research publications, to be displayed on a company's stand at an event

- Taking part in meetings organised by a company to inform patients about specific products

- Providing testimonials about a company's product or appearing in the company's promotional material or advertisements

- Including a company's logo on your website or contributing to the website of a company

- Be very careful about accepting funding or sponsorship from industry when it has conditions attached about the design or delivery of your service, the content of training or events you are running or the choice of guest speakers you want to invite or trainers you want to use

- If you decide to include a company's logo on your website, make sure you keep their logo small

- If you need to tell the media about a product, do so in your own press release, independent of the company or industry

- Be mindful of the potential conflicts of interest and unintended consequences that can arise from attending or taking part in corporate events

- Object in writing to a company using photos, quotes, communication material or mentioning your service in their communications or at events without your express permission, and ask for a retraction

- Develop clear policies around staff and/or volunteers accepting gratuities or honoraria from companies for their input to conferences, reading papers, delivering training, etc.

- If your service does take part in conferences or seminars for patients organised and/or run by a company, insist (in writing) that no photos of you are taken without permission and a range of sources of information (not just the company) are used

- Finally, think carefully before your service takes part in industry funded, sponsored, or run training. Important questions to ask are:
  - Is there an equivalent training course available from the Irish Cancer Society or other NGOs?
  - Is the topic general or product-specific?
  - Is the training sponsored by one company or a number of companies?
  - Who has been involved in the design and preparation of the training?

Section 5: Recruiting, Training and Supporting Staff and Volunteers

What this section covers

In this section you will find information on the following topics:

- The role of staff
- The role of volunteers
- Human resource principles
- Attracting volunteers
- Valuing and caring for volunteers
- Recruiting and selecting staff and volunteers
- Garda vetting
- Inducting and initial training for staff and volunteers
- Ongoing training for staff and volunteers
- Working with trainees and students
- Supporting and supervising staff and volunteers
- Supporting staff and volunteers with a cancer diagnosis
- Exit planning
- Preventing and dealing with workplace bullying and harassment
- Good employment practices

The role of staff

The term 'staff' is used throughout these guidelines to refer to paid staff employed directly by a cancer support service. It includes people your cancer support service employs to be managers, health professionals, therapists, social workers, kitchen and house-keeping, receptionists, administrators, support workers, outreach workers, etc.

The role of volunteers

In this section we distinguish between volunteers and members of support groups. Volunteers, in the context of this section, are unpaid workers who commit time and energy through their own personal choice. They can perform many roles in a cancer support service. Some services are run and operated solely by volunteers. Others have a mix of paid staff and volunteers. Volunteers can be co-ordinators, facilitators, helpers, fund-raisers, support personnel, workers or members of a committee or board.

Human resource principles

Whether or not your cancer support service uses volunteers and/or paid staff, the same basic principles apply. These are:

- Respect
- Fairness
- Equal opportunity
- Freedom from discrimination, harassment or bullying
- Adequate resources to carry out the tasks required
- Support systems in place

Attracting volunteers

Be clear about the rationale and reasons why your cancer support service wants to use volunteers. This will help you to decide what roles and responsibilities they should have. Treat volunteers in the same way you would treat paid staff in terms of job descriptions, recruitment and selection, induction and training and support and supervision. These topics are dealt with in more detail below.

Valuing and caring for volunteers

It is important to set out why volunteers are important to your cancer support service and to communicate this. The benefits for volunteers of taking part should also be outlined.

■ Recognise the contribution that volunteers make and thank them

■ Your cancer support service should have a policy around volunteer expenses

■ Where possible volunteers should not incur personal costs as a result of their volunteering activity

■ Consideration should be given to paying out-of-pocket expenses incurred by volunteers in the course of their work for your service; anything other than this could be seen to be taxable income. Other payments could affect rights, entitlements and benefits and change the legal status of the volunteer

■ Agreed expenses should be paid promptly

Volunteers should be included in any evaluation of the service and the impact made by volunteers should be evaluated and recorded.

In order to carry out their roles effectively ensure that volunteers:

■ Understand what their role is and the boundaries of this role

■ Receive sufficient information to enable them, to carry out their roles

■ Are informed of what is expected of them and the standard required

■ Receive adequate training (ongoing as well as initial training), supervision and support

■ Are included as part of the organisation, have clear reporting lines and know who to go to with a problem

■ Are matched appropriately based on the members/clients needs and the volunteer's capabilities

Volunteers should not feel discriminated against or pressurised. Volunteers should know that they can say 'no' if they are not comfortable or feel insufficiently qualified to carry out a role or task, no longer wish to continue with the service or do not have time.

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Recruiting and selecting staff and volunteers

Good practice in recruitment and selection is about having processes in place that will ensure your cancer support service has the best people for each post, whether paid or volunteer. These should include:

■ Developing clear job descriptions for each role, including those that will be fulfilled by volunteers

- Deciding what competencies are required for each job, i.e. what skills, qualifications, personal attributes and qualities will be needed to carry out the job effectively

- Providing and communicating the service's policy on equal opportunities

- Having application forms for volunteer and employee positions

- Deciding on the selection methods. These should assess the skills and qualities of the person who has applied for the job. It might include an interview and/or role-play exercise (e.g. if someone has applied to work on a helpline)

- Checking out references

- Obtaining Garda clearance, if necessary (see below)

- Maintaining recruitment records

- Providing feedback to applicants if requested

- Reviewing the recruitment and selection process regularly

When selecting volunteers and staff it is important to be aware of potential conflicts of interest. For example, conflicts of interest can arise when board members are also volunteers or staff, or when staff members are also volunteers, either in your organisation or another.

Where former members/clients or former staff want to be volunteers, it is prudent to leave at least a two-year gap from the time they were previously with your cancer support service and taking them on as volunteers. This should be followed by an annual review.

Word of mouth is an important strategy for recruiting volunteers. Information sites you can use to recruit staff or volunteers include websites (e.g. www.activelink.ie), leaflets/posters, advertising, recruitment fairs, information meetings, registering with FÁS (www.fas.ie) and Volunteer Centres (www.volunteer.ie).

Garda Vetting

Garda vetting is where a job applicant (staff member or volunteer) to an organisation consents to the Gardaí disclosing specific information about them in terms of convictions and prosecutions.

At present, there is no legal requirement to vet staff and volunteers, although this may be introduced at some point. Many organisations choose to make it a policy to vet people who work with children and vulnerable adults and/or are responsible for finances and this would be considered good practice. However, most organisations recognise that not all staff and volunteers may need to be vetted. For example, those doing practical work, providing professional services or a range of other volunteer opportunities may not need to be vetted as they are not interacting with clients or directly involved in finance and will never have an opportunity to do so.

It is up to the organisation to decide whether or not a position requires vetting. This should be assessed while the organisation is in the process of developing the role description for each individual staff or volunteer position. Whether the staff member or volunteer is being vetted or not, it is important to conduct reference checks as these provide vital character reference information that is not available in a Garda vetting check.

Garda vetting is not generally available to organisations outside of those registered with the Garda Central Vetting Unit and designated sectors.

In order to avail of Garda vetting, organisations must register with the Garda Central Vetting Unit. The designated sectors for which Garda vetting is currently available are:

- HSE and agencies funded by the HSE where work will involve children or vulnerable adults
- Teaching in primary and second level schools
- Youth work (and certain sports organisations)
- Childcare work
- Work in care homes for older people
- State employees
- Those covered by the Private Security Service Act 2004

Most cancer support services will not be registered with the Garda Central Vetting Unit because they do not meet the criteria set out above. However, as it is well recognised that it is good practice to ensure that people working for you are vetted, Volunteer Centres provide a Garda vetting service to local voluntary organisations that are not registered and that do not have access to an Authorised Signatory within their own organisation.

Your organisation will be required to sign an agreement giving the Volunteer Centre the authority to act on your behalf as an Authorised Signatory for Garda vetting purposes.

Your organisation will be expected to have certain policies and procedures in place before commencing Garda vetting, e.g. confidentiality policy, data protection policy, Garda vetting policy. Templates for all of these policies are available through the Irish Cancer Society's affiliation programme.

For details on how the process works, please contact your nearest Volunteer Centre. If you are not familiar with your local Volunteer Centre, contact Volunteer Ireland, the National Volunteer Development Agency at www.volunteer.ie.

Information provided by candidates to your organisation for a vetting procedure and the results of that procedure is considered to be sensitive personal information under the *Data Protection Acts*. The consent given by a candidate to your organisation to request a Garda vetting is specific to your organisation. You should not share this information or the vetting results with another organisation, even with the consent of the candidate [1]. This means that each organisation must make a separate application for Garda vetting for each candidate.

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1   An exception to this is where an organisation is undertaking the vetting on behalf of a related organisation.

It is good advice to suggest that people keep a copy of their completed application form so that they can refer to it if they make further applications for Garda vetting.

It is not recommended that you keep a copy of the application form. Vetting results must be stored in a secure manner with access to it restricted to a small number of authorised personnel. Under the *Data Protection Acts*, personal data must be destroyed when the manner for which it was sought has expired. The Office of the Data Protection Commissioner recommends that vetting results and all other personal data collected during the recruitment process should be routinely deleted after one year.

Induction and initial training for staff and volunteers

Staff and volunteers should receive initial induction and training. Induction should cover:

- An introduction to the cancer support service, a tour of the facilities and an introduction to other people working in it
- Basic cancer awareness
- An introduction to policies and procedures. Having a written employee handbook and volunteer handbook can be an important tool to inform staff and volunteers about your policies and procedures and to keep them up to date with any changes to these
- Procedures for emergencies and fire and reporting accidents or untoward incidents
- Management structure and reporting lines
- What training and supervision is available
- Initial training in the area of work, if required
- Familiarising the new recruit with the cancer support service's principles and ethics

Staff and volunteers should be educated about the different stages of the cancer journey and how different people respond to these stages.

The induction might also cover working with a 'buddy' to learn the job (i.e. someone who is familiar with the job and capable of passing on necessary skills) or 'shadowing' other workers until the new recruit is familiar with what is done and how it is done in the service.

There should be a probationary period (e.g. four months) which allows for the performance of new staff and volunteers to be reviewed before confirming an appointment to a job or volunteer post.

Ongoing training for staff and volunteers

It is important to remember that training should not just be once-off when a staff member or volunteer is recruited, but should also form part of the ongoing development of staff and volunteers. There are many new developments in the area of cancer support and cancer treatment and it is important that your staff and volunteers are kept up to date, both in terms of information and their skill sets. Training is a way to show that you value your staff and volunteers. It also supports sharing of knowledge and experiences and networking. It is important that you have a budget for ongoing training.

All training should be based on a needs assessment:

- What skills does the person already have?
- Do these skills need to be updated or improved?
- Does the person need training in new skills?

The cancer support service should evaluate the training offered to staff and volunteers. This can be achieved by:

- Asking participants what they thought of the training
- Observing what impact, if any, the training has in the workplace
- Periodically engaging in a formal evaluation process

Further information on training courses can be obtained from the Irish Cancer Society website (www.cancer.ie), the Carmichael Centre (www.carmichaelcentre.ie) and the Wheel (www.wheel.ie)

Contracting with volunteers

Even if your cancer support services does not provide formal training to volunteers it is important that you 'contract' with volunteers. This should cover:

- Expectations of the volunteers and what the volunteer can expect from your cancer support service
- The level of commitment the volunteer is prepared to give
- Boundaries of the role of the volunteer and the work they will do
- Confidentiality and data protection
- Code of conduct
- Times and nature of work
- Entitlement or otherwise to payment/refunding expenses
- Participating in training and supervision
- Insurance cover

The volunteer involvement in your cancer support service should be actively managed, whether by a line manager, board member or person dedicated to managing a volunteer programme in your organisation. When issues arise, adopt a solution-based approach. Common issues that may need to be addressed include:

■ Being late (e.g. do the hours need to be changed?)

■ Not attending (e.g. ring the person to see why, suggest they take a break for a while)

■ Appearance and hygiene (e.g. have a dress code)

■ Personality clashes (e.g. listen and if necessary reassign)

Asking a volunteer to leave is a matter that needs to be handled with sensitivity. It is important to develop criteria for terminating a contract with a volunteer. This will ensure that the process is transparent.

Working with trainees and students

Trainee therapists or students might offer to work for your cancer support service *pro bono* or seek work experience. You should not take on such trainees or students unless you have adequate systems and structures in place. These should include:

■ Induction and initial training

■ Supervision and support for trainees and students on work experience

■ Supervision of the work of trainee therapists by an experienced and qualified therapist. This is essential and if you cannot put this level of supervision in place you should not take on trainee therapists to work in your service

■ Use of a 'shadow' system or pairing with an experienced member of staff. Even when you have this system in place, the trainee therapist or student should not work with members/clients for at least four to six weeks

■ Adequate insurance cover

■ Ongoing monitoring and appraisal

Members/clients must be informed that the therapist supporting them is a trainee and written consent for this should be obtained from the member/client.

Supporting and supervising staff and volunteers

It is important to understand how loss and bereavement affects everyone in the cancer field, including your staff and volunteers and to have appropriate support mechanisms in place. It is important that staff and volunteers have access to support, particularly if they are dealing

with traumatic situations or listening to traumatic stories. Staff and volunteers can suffer from vicarious trauma if they are not made aware of the potential for this and how to recognise, prevent and deal with it.

Staff and volunteers can be supported through:

- Time for debriefing
- Training in self-care
- Access to peer support
- Access to external supervision
- Access to relaxation therapies or techniques
- Line management
- Regular communication with colleagues (while being mindful of confidentiality)
- Group meetings/team meetings
- Newsletter, notice boards or other means of keeping staff and volunteers informed
- Team building exercises, e.g. team training, social events, planning days, staff and volunteers having tea breaks or lunch together
- Thank you or celebration events

Staff and volunteers can also be supported to be aware of and to learn about self-care. This includes:

- Getting proper nutrition and rest
- Maintaining social networks and engaging in enjoyable activities
- Having someone to talk to (without breaching confidentiality) or a co-facilitator to share the workload
- Limiting imagining of distressing events or situations
- Using positive imagery
- Being aware of how they are feeling
- Having closing rituals or ways to release tension, e.g. after a session with a member/client.
- Having clearly defined roles and responsibilities

There should be an appropriate system in place to supervise staff and volunteers. This can include:

- Monitoring the work and performance of staff and volunteers by a manager, to ensure that potential problems are caught early on and addressed (e.g. through reminding, retraining, reassignment, motivation)

- Annual appraisals which discuss the job, training and development needs, and individual targets. Staff and volunteers should be afforded the opportunity to refresh and update their role through training or development or to change roles within the organisation and should not stay in a specific role for long periods of time, unless they have very specialist expertise

- Procedures for handling disciplinary matters and grievances. These should include time-scales and procedures for a resolution

The procedures for training and development, supervision, support, appraisal, discipline and grievance should be reviewed regularly to make sure they are relevant and appropriate and to make any changes needed to improve them.

Supervising Staff and Volunteers with a Cancer Diagnosis

Receiving a diagnosis of cancer is a distressing time for any staff member or volunteer of your cancer support service. You need to be conscious of the physical and emotional effects of cancer on the staff member or volunteer and on their colleagues. While this will be obvious to some, it is important to ensure that managers and supervisors have a basic understanding about cancer, its effects and its treatment. This will help them to be an effective support to the staff member or volunteer that has received a diagnosis of cancer. Putting in place a policy to address serious illness will also provide guidance for your manager and supervisors and will help to address many of the questions a staff member or volunteer may have about their work when they become seriously ill.

Communication

Sensitive communication through all stages of supporting the staff member or volunteer is very important. For example, provide a private confidential space for the person to discuss matters relating to their cancer with their manager/supervisor, show empathy and listen to what they have to say, give them space and time to express their emotions and remain calm. Consult with them whether or not they want colleagues and/or clients to know they have been diagnosed with cancer. The staff member or volunteer may need time off to digest a recent diagnosis and to be with family and friends or, they may not be able to return to work at all. Agree a communication plan with them – what should be communicated, by whom, to whom and when. Discuss what supports may need to be put in place for them and keep a written record of this.

Staff who become seriously ill

Be prepared to be flexible and to accommodate a staff member who expresses a desire to work for as long as possible. Cancer and its treatment can result in fatigue and be emotionally draining and the person may be unable to work for long periods of time. Flexible options you might consider include flexi-time, working from home, part-time working, reduced hours, lighter duties and more rest breaks. However, be conscious that it is not advisable for the person to work alone in case they become ill or need assistance.

Depending on the person and the nature of their cancer and treatment plan, some staff may require time off and/or sick leave, while others may be able to continue to work through their treatment. You should have a clear policy in place regarding sick leave over and above statutory requirements and this should be reflected in contracts of employment. Staff members who become ill are protected by employment legislation and may return to work if a medical practitioner declares them fit to do so. However, as an employer you have a duty of care to your employees and it is important to that you put in place support mechanisms to ensure a successful return to work.

If an extended absence from work means that you need to put temporary cover in place, discuss this with the staff member so they understand why this is necessary. Discuss any permanent or substantial changes to working conditions that may be necessary either during their cancer treatment or after their return to work with the staff member and confirm the agreed changes in writing, signed by them.

As you well know, a cancer diagnosis can have significant financial implications for an individual, e.g. extra travel costs, healthcare costs, reduction in income, etc. This can be particularly the case if the person feels they need to resign or retire early. Having worked in a cancer support service may make it more difficult for someone to discuss things like welfare entitlements and the financial consequences of a change to work. Sometimes having a professional relationship with service providers can create a barrier for people when they may need to seek support for themselves. Try to be sensitive to this possibility and encourage the person to ensure their needs are being met.

Volunteers who become seriously ill

People who volunteer do so for many reasons. As with employees, you have a duty of care to your volunteers. When a volunteer is diagnosed with cancer and you become aware of this, you should provide a private space and time to discuss their situation with them in a confidential manner. You should have a clear policy on whether or not a volunteer may continue with your cancer support service when they receive a diagnosis of cancer. The Irish Cancer Society recommends that volunteers should be encouraged to take time out from volunteering from the cancer support service for a suitable period, a minimum of one year and preferably two, in order to have an opportunity to integrate the experience of their cancer journey.

Clients of a cancer support service who express a desire to become a volunteer should be welcomed but encouraged to take a break period of at least one year from the time they cease to be a client to the time they return as a volunteer. This is essential to ensure that your former client is physically and emotionally ready to deal with cancer in this new context. It also seeks to minimise any ethical issues you might face if your former client offers to volunteer out of feeling beholden to your organisation. Put a clear policy in place with regard to a suitable break period. After the break period, if the person still wishes to be a volunteer they should undergo the normal recruitment process, induction and training offered by your cancer support service and should be given a probationary period of six months doing work that does not involve contact time with clients of the cancer support service, e.g. fundraising, administration, etc. If this probationary period proves successful and there is a suitable role, then the volunteer can commence contact time with clients.

Returning to work

Keeping in touch with staff members or volunteers who take time out while on their cancer journey can ease their return to work. However, it is important that such communication is sensitive and is not perceived to be a form of pressure to return early.

Have and document a conversation with the staff member or volunteer about their return to work and agree a plan with them regarding their return.

Use a supportive and phased approach to a person's return to work. Provide flexible options to ease the staff member or volunteer back into work and put additional supervision and support mechanisms in place for the first six months after their return. Offering access to training in self-care, self-resourcing and mindfulness can be a good resource to those returning from illness.

Some staff members or volunteers may decide not to return to work or may be unable to return to work. It is important that you recognise their contribution to your cancer support service in some way. You should ask the staff member or volunteer if they would like some kind of event to mark their time with your organisation.

Death of colleagues

Sadly, some staff members or volunteers who receive a cancer diagnosis will be very seriously ill and may pass away. Even when this is expected, it can still come as a shock to work colleagues. You should personally inform close colleagues of the person of their passing and then inform the rest of the organisation soon afterwards. Have an open door for colleagues who are upset and wish to talk about the passing of the staff member or volunteer. It may even be necessary to arrange access to bereavement counselling for some staff members or volunteers.

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Exit planning

There should be an appropriate system in place for staff and volunteers ceasing to work with your cancer support service. This can include:

■ Written policies on the circumstances in which employment/volunteering can be terminated and the processes for doing so, including any appeals system

■ Exit interviews

■ Procedures to be followed where staff and volunteers themselves decide to leave the service.

■ Providing staff or volunteers who are leaving with references

■ Planning for the retirement of staff or volunteers

■ Planning for redundancy

When a staff member or volunteer leaves your cancer support service, it is useful to reflect on what can be learned from the experience.

Courtesy calls to volunteers who have retired or voluntarily left your cancer support service ensure that their hard work is appreciated and not forgotten, and that the door is open for them to return and/or be a champion of your service.

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Preventing and dealing with workplace bullying and harassment

Bullying and/or harassment can have serious psychological, physical and behavioural impacts on individuals who are the subject of bullying or harassment. These can include depression, mood swings, headaches, nausea, shaking, sweating, crying, forgetfulness, etc.

Bullying in the workplace has been defined as repeated inappropriate behaviour conducted by one or more persons against another or others that undermines the individual's right to dignity at work.[2]

Sexual harassment is defined as any form of verbal, non-verbal or physical conduct of a sexual nature, which violates the person's dignity and creates an intimidating, hostile, degrading, humiliating or offensive environment.[3]

Non-sexual harassment is defined as any act or conduct that is unwanted by the recipient and that is related to the discriminatory grounds set out in legislation.[4]

It is the responsibility of the employer to ensure that employees (including volunteers) are protected from harassment, not only by members of staff or volunteers, but also by members/ clients and other people whom the employee comes in contact with. It is important, therefore, that you have a policy and clearly defined procedures for dealing with bullying, sexual harassment or harassment should they arise.

Your policy should define what bullying, sexual harassment or harassment mean and set out how your organisation will deal with such complaints. It should also assure employees and volunteers that they will be protected against intimidation, victimisation or discrimination for making a complaint or assisting in any investigation of a complaint. Communication and providing training in your policy can play a key role in preventing bullying or harassment in the workplace.

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2   Based on a definition provided in the Code of Practice under the Industrial Relations Act and the Safety, Health and Welfare at Work Act.

3   Based on definitions provided in the Employment Equality Acts, 1998-2008.

4   The equality legislation covers nine grounds – gender, sexual orientation, marital status, age, disability, race, family status, religion and membership of the Traveller community.

Should an incident arise the key steps include:

- Maintaining confidentiality
- Discussing with the employee or volunteer who is being harassed if they wish to deal with the matter in an informal or a formal way
- Investigating complaints fully and impartially, including discussing the complaint with the individuals involved separately
- Taking action

Good employment practices

To summarise, the core elements of good employment practice include:

- Having job descriptions, including required competencies, for staff and volunteers
- Having written contracts of employment for staff
- Having written contracts for volunteers. These can be less formal than an employment contract
- Having a written staff policy and a written volunteer policy and/or handbook that is kept up to date to reflect any changes in employment legislation or regulations or internal policies and procedures
- Ensuring equality of opportunity in recruiting and selecting staff
- Ensuring that staff and volunteers are not discriminated against
- Inducting new staff and volunteers
- Using a probationary period
- Providing initial and ongoing training and development
- Having systems to supervise, support and appraise staff and volunteers
- Having flexible work practices and arrangements that support a good work-life balance where possible (e.g. time in lieu, career breaks, study leave)
- Having written disciplinary and grievance procedures for staff and volunteers
- Having policies regarding pension contributions and health care cover for staff
- Keeping up to date with employment legislation. See *Section 11: Where to Find Further Information* for a list of the main relevant legislation
- Seeking legal advice on the nature of contracts for service and contracts of service. The former generally refers to services that are purchased or contracted, while the latter generally refers to employment situations

If your cancer support service is in doubt about any of its legal obligations, then seek legal advice.

Section 6: Confidentiality and Data Protection

What this section covers

This section addresses the following topics:

- What is confidentiality?
- Information policy
- Managing information
- Gathering personal data from members/clients
- Direct marketing
- Right to access
- Recording information
- Storing information
- Using computers
- Using external researchers

What is confidentiality?

Confidentiality is a core principle of cancer support. This means that you do not talk specifically about the member/client (particularly naming them), their issues, views, personal details or medical history to anyone else without their express permission. This includes casual conversations you may have with friends, family, neighbours, health professionals, etc.

Your cancer support service should have a written policy about confidentiality. There are a few special circumstances in which confidentiality may have to be breached. Wherever possible in these circumstances you should obtain the consent of the member/client involved but this may not always be possible. These special circumstances are:

■ When there is immediate risk of possible harm to the life of the member/client

■ When required by a court of law

■ When a child is deemed to be at risk of current or immediate abuse, whether by disclosure by a child, a member/client or other person

Information policy

It is very important that your cancer support service develops a written policy covering confidentiality and the management of information. This policy should be communicated to members/clients, members of the governing body (e.g. committee or board), staff and volunteers. It should be reviewed regularly and kept up to date to take account of new legislation or other relevant developments.

Managing information

Two Acts are relevant to information. The *Freedom of Information Acts, 1997* and *2003*, give a patient/client the right to access a copy of any healthcare record that applies to them held by a public body. If any person or service provides a service for a public body under a contract for service, then that person or organisation is also covered by the Acts.

The *Data Protection Acts, 1988* and *2003*, protect an individual's right to privacy with regard to any data that is kept in hard (e.g. manual files) or electronic format (e.g. computer records). Under the Acts, such records must be accurate. Where necessary, they must be kept up to date. The *Data Protection Acts* apply to your cancer support service and to any of your staff, volunteers, members/clients who separately collect, control or process personal data. An individual has the right to know about the existence of such records and to access them and have them amended or corrected if they are incomplete, incorrect or misleading.[1] You can get copies of the Acts from www.irishstatutebook.ie.

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1   Under the *Data Protection (Access Modification) (Health) Regulations, 1989*, access to records may be refused in certain circumstances.

Copyright is another area that your cancer support service should be aware of. For example, you may like a particular booklet or piece of research and wish to copy it. Copyright is breached when a person or organisation does anything with the work without the copyright owner's consent. Certain uses of a work may be allowed, for example when the work is sufficiently acknowledged.

> **If your cancer support service is in doubt about any of its legal obligations, then seek legal advice.**

Gathering personal information from members/clients

If you gather personal data from your members/clients:

- Be clear why you are collecting the personal data and for what purpose
- Be clear who will have access to personal data
- Tell the person you are obtaining information from why you are gathering the data
- Personal data should only be gathered for a specific and/or lawful purpose and not used inappropriately
- Gather personal data that is necessary and relevant but not excessive
- Personal data should be gathered and processed fairly
- Reassure the person you are obtaining information from that it will be kept safe and secure and will be retained for no longer than is absolutely necessary
- Inform people you are obtaining personal data from that they have the right to access the personal data records you keep about them and to request that any errors or omissions are corrected

Direct marketing

Direct marketing can involve interactive marketing, direct mail (postal or electronic), telemarketing and SMS text messaging.

Some organisations use it to market themselves. Others use it as part of their fundraising strategy. No matter what you use it for or how, your organisation must comply with the Data Protection Acts (1998 and 2003) and the Data Commissioner's guidelines on direct marketing (see www.dataprotection.ie for guidance). You must obtain the consent of an individual to use their personal data for direct marketing. You must provide opt-ins and opt-outs as appropriate:

- opt-ins are where explicit consent is required to market to the person, e.g. text/email/mobile calls to individuals and businesses

■ opt-outs give the person the option not to receive direct marketing, e.g. postal marketing to individuals, all forms of direct marketing to existing customers, most forms of direct marketing to businesses

Right to access

Under the *Data Protection Acts (1988 and 2003)* a person has the right to access personal data that you keep about them. They have the right to have their records corrected. Your cancer support service's policy on data should clearly state how access to records and requests to amend data kept on record can be made. For example, must such requests be made in writing or on a form (recommended) or will you accept requests by telephone, email or text (not recommended).

Recording information

Records of members/clients:

■ Should be factual, consistent and accurate

■ Should be legible if hand-written

■ Should contain useful and relevant information (e.g. relevant disclosures about treatment, correspondence)

■ Should not include any derogatory remarks, unnecessary abbreviations or jargon, or irrelevant personal opinions

■ Should be dated and signed, particularly if more than one person makes entries into a record

■ Multiple records or supplementary files on one individual should be avoided. Keep a single record wherever possible

■ Members/clients should have the right to access and view their records and to correct any factual inaccuracies in them

■ If your organisation has a quality assurance system, regular audits of the quality of records and record keeping should form part of this system

Storing information

Information about members/clients should be stored in a secure place (e.g. locked cabinet or a password protected computer file). Unauthorised access, alteration or destruction of personal data should be prevented. If you keep electronic files a few simple rules communicated to staff and/or volunteers will keep data protected:

- Be conscious of member/client confidentiality in all that you do
- Always log-off when work is finished on any file or application
- Do not leave computer terminals or laptops unattended when logged in
- Do not share logins with other people. Have separate access identities for different people who need to access the same records
- Change passwords at regular intervals
- Avoid using passwords that are short, or use words or names associated with the member/client
- Use a password-protected screen-saver to prevent casual viewing of member/client information
- Do not have one member/client's file open on screen while seeing another

If you keep manual records, the key features of data protection are:

- Keep records closed when not in use to avoid accidental viewing
- Records should not accessible to the general public
- Records should be stored securely (e.g. locked cabinet)
- Records should only be available on a 'need to see' basis
- Records should be formally booked out of a filing system, returned as soon as possible and tracked if transferred elsewhere
- Records should be arranged so that they can be found easily if required urgently

The names, addresses, telephone numbers and email addresses of any member/client should never be revealed to a third party without the specific consent of the member/client.

Using computers

Computers now form an important part of our world and it is becoming increasingly difficult to operate an organisation without their use:

- If your cancer support service has more than one computer then ideally they should be networked
- If your cancer support service has many computers then having a separate server should be considered
- Use only legitimate licensed software
- Have systems in place to block computer viruses and keep anti-virus software up to date
- Files should be backed-up regularly and preferably on an ongoing basis

- Passwords should be used to protect access to sensitive member/client information
- Store computer files safely, e.g. off-site, in a safe
- Have a policy on internet and email usage, including personal use

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Using external researchers

In the event of your cancer support service employing the services of an external person to conduct research or an evaluation of the work of your service, it is important to check the ethical practice of the evaluator/researcher. It is also important to ask how sensitive information will be gathered and stored.

The researcher/consultant should inform those providing information to the researcher that no individual will be named or identifiable in any reports.

If you want to carry out research involving your members/clients, invite them to take part on a voluntary basis.

Section 7: Providing Support

What this section covers

In this section you will find guidance on the following topics:

- Types of support
- Developing a self-help group
- The process of providing support
  - *Confidentiality*
  - *Building trust and respect*
  - *Being non-judgemental*
  - *Identifying needs*
  - *Listening*
  - *Questioning*
  - *Reflecting*
  - *Giving information*
  - *Sharing stories and experiences*
  - *Supporting members/clients through disease progression, loss or bereavement*
  - *Recognising your limitations*
  - *Reviewing and reflective practice*
- Family support
- Emotional support
- Survivorship programmes
- Providing support to terminally ill members/clients
- Home and hospital visiting
- Providing practical support
  - *Boundaries*
  - *Referral*
  - *Form filling (e.g. for Carer's Allowance, medical card, social welfare entitlements)*
- Providing telephone support
- Providing email support
- Providing a drop-in centre
- Providing therapies or counselling on-site
- Providing a transport service
- Respite as a source of support
- Dealing with disclosure
- Working with professionals – doctors, nurses, therapists, counsellors and others
- Self-care, support and supervision for support workers

Types of support

Cancer support services can offer as narrow or broad a range of services as meets the needs of their members/clients. These can include:

- Self-help group
- Family support
- Information – general (e.g. rights and entitlements) and/or cancer related
- Professional counselling
- Complementary therapies
- Telephone helpline
- On-line support group
- Access to health professionals
- Transport services
- Befriending, home or hospital visiting
- Drop-in centres

No matter what type of support your cancer support service offers or plans to offer, the principles of equality, inclusion, honouring diversity, respect and confidentiality should apply. *Section 3: Getting Started* and *Section 6: Confidentiality and Data Protection* provide guidance in this regard. You should also revisit the sub-section on psychosocial support in the *Introduction*.

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Developing a self-help group

The section on *Getting Started* should be read, especially the sub-sections on doing your research, setting your intentions and providing a safe space. *Section 8: Facilitation* will also provide you with useful guidance.

The early stages of a group's formation tend to set the scene for future patterns, (e.g. all female, all male, couples, younger or older age groups) so it is important to think through your goals in relation to the make-up of your self-help group.

Through a range of processes including referral, family members making contact with the group or some initial members drawing together, a first meeting of the self-help group will be arranged. The first meetings will be formative, where the group will discuss its ethos, mission, values, process and logistical arrangements.

New members should be met in advance, at least twice, to understand their needs and expectations and to prepare the new member to join the group, whilst honouring the existing group members. This process of drawing in new members may be done by the group's facilitator or by member(s) of the group who feel comfortable explaining the process and introducing the

new member. The new member should be given a contact number. Some groups organise a mobile phone for the group and this is held by one of the members or the facilitator, or it can be rotated around different members of the group.

New members will need to know the following:

- Who to contact if they wish to join the group
- How the group might benefit them
- Meeting times, duration and venue
- Values and principles, particularly around confidentiality
- Guidelines around punctuality and confirming attendance
- Brief description of the process of meetings and the facilitation role

Respond to any questions that new members pose.

In an open support group it is important to convey that it is okay for a member to leave the group whenever they wish and also to return at some later time.

There is no optimum time or form for a self-help group. You need to choose the model that best suits the needs of your members and make a plan around this.

The process of providing support

This section describes the main features of providing support to a member/client on a one-to-one basis or in a group setting.

Confidentiality

- Always seek permission before revealing personal details of people you are helping to others
- Keep group membership details to yourself
- Another person's story is their own and must be treated with respect
- During group meetings, the experiences of those who are present are all that is relevant and the group should resist discussing the issues of those who are absent
- Be meticulous with all personal information, files or notes from meetings or telephone conversations and ensure that they are retained in a secure place, e.g. locked filing cabinets, and not left lying around
- Lock away confidential information (whether in filing cabinets or password protected computers). When a member/client no longer needs the service, safeguard or destroy any personal care notes
- Always seek permission before referring a member/client to a professional or other service
- Always seek permission before you make any information public that will identify an individual

Building trust and respect

- Value what the member/client has to say
- Ask the member/client how they feel about their situation
- Listen to their views and needs
- Ask what support they feel they have (e.g. from family, friends) and if it is helpful
- Be genuine in your expressions

Being non-judgemental

- Be impartial
- Be gentle and encouraging with your members/clients and be careful about making any assumptions – always ask
- Work at remaining neutral and detached and resist taking sides
- Accept people as they are, without judgements about a person based on their address, appearance, speech, nationality, etc.
- Be careful in your use of language and clichés and seek to be encouraging in your choice of words and expressions. For example, do not use judgmental phrases such as 'can't you pull yourself together?'
- In group situations, take active steps to encourage and include those who are different, e.g. members/clients from ethnic minorities, and to put them at ease

Identifying needs

The role of the support person is to help the member/client to manage their situation more effectively and to support them to identify their needs (e.g. self-empowerment). The needs of members/clients will vary and are likely to include any or all of the following:

- Someone to listen
- Someone to give support
- Someone to advocate
- Self-help group
- Information
- Referral
- Respite
- Access to services
- Counselling
- Practical help

- A place or events to relax and receive respite from distress or worries and to restore the heart, mind and spirit
- Understanding, both in terms of empathy and knowledge

Listening

- How you listen is more important than what you say
- Let the member/client dictate the pace of conversations – do not rush to fill the gaps of silence or take over the conversation
- Maintain eye contact
- Listen attentively and without interruptions and avoid changing the subject
- Confirm that you are hearing what they have to say, e.g. by nodding your head
- Read the member/client's body language
- Clarify that you are receiving the message correctly, e.g. by asking, 'Can I check that you are saying …?'
- Reassure the member/client about confidentiality
- Be mindful of your body language and choose open, positive and encouraging modes of expression, e.g. being attentive, leaning slightly forward, sitting with uncrossed legs, good eye contact, serene facial expression, open hands. Avoid fidgeting and looking at the clock or your watch

Questioning

- Ask open questions, e.g. 'how did you find out about your cancer?', 'what information are you looking for?'
- Help the member/client to find their own solutions through questioning rather than presenting a solution that may not be theirs
- Be mindful of body language (see above)
- Clarify the messages you are receiving, e.g. by asking, 'Can I check that you are saying …?'
- Use 'when', 'who', 'what', 'how' questions to get the facts of a situation
- Avoid questions starting with 'why' as it can sound like an interrogation
- Only use challenging questions when you have developed a trusting relationship with the member/client
- Use positive questioning to help the member/client to recognise their strengths and to consider the future
- Ask only one question at a time

Reflecting

■ Practice looking at the world from the perspective of the member/client

■ Summarise and paraphrase what the member/client has said – this will help you to clarify the messages and also help the member/client to become clearer about what they want to say

■ Be aware of the feelings behind the words (e.g. from the tone of voice, gestures, posture)

Giving information

■ Start by finding out how much information the member/client already has

■ Information must be accurate and as up to date as possible

■ Break down lots of information into smaller, more manageable blocks – do not overload the member/client all at once

■ Information should be given impartially – let the member/client consider options and choose You can help them think through the decision or refer them to someone else who can help, but do not make the decision for them

■ Check that the member/client understands the information they have been given and knows how to use it to manage their situation

■ Have a basic understanding of what cancer is, the various types of cancer, the main treatments and palliative care

■ Have a basic understanding of how cancer affects health and well-being and what can support better health and well-being

■ Do not give false reassurances

■ Do not initiate discussion about alternative or unproven treatments. Stick with evidence-based methods

■ Allow the member/client space and time to make their own choices, offer quality and accurate factual information. Resist making judgements and offering advice

Sharing stories and experiences

■ Sharing stories and experiences can help a member/client to feel that they are not isolated, to share with others with similar difficulties and to learn from the experience of others

■ Allow members/clients to express themselves and let all who wish to have their say

■ Be prepared to share your story and experiences with the member/client if this is what they seek

■ Stories should be relevant and supportive to others in the group

■ In a support group, if someone is particularly distressed and needs to talk, give them the time and space they need

Supporting members/clients through disease progression, loss or bereavement

Members/clients can suffer many different types of loss as their cancer progresses including health, bodily function, income, job, social networks, sexuality, body image, role in the family, and the death of a loved one.

■ Recognise that everyone reacts differently to loss and respond with sensitivity to this

■ Show that you care

■ Understand the meaning of loss and the impact it can have on people affected by cancer (e.g. by reading, getting training, asking your manager)

■ Be aware of how hearing about loss or the death of a member/client you work with can impact on you

■ A listening ear and empathy can be the most valuable support you can provide

■ Let members/clients express their emotions or feelings – encourage this expression

■ Know what type of practical help you can offer or can access, e.g. help with cooking, shopping, funeral arrangements

■ Know where you can refer a member/client for help, e.g. if they are depressed

■ Be aware that you often cannot make a difficult situation different, but you can help to make it more manageable

■ Be aware that in a group situation some members can feel uncomfortable with those who have advanced disease and the latter can feel unwelcome. Do not be tempted to segregate, if at all possible. Instead, encourage and support members to talk about their feelings and experiences and invite speakers who can talk about palliative care to meetings

■ Some people may choose to opt out of their treatment. It is important to recognise and respect that this is their choice and that they are entitled to support

■ Deal openly with the death of a group member or loved one of the member/client and spend time to reflect and remember

Recognising your limitations

■ Ask for help or support if you are unsure of your role

■ Take part in training and supervision and avail of supports

■ Be courageous and say 'I don't know' if a member/client asks you a question that you do not know the answer to, and vow to make an effort to get an answer for them from someone who does

■ Actively encourage members/clients to be independent as opposed to becoming overly reliant on you. Let them know that there are others who can support them

■ Explore when a member/client needs counselling or therapy

■ Accept that some personalities do not get along and in some instances there made be need for a change

Reviewing and reflective practice

■ Reflective practice is a form of evaluation that can be used to review how a session has gone, how a group meeting went, what people thought about a guest speaker, etc.

■ Invite members/clients to share how they felt about the session/meeting/speaker, etc. how it helped them, what they learned, what they would wish for more or less of

■ Use this information to learn and improve your service

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Family support

If your cancer support service is considering providing support to families it is important that you do not duplicate existing family support services in your local area.

The guidance contained in this section as well as that provided in the *Section 8: Facilitation* is also relevant to providing support to family members or groups of families.

If your cancer support service provides support to children, it is imperative that written consent from parents/guardians is sought and granted before you commence working with children. The guidance in the sub-section on child protection in *Section 10: Meeting Your Responsibilities* is also relevant.

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Emotional support

Cancer patients can find it difficult to talk about their situation to their friends or family. A cancer support service can provide the opportunity to talk to someone who understands and has been through a similar experience and to help the person overcome any awkwardness they may feel about talking to others about their circumstances. A key aspect of providing emotional support is to show empathy (not sympathy), i.e. that you acknowledge and show sensitivity to the feelings and emotions of others.

Emotional support needs that your service should be prepared for include supporting people to:

■ Manage their fears about recurrence of cancer

■ Cope with the frustration of not being able to do things for themselves or the things they used to do

■ Cope with fears about losing their independence

■ Feel in control

■ Cope with feeling bored and/or useless

■ Make the best use of their time

- Deal with changes to their normal routine, activities or lifestyle
- Deal with concerns about their family's worries or fears
- Ask for and to accept help
- Cope with changes in the attitudes and behaviours of others towards them
- Find out what they can do to help themselves
- Deal with stress
- Access support to deal with anxiety or depression
- Work through their feelings about death and dying
- Maintain a positive outlook – practising hope
- Deal with financial worries

International research indicates that people have different preferences for support depending on the level of psychological distress they are experiencing and it is important that you are aware of this. The box below summarises the main points from a recent piece of research into this.[1] People with low to moderate levels of distress generally prefer informal sources of human contact such as family, friends, their General Practitioner and exercise and complementary therapies. People experiencing high levels of distress prefer talking therapies such as counselling and psycho-oncology, medication and support groups. The research found that neither group liked self-help booklets, leaflets or the internet.

Preferences for Support for Psychological Distress

Level of Distress	Preferred Sources of Help
Mild to moderate	- Informal, e.g. family, friends - Exercise - Relaxation, e.g. massage, yoga - Complementary therapies - Self-management - General advice from General Practitioner - Talking therapies, e.g. counselling
Severe	- Talking therapies, e.g. counselling, psycho-oncology - Medication - Support groups

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1   Based on Walters, K., Buszewicz, M., Weich, S., King, M., *Help-seeking preferences for psychological distress in primary care: effect of current mental state*, 2008, British Journal of General Practice.

Survivorship programmes

Increasingly, more and more people are surviving cancer. However, living with cancer and beyond is not easy and can be traumatic. Cancer survivors may have an increased risk of recurrent or secondary cancers as well as suffering from physical, emotional or practical issues as a result of their cancer and its treatment.

Survivorship programmes aim to empower cancer survivors by imparting survivorship skills and knowledge and by providing emotional support. They can include many forms and some examples are given below:

■ Emotional support

■ Education, including lifestyle education

■ Physical rehabilitation

■ Survivor-to-survivor mentoring

■ Support groups

■ Information provision

■ Drop-in centres

■ Patient navigation skills

■ Links with healthcare providers

■ Practical support, e.g. insurance, estate planning, finances

■ Care planning

■ Supported self-management

Common topics that survivors might like to have addressed are set out in the box below.[2]

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Common Survivorship Topics

Topics	Examples
Physical	• Rehabilitation, after effects of treatments, behaviours that will promote health.
Emotional	• Fear of recurrence, gaining hope, living with uncertainty, emotional effects and supports.
Practical	• Financial planning, communicating with healthcare providers, finding and evaluating resources.

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2   Based on Lance Armstrong Foundation, *Livestrong. Resource for Cancer Survivors.*

No matter what the component parts of a survivorship programme it should:

- Be clearly thought out with clear aims and objectives
- Include a comprehensive needs assessment for the member/client
- Focus on empowering the member/client
- Provide relevant information and/or education
- Help the member/client to develop coping skills. For example goal setting, planning for the future, self-management, self-advocacy, stress management, problem solving

Providing support to terminally ill members/clients

Terminal illness and death are difficult topics for people to talk about and in some cultures talking about it is taboo. In our desire to be positive, we can inadvertently exclude the person who is terminally ill by not recognising the reality of their situation and being open about it. As a result, the terminally ill member/client may not feel able to talk about their situation and this can deprive them of the opportunity to express their fears, hopes, anger, acceptance or despair. It also means that other members/clients, staff and volunteers are deprived of the opportunity to learn from members/clients who are terminally ill.

Being open about terminal illness can help the member/client in many ways including:

- Helping them to work through negative feelings
- Allowing them to plan for their death

Key elements of good practice in dealing with terminally ill members/clients include the following:

- Be open about terminal illness and death. It is the only certainty we all have
- Make the cancer support service a comfortable (not awkward) place for the member/client to be
- Enable the member/client to talk about their feelings and to express their emotions. But also be aware that some members/clients may not accept that they are dying
- Keep in touch with the terminally ill member/client if they cannot attend your cancer support service, e.g. by phone, text, home visits
- Offer to help the terminally ill member/client to prepare for death. For example, by listening to them, letting them know they will be missed, helping with funeral arrangements, talking about how they would like to be remembered, accessing other services or practical help for them
- Be aware that other members/clients may feel uncomfortable or find the situation difficult and offer them support

■ Offer support to other members/clients and staff and volunteers who are in contact with the terminally ill member/client to deal with the loss of a member/client. This may mean for example providing training or talks on understanding bereavement and grief, offering access to bereavement counselling, attending the funeral, having a remembrance book, or setting up a support group

■ Remember the carers and bereaved and offer them practical and/or emotional support

For information about training go to the Irish Hospice Foundation website (www.hospice-foundation.ie) and the Irish Association of Palliative Care website (www.iapc.ie).

Home and hospital visiting

Visiting someone in their home can create risks that may not be immediately obvious, particularly if the person lives alone. Assessing risks that might arise must be given careful consideration to protect the volunteer/staff member, the member/client and your organisation. The sub-section on managing risk in *Meeting Your Responsibilities* provides further guidance.

Important features of a home and/or hospital visiting programme are:

■ Ensuring a good match between the visitor and the member/client

■ Monitoring the match between the visitor and member/client and seeking feedback from the member/client about the match

■ Establishing clear boundaries and understanding by both the member/client and the visitor of the role of the visitor, including what needs can or cannot be met by the visitor, the number of visits, the length of visits, contact by telephone and email (i.e. 'contracting')

■ The visitor being sensitive to the feelings and concerns of the member/client

■ The visitor being knowledgeable about the journey of cancer

■ The visitor being able to provide reliable information that the member/client trusts

■ The visitor engaging in active listening

■ The visitor being respectful of the person and their wishes, including what they want to discuss and the level of engagement

■ The visitor being supportive

■ The visitor abiding by requests made by the hospital, e.g. visiting times

Providing practical support

Many people with cancer can experience significant change in their daily lives and find it difficult to manage things they previously could do easily such as cooking, shopping, getting out and

about, socialising, etc. Your cancer support service needs to be clear on what type of practical support staff and volunteers can give to members/clients and to communicate this to both your staff/volunteers and to members/clients.

Boundaries

Cancer support *is not a substitute* for professional healthcare, but a complement to it. There is increasing evidence that cancer aftercare that is planned between the patient and healthcare professional and that promotes self-management improves quality of life and survivorship.[3] This process can be supported by cancer support services through the provision of information and education programmes and providing access to psychological supports, such as stress management, or complementary therapies.

The role of cancer support is not to substitute for other services but to work in tandem with other services. For example, if a person has financial difficulties, the cancer support service should inform the person about other sources of support (e.g. Irish Cancer Society, Money Advice & Budgeting Service (MABS), Community Welfare Officers, Society of Saint Vincent de Paul, etc) and refer them if necessary, but it should not pay that person's bills.

Under current EU legislation, the promotion of prescription medicines is prohibited and cancer support services must ensure that they do not engage in activities that could be associated with the promotion of prescription medicines. Guidelines for cancer support services define 'promotion' quite broadly and include speaking at seminars or launches of companies' products, being quoted in a company's literature or appearing in commercials for a product, disseminating unbalanced or unvalidated or partial information about a product, etc.[4] Cancer support services should clearly identify promotional activities that could compromise the service in respect of prescription medicines.

Referral

In order to refer effectively to other services, staff or volunteers need to be aware of:

- The nature and relevance of services or supports provided by the organisation to which they plan to refer a member/client
- That the organisation and services they plan to refer to are reputable
- The referral protocols and procedures of the organisation or service and whether or not specific eligibility criteria apply

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3   For a summary see for example Fenlon, D., Foster, C., 2009, *Care after Cancer: Research evidence supporting Macmillan's promotion and trialling of a new approach to cancer aftercare based on four key principles*, Macmillan Survivorship Research Group, University of Southampton School of Health Sciences.

4   See *Code of Practice between Patients' Organisations and the Healthcare Industry*, 2009, European Cancer Patient Coalition http://www.ecpc-online.org/advocacy-toolbox/code-of-practice.html

Form filling (e.g. for Carer's Allowance, medical card, social welfare entitlements)

The State system for claiming benefits can seem confusing to someone who has not used the system before. Providing access to information and assisting the person to fill out forms can greatly reduce their levels of stress and anxiety. Cancer support services are encouraged to build relationships with their local Department of Social Protection (formerly known as Community Welfare Officers) and Citizens Information Board, both of whom may be happy to provide outreach services on your premises. (www.welfare.ie)(www.citizensinformation.ie)

Providing telephone support

It is inevitable that when you have a telephone, there will be some element of support required for people who ring your service. Your staff and volunteers should be clear about the level of support they can offer over the phone. However, if you plan to provide more formal telephone support as part of your service there are many things that need to be considered, such as:

- Ensuring that information is factual and accurate
- Ensuring that no extreme claims are made
- Ensuring that only those with relevant professional expertise provide medical information
- Ensuring that adequate training has taken place and there is a consistent standard in call handling
- Providing information about cancer and treatments and therapies that is based on evidence from published medical research
- Ensuring the information provided, especially medical information is up to date (i.e. within last two years)
- Using language that is not hyped or sensational
- Disclosing conflicts of interest
- Maintaining adequate caller records (see *Section 6 Confidentiality and Data Protection*)
- Adhering to confidentiality policy (see *Section 6 Confidentiality and Data Protection*).

If you are considering setting up a helpline, please refer to The Helplines Association www.helplines.org.uk which offers very good advice and support for helpline service providers.

Providing email support

Email is another way that you can provide support and information. Email support can appeal to people who are housebound, who live in remote areas, who find it hard to be available at set times or require flexibility, or who prefer anonymity. Refer to the guidance given above

regarding the telephone and the process of providing support, including giving information. The sub-section on using the internet and evaluating information from *Maintaining and Growing an Effective Cancer Support Service* and the section on *Confidentiality and Data Protection* are also relevant to an email support service. If an email query requires expertise beyond what you can provide, you can refer the enquirer to the Irish Cancer Society email service – helpline@irishcancer.ie or get their permission to forward the email on their behalf.

Providing a drop-in centre

A drop-in centre can be a useful resource to members/clients in terms of access to information and social networking. Good practice in the provision of a drop-in facility includes:

- Warm, friendly greeting
- Ask the person how they might be helped
- If needed, explain the service and what it can offer to new members/clients
- Inform existing members/clients of new developments or services in the centre
- Allow the member/client to use the service without pressure, e.g. if they wish to browse reference material
- Allow the member/client to supply details about themselves and their needs in their own time and words and at their own pace
- Have guidelines for the type of enquiries volunteers can deal with and the type that a member of staff must deal with
- Ensure that any promises or undertaking are realistic and can be delivered

Providing therapies or counselling on-site

Some cancer support services have on-site therapies or counselling services. Good practice in the provision of such services includes:

- Ensuring that staff, or counsellors and/or therapists on contract are fully qualified and competent and have a reputable track record
- Ensuring that members/clients have medical consent to take part in therapies (from General Practitioner or Oncologist), particularly if they are in treatment
- Offering the member/client the first available appointment
- Conducting a needs assessment for the member/client by the therapist/counsellor, followed up with regular reviews
- Where an accreditation body is in place, therapists/counsellors should be a member in good standing and provide a copy of their accreditation

Providing a transport service

Some cancer support services provide transport services for their members/clients, e.g. buses, volunteer drivers. Important decisions that need to be made in respect of such a service are:

- Who is it for – will there be eligibility criteria?
- What type of transport service will be provided?
- Who will provide the service, e.g. staff, volunteers, paid contractor?
- When will it be provided, e.g. times of day and days of week?
- What locations will it cover, e.g. from home to specific hospitals?
- Will it be free?
- How will members/clients access the service? Will they have to be referred to it?
- How will members/clients make an appointment/book the service?

Good practice in the provision of this type of service includes:

- Ensuring that any volunteers or other service providers used to transport members/clients are qualified to do so. They should have a full and clean driver's licence, roadworthy vehicle, proof of insurance and valid NCT documentation. Ask for and check out references
- All volunteer drivers should undergo Garda vetting
- Ensuring that volunteers providing transport have notified their insurance company about their role as a volunteer driver. The insurance company should be prepared to confirm that the volunteer's insurance will cover them at no extra cost. If this is not the case, the Irish Cancer Society may be able to help you in dealing with insurance companies or in getting access to group schemes
- Obtaining written consent from the member/client to take part in the service and to agree to its rules
- Clearly communicating to volunteer drivers the nature of their commitment, e.g. time, days of the week
- Providing relevant training to any volunteers and ensuring that they have completed it satisfactorily before commencing as a driver for your service. This should include confidentiality, privacy, the boundaries of their role, what to do in emergencies, record keeping (e.g. logs of journeys)
- Having a clear policy that is communicated to volunteer drivers about the reimbursement or otherwise of expenses, e.g. petrol
- Having a written contract with any transport company or other commercial contractor that you might use to provide the transport service
- Having a complaint procedure to handle any possible complaints from members/clients and/or drivers

Respite as a source of support

Members/clients or their families, either individually or collectively, can benefit from respite outside of the home environment. Respite involves constructive activities and/or an opportunity for some time away. A period of respite should enable the person to come back rested and better able to cope. Examples of respite include having a group weekend away, going to a conference, availing of a respite service and doing workshops in self-care. A good example of this is the Lakelands Area Retreat and Cancer Centre, which offers a range of residential programmes of varying length (www.larcc.ie).

Dealing with disclosure

It is important to know there may be times when a member/client shares something that evokes a sense of responsibility, i.e. an imperative to report to the authorities or draw on external advice. Examples include murder, child abuse, rape, suicide and self-harm. Your cancer support service should develop a policy and prepare in advance how you are going to manage such disclosures if they arise. The Irish Cancer Society can provide you with advice. There are also training courses available to help groups to deal with these issues. Also see the sub-sections on child protection and elder abuse in *Section 10: Meeting Your Responsibilities*.

Working with professionals – doctors, nurses, therapists, counsellors and others

Health professionals can be directly involved in your cancer support service, e.g. by providing health services on-site, by facilitating self-help/support groups, or indirectly through referral (either from them to you or from you to them).

Your cancer support service should be clear on the level of direct involvement by health professionals in your service as this has implications for its image, ethos and members/clients.

Involving health professionals in your cancer support service can have many benefits, e.g. practical help, professional expertise, independent voice, access to services, credibility. It is important that you and they are clear about the nature of their involvement and how they will engage with your service. It may take time for your cancer support service and health professionals to learn to work together.

Health professionals or any other professional, e.g. counsellors or therapists, will only refer patients to your service if they:

■ Are aware of its existence

■ Know who the service is suitable for

■ Have confidence in the quality of service

■ Know your service is responsible and safe

■ Understand the range of services offered

■ Can see that patients will benefit from the service

You might consider inviting professionals to visit your service or to give a talk to members/clients. Similarly, you might suggest that your service supports member/client consultation exercises or gives talks to professionals about the experience of those with cancer.

If your cancer support service refers members/clients to healthcare or other professionals, it is important that you:

■ Establish a good working relationship with the service or professional you are referring members/clients to, e.g. by listening to their concerns, understanding their perspective, knowing how their service operates, staying in touch

■ Understand eligibility criteria (if any)

■ Follow agreed referral protocols (e.g. you may have to complete a referral form)

If your cancer support service uses external therapists or refers members/clients to therapists it is important that you:

■ Use a qualified and experienced therapist who adheres to a code of conduct and fits with the ethos of your service

■ Obtain recent references from similar work

■ Ask to see their insurance cover

■ Agree if there will be a fee for the services. If there is a fee, check if this is standard

■ Agree the length and frequency of sessions if a therapist is coming in to support a group

■ Ideally, choose a therapist who has worked with people with cancer at different stages

Self-care, support and supervision for support workers

Volunteers or staff who provide support to members/clients, particularly on a one to one or group basis, should be consciously aware of the impact of other people's stories on them (this can lead to burn-out or vicarious trauma). Some basic tips in self-care for the person giving support include:

■ Getting proper nutrition and rest

■ Maintaining social networks and doing enjoyable activities

■ Having someone to talk to (without breaching confidentiality) or a co-facilitator to share the workload

■ Limiting imagining of distressing events or situations

- Using positive imagery
- Being aware of how you are feeling during a session
- Having closing rituals or releasing tension at the end of a session
- Having a clearly defined role and responsibilities

Supervision is an additional source of support and guidance for support workers. This is a model adopted from the counselling profession based on the principle that the carer or helper needs support and coaching too. Supervision should offer a safe, separate and confidential space for support workers to receive support and to talk through their experience and any challenges that they face.

The process of supervision should help the support worker to build on their skills and experience. The ideal arrangement is to meet periodically (at least once every three months) and devote time to reflect and review.

Supervision can be provided in a number of ways:

- Internal supervision is where a line manager provides supervision for the support worker
- Professional supervision is where an external professional, usually a psychologist, provides supervision
- Peer supervision is where support workers come together to share their experience and to learn from each other

Training is another means of providing support and of showing that the support worker is valued.
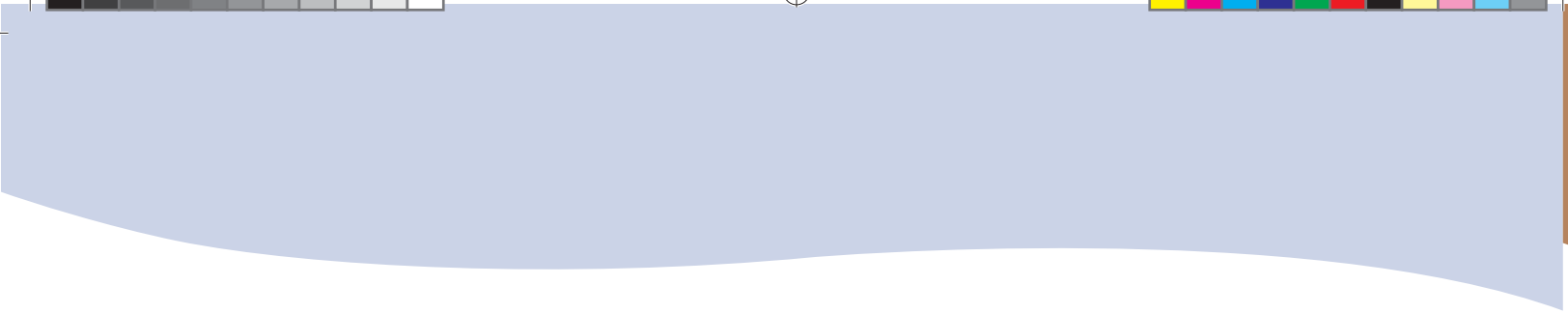
Section 8: Facilitation

What this section covers

This section covers the following topics:

- What is facilitation?
- How is facilitation different from co-ordination?
- Managing group meetings
- What are the competencies of effective facilitators?
- Boundaries of the facilitation role
- Facilitation tool kit
- Troubleshooting for facilitators
- Support and supervision for facilitators
- Training for facilitators

What is facilitation?

The purpose of facilitation is to guide a group of people to achieve its purpose and to ensure that the group abide by their values and principles. It is about honouring the members/clients and easing the group process in response to the needs of members/clients.

Informal facilitation is where a group discussion is led or guided by a person (or a group of people) who may not be formally trained in facilitation but who support the members/clients of the group in a facilitative way. This is often how facilitation occurs in self-help groups. As the group grows and develops and gains experience, the members/clients who facilitate it may decide to get formal training in facilitation in order to hone their skills.

> **If members of a self-help group guide discussion at group meetings and facilitate members to tell and share their stories and experiences, it is recommended that they receive training in facilitation.**

If you need help to source facilitation training, the Irish Cancer Society can help.

Formal facilitation is where a trained facilitator supports the group. This person may be a professional such as a psychotherapist, psychologist or healthcare professional. The group might be a closed group that is tailored to the specific needs of its members, e.g. bereavement, specific types of cancer, different stages in the journey of cancer. It could be an open group where members/clients come and go. It could be a psycho-educational group, which is time-bound with a definite beginning and end and these groups are often topic-specific.

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How is facilitation different from co-ordination?

The role of the facilitator is to provide opportunities for positive group experiences, to guide conversations and discussions, to ask open-ended questions, to steer the group to possible solutions and to foster a caring and safe atmosphere.

Facilitation is achieved through personal attributes, a set of skills and certain tools and techniques. Effective facilitation is determined by the skill set of the facilitator and his/her personality and motivation. It is recommended, therefore, that all facilitators supporting cancer support services be trained in facilitation. A good facilitator will be self aware, self assured and self-developed. They will invest time in their own continuous professional development e.g. through reading, practising, reflecting and attending training to build up his/her skill set.

The role of the co-ordinator is to bring the different elements of a group together to make sure it works well. It is not essential that a person receive training in co-ordination. Good inter-personal and organising skills are important, however. It is also important that the co-ordinator is aware of the boundaries of their role.

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Managing group meetings

Both co-ordinators and facilitators can be involved in different roles when managing group meetings. In some cases, the facilitator may also be the co-ordinator of the meeting.

The co-ordinating aspects involve:

- Arriving ahead of members/clients to prepare the room
- Welcoming members/clients as they arrive
- Opening the meeting
- Drawing attention to the ground rules for the group, in particular confidentiality
- Outlining any particular agenda items or prior commitments
- Introducing any guests
- Administrative details, if relevant, such as timing of next meeting, announcing any guests, events of interest
- Agreeing any next steps
- Inviting feedback

The facilitating aspects of a group meeting include:

- Facilitating the discussion and being attentive to each person as they speak and all points of view, including those that including those that may cause disruption or conflict within the group
- Allowing space to discuss any challenges or difficulties that individual members/clients bring up in the context of their own personal experience and the topic under discussion
- Allowing time for responding to stories, challenges, or emotions as they arise, including emotional support, giving information, sharing experiences in support of a member/client in particular need
- Facilitating the identification of any additional support needs of members/clients, e.g. referral to counselling, one to one support
- Inspiring reflection and creating a space for silence and peace
- Inviting feedback
- Drawing the meeting to a close with warmth and hope and making sure people leave the meeting with a sense of support

What are the competencies of effective facilitators?

Volunteers, staff, health professionals or advisors can carry out facilitation.

The core competencies of an effective facilitator include:

- Self awareness and self confidence and being able to balance this with the needs of the group. The facilitators should know their own limitations and be themselves

- Empathy through active listening, understanding each perspective, being able to read and manage the energy and mood of the group, and being open to new ideas and information

- Ability to guide, not control. The facilitator makes it easier for the group to achieve its aims. The facilitator does not determine the aims and outcomes, the group does

- Flexibility. The effective facilitator will be able to adjust to meet the needs of the group on a particular day. This means that some days the intended work or agenda does not get done. Some people may not be ready for a group but they still need support. The facilitator should be prepared to give this to them on a one to one basis until they are ready for a group session

- Process-driven rather than task-driven. The facilitator must trust the process and the resources and experience of the group as well as their own instincts. How things are done is more important than what gets done. The facilitator must be open to different ways of doing things if one way is not working and respect the wishes and preferences of the group. A good measure of creativity helps. Being able to ask for information or support from the group members is also an important attribute

- Organisational skills, e.g. planning, preparation, time management

- A sense of humour, as appropriate, to lighten the mood and laugh at themselves and with others

- Being inclusive by achieving a balance in the time and attention given to members/clients and creating a safe space where every person can contribute. This may mean breaking a larger group into smaller groups so that quieter people get a chance to participate. The facilitator must also have the skills to know when to let a member/client just be

- The skills to open up a group at the beginning of a meeting and seal up a group sensitively and safely at the end

- The skills to build the confidence of the group, to challenge the group to grow and to manage the challenges as they arise within the group, particularly traumatic or conflict situations

- Knowing when to refer a member/client for supplementary or professional support

The above skills are learned and honed through experience and professional accredited training.

Boundaries of the facilitation role

All roles have boundaries, which impact on the quality and effectiveness of the facilitation. Some of the pitfalls to watch out for are:

- When the process of facilitation crosses over into counselling
- When the process of facilitation crosses over into directing
- When the process of facilitation crosses over into taking control
- When the process of facilitation crosses over into friendship

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Facilitation tool kit

The tool kit of the facilitator is built up over time and through experience. It contains a set of skills, exercises, templates, books/manuals, contacts, referral opportunities and ideas that will facilitate the group process and includes:

- Warm up exercises
- Listening exercises
- Solution focused problem-solving exercises
- Relaxation
- Reflective practice templates
- Self-care exercises
- Crisis/trauma supports
- Creativity
- Meditation
- Silence
- Contacts and reputable referral options
- Resources, e.g. books, reflections, poetry, music, quotes
- Being aware of own body language and reactions when listening or responding to speakers
- Being able to read the body language of others
- Mindfulness

The role of the facilitator can be complex and even lonely. Sharing facilitation with another person (co-facilitation) can be a good way to overcome this. It also means that while one person is working with the group, the other can listen and observe the interaction and body language. The co-facilitators can also support and debrief each other after each session and share the workload of organising or follow-up work.

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Troubleshooting for facilitators

From time to time the group will encounter challenges and it is important to see these as opportunities to learn and grow.

If there is conflict within the group, the facilitator first seeks permission from the group to look more closely at the issue. They then gather all the facts and discuss the underlying issues and emotions, bringing these out into the open, and agreeing a course of action. The process should be managed with a simple, direct, open session, but also recognise that it may take time and more than one session to resolve.

Some people can feel uncomfortable sharing their story or speaking out in a group situation. This can make other members of the group feel anxious or uncomfortable. If and when such instances occur, the facilitator needs to explore the underlying causes. Key questions to guide this process include:

■ Do members/clients feel excluded or discriminated against?

■ Do members/clients feel that trust or confidentiality has been broken?

■ Do members/clients feel that there are cliques in the group operating their own agenda?

■ Do members/clients feel shy?

■ Do members/clients feel that their story isn't 'big' enough or serious enough to discuss having heard the stories of others?

■ Do members/clients feel frightened by the stories of others?

If someone is being disruptive, the group needs to challenge this. The facilitator should be aware of who is interrupting, who is listening, who is responding, who speaks very little, and when the disruptive behaviour happens. Rather than trying to discourage the domineering person, the facilitator should encourage others to participate. The facilitator may need to get the group to break up into smaller groups or pairs to give everyone a chance to express themselves.

People can get angry when discussing their experience of cancer. While it is important to let the person express their anger, it is equally important to ensure that the anger is not directed at any one individual in the group. Clarify what the person is angry about and ensure that people feel supported. Acknowledge that anger can be a normal reaction and get the rest of the group to discuss situations in which they got angry. Take short breaks if necessary. Facilitate the group to talk about what happened in the meeting and what they would like to happen next.

The facilitator also needs to be prepared to deal with tears. People who express their emotions through tears should be given the space to do so. Ask if they would like a tissue. Talk quietly with the person and ask what they would like to happen.

Section 7: Providing Support gives guidance on how to deal with loss and bereavement.

Support and supervision for facilitators

Facilitators should be consciously aware of the impact of other people's stories on them. Some basic tips in self-care for the facilitator include:

- Recognising the symptoms of burn-out[1]
- Getting proper nutrition and rest
- Maintaining social networks and doing enjoyable activities
- Having someone to talk to (without breaching confidentiality) or a co-facilitator to share the workload
- Limiting imagining of distressing events or situations
- Using positive imagery
- Being aware of how you are feeling during a session
- Taking a break or holiday
- Having finishing rituals or releasing tension at the end of a session
- Having a clearly defined role and responsibilities

Supervision is an additional source of support and guidance for facilitators. Good practice supervision will offer a safe, separate and confidential space for facilitators to receive support and to talk through their experience and any challenges that they face. The process of supervision should help a facilitator to build on their skills and experience. The ideal arrangement is to meet periodically (at least once every three months) and devote time to reflection and review. Supervision can be provided in a number of ways:

- Internal supervision is where a line manager provides supervision for the facilitator
- Professional supervision is where an external professional, usually a psychologist, provides supervision
- Peer supervision is where facilitators come together to share their experience and to learn from each other

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Training for facilitators

Facilitation is a complex and important role. It is recommended that all facilitators, including volunteer facilitators, receive training in facilitation. There are many good courses available. A starting point is the Irish Cancer Society (www.cancer.ie) who can help you to source training. Another good source is the Carmichael Centre (www.carmichaelcentre.ie).

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1   These can include feeling frustrated, hopeless or helpless, low energy, mentally or emotionally or physically drained or tired, unable to get adequate sleep, not feeling satisfied when completing tasks, having a sense of failure, not being able to hear the stories of others.

Section 9: Advocacy

What this section covers

In this section you will find information on the following topics:

- Advocacy – What and Why
- Types of advocacy
- Features of effective advocacy
  - *Clarity of purpose*
  - *Clarity of understanding*
  - *Clarity of boundaries*
  - *Communication, feedback and reflection*
- Advocating on behalf of individuals
- Advocating on behalf of groups
- Representation

Advocacy – What and Why

The concept of advocacy provides a useful parameter with which to define the different ways Community and Voluntary organisations attempt to add to the "public good". Advocacy is defined as the pursuit of influencing outcomes - including public policy and resource allocation decisions within political, economic, and social systems and institutions - that directly affect people's current lives.[1]

Advocacy is a *process* of supporting an idea, a person or a group because, for some reason, they need another to operate on their behalf. It is a form of communication that involves explaining or expressing an issue or a need on behalf of another with a view to evoking a response or influencing a desired change. This can be a change in attitude and/or behaviour, a change in the way a service is accessed or delivered, or a change in society, policy, practice or legislation. According to the Oxford English Dictionary, to advocate is to plead on behalf of; to argue in favour of; to recommend publicly. In short, advocacy is a process of speaking or acting on behalf of another, by explaining their situation and expressing their needs so that they can access the appropriate support or services.

Advocacy activity includes a diversity of strategies. It may include 'insider' approaches in which organisations participate within official policy-making spaces, such as through writing submissions to government and sitting on government committees. It may also include more 'outsider' approaches, such as the more radical activities of street protests or occupying spaces.[2] Organisations that engage in advocacy do so on behalf of the interests they represent. Their hope is that by engaging in the public sphere, they will influence 'public policy or the decisions of any institutional elite'.[3] Hence, advocacy organisations are political - it is their job to 'get up the government's nose'.[4] The point of these organisations is not simply to do the work of government; it is to *change* the work of government. Their intent is to influence change or to shore up support for an existing position and they are likely to encounter some form of opposition because advocacy can affect other stakeholders' interests.[5]

Community and voluntary organisations' advocacy work is grounded in the premise that social change occurs through politics and that the power of the State can be moved to act on behalf of people.[6] Organisations that engage in advocacy articulate policy positions on behalf of citizens or interest groups. They direct their efforts at a range of audiences and seek to use ideas and speech

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1   Cohen, D. et al (2001) Advocacy for social justice, Bloomfield: Kumarian Press Inc
    Keenan O. Montague P., *Advocacy Initiative Project Report*, 2010, Advocacy Initiative: Dublin

2   Carbert, A. (2004) 'Learning from Experience: Activist Reflections on 'Insider- Outsider' Strategies, *Spotlight* 4. Association for Women's Rights in Development

3   Casey, J. et al (2008) 'Advocacy in the Age of Compacts: Regulating Government-Community Sector Relations – International Experiences' Centre for Australian Community Organisations and Management. University of Technology, Sydney. Working Paper Series 76

4   Sawer, M. (2002) 'Governing for the Mainstream: Implications for Community Representation', *Australian Journal of Public Administration* 61(1) pp 39-49

5   Keenan O. Montague P., *Advocacy Initiative Project Report*, 2010, Advocacy Initiative: Dublin

6   Reid, E. (1999) 'Nonprofit Advocacy and Political Participation' in Elizabeth T. Boris and C. Eugene Steuerle (eds.) Nonprofits and Government: Collaboration and Conflict, Washington, D.C.: Urban Institute Press 127

to shape the environment in which they operate. If one's aim is to shape public priorities, some believe advocacy is a way of achieving substantial leverage. While direct service programmes change the world one client at a time, advocacy efforts focus on broad changes in systems and policy. It works like the wholesale part of the nonprofit sector. The reason it creates leverage is simple; instead of converting nonprofit resources into units of service on a one-to-one basis, advocacy work takes a small number of resources and tries to multiply their impact by changing public priorities. The appeal is that many issues are so broad and intractable that their resolution would require government action at a national level over a long period of time. Nonprofit activity may create useful models for change. However, achieving scale and mobilising resources are difficult tasks for a sector that does not have the State's enforcement power and relies on voluntary action.[7]

Lobbying, which is a part of the broader repertoire of advocacy work, is a form of action that relates to influencing a specific piece of legislation or a policy process, like the annual budgetary process. While trade associations generally use paid professionals, community and voluntary organisations tend to rely on mobilising networks of volunteers. Critical to success in lobbying is knowledge of the issues and personal contact with decision makers. It requires knowledge about the legislative or policy making process; an understanding of the details of the piece of legislation or piece of policy and its effects on legislators' constituents; and a strategy for communicating with concerned citizens at grassroots level. The type of lobbying carried out is usually related to the type of organisation carrying out the work.[8]

Types of Advocacy

There are many different types and levels of advocacy ranging from formal, organisational and professional to more informal 'everyday' advocacy. For example, parents regularly speak up for their children and advocate on their behalf in crèches, schools and hospitals. Family members and friends speak out from time to time on behalf of vulnerable persons (e.g. an older family member or person with a disability) and seek their human rights and entitlements.

At the more formal and structured level there are professionals who regularly advocate on behalf of their clients. For example, youth workers, social workers and probation officers advocate on behalf of their clients to build their cases, access services and seek better outcomes. There are many organisations that adopt a specific advocacy role. For example, the Irish Cancer Society advocates on behalf of those affected by cancer. Its mission is to prevent as many people as possible from developing cancer and ensure those that do have world class services available to them. They do this by developing relationships with politicians and stakeholders, sharing information and making recommendations, and by raising awareness through the media.

7   Frumkin, P. (2002) On Being Nonprofit. A Conceptual and Policy Primer, Cambridge: Harvard University Press
    Keenan O. Montague P., *Advocacy Initiative Project Report*, 2010, Advocacy Initiative: Dublin
8   Keenan O. Montague P., *Advocacy Initiative Project Report*, 2010, Advocacy Initiative: Dublin

Self-advocacy is the act of speaking and acting for oneself. This is true empowerment and can be achieved when an individual has a sturdy sense of self, clarity of purpose, self-confidence and is surrounded by good support systems in terms of accurate information and encouragement.

Individual advocacy is the act of speaking and acting on behalf of another person. It can be done informally, as in the example of parents above, or formally, for example where a cancer support service advocates on behalf of one of its members/clients.

Group advocacy is a form of self-advocacy and it occurs when a group of people with a common purpose or cause come together to activate their collective power. This type of advocacy tunes into the energies of the group and is based on the strength of the combined focus of more than one person who can share experiences and support each other to be empowered to seek the change that they wish for.

Representation can be another form of advocacy whereby you act as a representative on committees, statutory bodies, forums, etc.

Features of effective advocacy

There are general principles or features that characterise good practice advocacy and take account of the ethical considerations that surround the advocacy process. These are:

Clarity of purpose

- This means having a clear sense of purpose and a plan for advocating on behalf of an individual, a group, an organisation or an issue
- It is important to ask:
  - Who or what are we advocating for?
  - What is the purpose?
  - What is the goal?
  - Whose needs are we serving and in whose interests?
  - What evidence are we basing our advocacy on?

Clarity of understanding

- There should be a clear understanding between the advocate and the person or group on whose behalf they are advocating.
- It is important to ask:
  - Has the advocate received permission to advocate?
  - Is there a shared understanding of the precise needs and wishes of the person or the group who needs advocacy?

- How can we be sure that we are doing the right thing and honouring the dignity of the individual(s)?

■ Good communication skills, including active listening, are necessary to allow a person to express their needs, to be heard and understood, to tease out and ascertain their true perspective, wishes and needs

■ It is good practice to develop a plan of action for advocacy in consultation with the person or group and to map out clearly understood steps and goals

■ It is important to keep the lines of communication open and to constantly be alert to changing moods, motivation and needs

Clarity of boundaries

■ Advocacy is about supporting a person or group to ensure that their needs are met and their rights upheld. Advocacy should promote respect for humanity, autonomy, inclusion, empowerment and equity. It is about sharing power and being the voice of another with their permission and understanding that you are on their side

Communication, feedback & reflection

■ Good communication is central to good practice advocacy

■ Constant, compassionate and clear communication is necessary on an ongoing basis between the advocate and the person or group that they are serving

■ It is important to build in time for checking in, having feedback discussions and reflection and being open to refining the process in response to changing needs

Advocating on behalf of individuals

Members/clients may experience challenges in accessing information or services or in how they are treated. In order to advocate effectively on their behalf you need to:

■ Listen to the member/client

■ Gather the facts

■ Feedback and reflect to ensure you understand fully their perspective and issues and needs

■ Agree a course of action with the member/client

■ Be the voice of the member/client

■ Network and develop appropriate links

■ Be a good communicator

■ Adopt a balanced approach

■ Be professional

- Act as a channel to the right supports for members/clients

- Be empowering

- Engage in ongoing communication and feedback to the member/client

- Respect the wishes of the member/client if they choose at any time to halt the advocacy process

Advocacy should empower and support the member/client to navigate through the system they have experienced difficulties with.

Advocating on behalf of groups

Sometimes the issues faced by an individual or group are common amongst many individuals and groups. It can be more effective and powerful to address the issue collectively and to advocate on behalf of groups. The same skills that apply to advocating on an individual's behalf apply in a group situation. Other important elements for group advocacy include:

- Getting the group members together to identify and discuss the issues

- Getting agreement on prioritising the issues if there are many

- Getting agreement on a strategy and a way forward. This might for example include forming a delegation of members, the use of petitions or letters, or agreeing that different members will contact different individuals who can progress the issues

Representation

The Health Service Executive or other statutory body may look for representatives from local groups to attend and contribute to meetings in order to have the views of families, patients, etc represented.

If your cancer support service is invited to send a representative, you should call a meeting of its members or of the committee/board to agree who will represent the service. Ideally, this should be done by way of election whereby people put forward their names for nomination. Others then propose and second the nominations and then the group votes on each of the nominations. The person with the highest number of votes is elected to represent the cancer support service.

Attending the first meeting in your role as representative can be intimidating or daunting, but by listening and not being afraid to ask questions you will learn. Remember you are there to ensure the voice of members/clients is heard. Do not be afraid to ask for support in this role if you feel you need it.

Section 10: Meeting Your Responsibilities

What this section covers

The topics covered in this section are as follows:

- What is governance?
- The Governance Code
- Structure for your cancer support service
- Governing documents
- Setting up an unincorporated body
- Setting up as a company limited by guarantee
- Setting up as a charity
- Tax reference number
- Annual general meetings
- Annual report
- Role of the board and boundaries
- Board as employer
- Roles of the chairperson, secretary and treasurer
- Delegation
- Succession planning
- Strategic planning (forward thinking)
- Managing money
- Bank accounts
- Managing assets
- Sources of funding and applications
- Contracting to third parties
- Health and safety
- Managing risk
- Insurance
- Child protection
- Elder abuse
- Complaints
- Evaluation and review
- Legal advice

What is governance?

Governance is essentially about ensuring that the cancer support service is run well and meets its obligations. The 'governing body' is the overall decision-maker for the service. It can be a board of directors, a management committee, a board of governors, a core group, etc.

In cancer support services that are run entirely by volunteers or in very small organisations, the governing body often includes everyone and involves those involved in management and operations. However, as an organisation grows, the roles of governance ('governing'), management ('organising') and operations ('doing') become more distinct. What is important is that the boundaries between the roles of governance, management and operations are clear. The governing body's primary responsibility is to act in the best interests of the cancer support service. If individual members of the governing body have conflicts of interest, they should declare these and abstain from the discussion and any voting.

The Governance Code

With the introduction of the Charities Act (2009), a greater degree of regulation and accountability will be placed on charitable organisations. The Governance Code was developed by the community, voluntary and charitable sector to help the sector to ensure that it is practicing good governance. In this way, the sector will maintain and build public trust and confidence in the sector.

The Governance Code sets out the key principles of good governance and outlines good practice for organisations at different stages of development. The core principles are as follows:

- Providing leadership
- Exercising control
- Being transparent and accountable
- Working effectively
- Behaving with integrity

To obtain more information about the Governance Code and good governance practice visit www.governancecode.ie.

Structure for your cancer support service

There are a number of options for the structure of your cancer support services. It can be a loose gathering of people with no incorporation. Often this is how services are when they first start. As they grow and develop, however, they may feel the need to become more structured, particularly if they want to access grants or sources of funding from statutory bodies.

Governing Documents

The key governing documents for your cancer support service are your Memorandum and Articles of Association if you are an incorporated body or your Constitution and Rules if you are an unincorporated body. These governing documents outline the purpose of your organisation, the activities it can engage in, the powers it has (e.g. to borrow money, to own property, to raise funds, etc.) and how it conducts itself.

Templates for Memorandum and Articles of Association for companies limited by guarantee are available from the Revenue Commissioners (www.revenue.ie).

It is important that every five years you take time out to review your governing documents to ensure they remain fit for purpose, reflect the mission and activities of the organisation and are updated to reflect any changes in how the organisation conducts itself and any changes in legislation relevant to the governing of an incorporated or unincorporated body.

Setting up an unincorporated body

An unincorporated group or association does not have a separate legal existence of its own. It is relatively easy and inexpensive to set up and there are relatively few regulations to deal with. However, members can be personally liable for the debts or actions of the association and it can be difficult for unincorporated bodies to enter into contracts.

For most types of events run by unincorporated bodies, e.g. outings, social evenings, peer support meetings, adequate insurance cover can cover most eventualities. While not essential, drawing up a written constitution to run your association is beneficial. This can set out who can be members of the group, how to become a member, in what circumstances (if any) membership can be taken away, how often meetings are held, voting rights, quorums (i.e. minimum needed to hold a meeting) and how the management committee will be elected and function.

Another form of unincorporated body is a Trust. Trusts are usually set up to hold and administer funds or property donated to the service. A legal document called a Deed of Trust must be set up and a number of people appointed as the trustees. The law around trusts is complex and the process can be costly.

Setting up as a company limited by guarantee

A company is a legal form of organisation that is separate from the people that start or run it. By setting up a company the people who run it are protected from being sued for the payment of unpaid debts incurred by the company. It also means that the cancer support service can continue in existence even if its membership changes. A company format enables the members

to assign specific responsibility for meeting legal responsibilities under the various Companies Acts to a board of directors. There are a number of different types of company. The most relevant to cancer support services are a company limited by guarantee with no share capital.

A company limited by guarantee with no share capital means that the members do not have shares in the company. However, the company must still have members and a minimum of seven is required. The company must also have at least two directors. This structure suits many charitable organisations as it provides a separate legal entity with the benefits of limited liability status but without the need to raise funds from members. The members' liability is limited to the amount they have undertaken to contribute to the assets of the company in the event it is wound up.

To set up a company you will need to do the following:

■ Select a company name and check its suitability and that no one else is using this name already

■ Agree what the registered address of the company will be

■ Name the company secretary and at least two directors

■ Name the members and the number of shares they hold (if any)

■ Develop the Memorandum of Association and the Articles of Association of the company (there are templates for these and they should be discussed with a solicitor or accountant so as to meet your specific needs)

■ Complete the relevant company registration forms

An accountant or solicitor is the best person to organise all of the above. There are also on-line services that can help. For further information go to the Companies Registration Office website www.cro.ie.

Setting up as a charity

The introduction of the Charities Act (2009) means that there will be for the first time in Ireland a legal framework for the registration of charities. Until the Act comes fully into force, the Revenue Commissioners have maintained a database of organisations that have received charitable tax exemption status (CHY).

Charitable status (CHY) means that your company or service is exempt from certain taxes. In addition, individuals that donate to you may be able to reclaim tax on their donations. It does not mean that you are necessarily a registered charity.

You must apply to the Revenue Commissioners to get charitable tax exemption status and you should seek legal advice in doing so. You do not have to be incorporated to get charitable status but you must meet certain conditions. These include having a 'governing instrument', being

set up as a Trust or as a company limited by guarantee or as an Incorporated Entity under the Charities Act.

The *Charities Act (2009)* reforms charities' legislation and will be implemented on a phased basis. These reforms are to:

- Ensure there is greater accountability and transparency in charities
- Protect against abuse of the charitable (CHY) status
- Protect against fraud
- Enhance public trust and confidence

A new regulatory authority will be established to oversee charities, the Charities Regulatory Authority. This authority will establish a Register of Charities, which all charities must register with within six months of the Register coming into force. Organisations that already have, or that obtain CHY status in the future, will be automatically registered by the Revenue Commissioners. Even if your organisation does not have CHY status, and if you plan to operate as a charity, you will be required to register. Charities will be required, at a minimum[1], to provide an annual report of activities to the regulatory authority. There will be no automatic entitlement to charitable tax exemption status and the Revenue Commissioners will continue to determine eligibility for tax relief for charities that will be registered with the Charities Regulatory Authority.

It is intended that under the Act, a Code of Practice will be developed for fund raising by charities. Charities will be expected to comply with this Code when it is developed and with the Non-statutory Statement of Fund raising Principles (see www.ictr.ie for further information about the principles).

The Act also defines what constitutes a charity for the first time in legislation. The definition is very broad (you can view it on www.wheel.ie). It also defines a charities trustee. Members of the board of directors (in the case of companies) or management committee or core group (in the case of unincorporated charities) will be regarded as trustees. A charity will not be permitted to pay trustees for their work as trustees (other than for vouched expenses), but will be permitted to pay them in respect of work that is not related to their role as trustees. For a copy of the Act view www.oireachtas.ie/viewdoc.asp?DocID=11424 or for a summary of its main provisions view www.wheel.ie.

For further information about frequently asked questions on obtaining charitable status go to www.revenue.ie

Tax reference number

If your cancer support service intends to employ staff or to apply for a tax exemption, you will need to apply for a tax reference number from the Revenue Commissioners.

1   The requirements for annual returns vary depending on the size of the charity with larger organisations having to provide audited accounts.

Annual general meetings

Companies are required by law to hold an Annual General Meeting (AGM) of the members. At this meeting the chairperson, secretary and treasurer are usually elected by the members. The Annual Report and Accounts of the company are presented to the members for discussion and agreement and the chairperson usually gives a short review of the year's activities.

Even if your cancer support service is not incorporated, it is a good idea to hold an AGM to review:

- What the service did during the year
- Who the service is for or if this needs to be changed
- How the service has functioned during the year and decide if any changes are needed to how it operates or to its rules or principles

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Annual Report

Incorporated bodies are legally obliged to produce an annual report. Even if you do not yet have charitable status and are unincorporated, it is good practice to produce an annual summary of your activities to inform all of your stakeholder groups.

Your annual report should:

- Contain a statement from the chairperson reflecting upon the year gone by
- Outline your mission
- Outline your structure (e.g. a diagram)
- Summarise the key activities that happened during the year
- Present a financial summary or audited accounts

Under the Charities Act (2009), all charities will be obliged to submit an Annual Activity Report to the Charities Regulatory Authority (CRA) when the relevant section of the Act comes into force.

Where a charity is structured as a company limited by guarantee, the Annual Return it must already make to the Companies Registration Office (CRO) under company law will be forwarded by the CRO to the CRA.

Charities that are not structured as companies and that have an income of less than €10,000 in any given year will not have to file an Annual Return to the CRA. However, along with all other charities, they will have to file an Annual Activity Report to the CRA.

Charities with an annual income over €10,000 will be obliged to file Annual Returns. The level of detail required will vary depending on the size of the organisation. Audited accounts will be

required for charities over a prescribed threshold (yet to be determined). Charities under this threshold and over the €10,000 threshold mentioned above will have to file Examined Accounts. This is a less onerous and less expensive form of reporting.

The Revenue Commissioners will continue to determine whether or not a charity is eligible for tax exemption.

Role of the board and boundaries

The primary responsibility of the board is to act in the best interests of the cancer support service at all times. If your cancer support service has been established as a company with a board of directors, then the board is legally bound to act in the best interests of the company.

There are specific requirements that a company board must comply with. These include:

- The Companies Acts
- The organisation's Memorandum and Articles of Association
- Ensuring the organisation is financially solvent and proper books of account are maintained and audited
- Ensuring that relevant annual returns and any notifications or declarations required under the law have been filed
- Ensuring that a current health and safety statement is in place

The board provides oversight to the work of the cancer support service. It should bring an objective assessment of strategy, performance, risk and resource allocation.

Members of the board should bring specific expertise that will benefit the cancer support service. They are responsible for reviewing and approving the finances of the service, its strategy, resource allocation and addressing significant risk issues. So having people on the board with legal, financial, fund raising, communications and human resource expertise can be of benefit.

Unless it is an executive board, the role of the board is one of oversight, compliance and strategy, not day to day management. It is very important that there are clear boundaries between the role of the board and the roles of management, staff and volunteers. A respectful relationship between the chairperson and senior manager is also very important.

Some boards have a staff representative. Again, the staff representative must be clear that as a board member, they must act in the best interests of the cancer support service. More often, staff members are invited to make presentations to the board to inform its members about the work of the organisation. Persons attending a board meeting in an observatory capacity must maintain their independence.

If members of the board have a conflict of interest when a specific issue is being discussed, they should declare that they have such a conflict of interest and abstain from any discussion and voting.

The board acts as a whole when a quorum is present. A quorum is the minimum number of board members that must be present at a meeting to make decisions valid. Individual members do not have the authority to make governance decisions on their own. When individual board members act alone or in small groups (e.g. sub-committee or working groups), they do so in an advisory capacity, not a decision-making capacity. On occasion, it may be necessary for the chairperson and some other member(s) of the board to act in a particular situation (e.g. settling an unfair dismissal case) but they must be authorised by the board to do so and within defined parameters.

The work of sub-committees or working groups should be agreed with the board and clear terms of reference provided to its members. Sub-committees and working groups often exist for a defined period of time.

The board must honour and respect confidentiality and the duty of care to the cancer support service's members/clients. It is important, therefore, that the board is very clear about the purpose of information audits, access to files, why information on members/clients is being sought and what purpose it will serve.

Board members should respect member/client confidentiality and not put undue pressure on staff or volunteers to provide information about their members/clients. In any event, the express permission of the members/clients must be sought when accessing information held on file about them.

Board as Employer

A Board has a duty of care to all of its employees. It is the Board's responsibility to ensure that the organisation complies with all relevant legislation, regulations and tax law pertaining to employment and to ensure that employees do not engage in reckless or fraudulent activities that affect the organisation.

The Board should put in place relevant policies and procedures such as health and safety, dealing with disciplinary matters, complaints and grievances. The Board sets the terms and conditions of employment and should be involved in recruiting and selecting employees. Useful websites for information about employment legislation and employments rights include www.citizensinformation.ie and www.nera.ie.

The Board should ensure that employees are adequately inducted and trained and understand the mission and ethos of the organisation. The Board should support the manager but also hold them to account.

Roles of the chairperson, secretary and treasurer

Whether or not you set up as a company or decide to remain unincorporated it is good practice to elect a chairperson, secretary and treasurer for your cancer support service each year.

The chairperson is responsible for calling meetings, steering and guiding the group and running of meetings. The chairperson should be able to take on board all points of view, manage time keeping, enable people to participate and express their views, and guide a meeting through an agenda or agreed set of topics. The chairperson also makes recommendations on the composition of the board.

The secretary is responsible for circulating all papers to allow for conducting of meetings, taking the minutes/notes of meetings, keeping a record of decisions made by the group and handling of any correspondence. The secretary is responsible for calling the annual general meeting, ensuring records are maintained and any annual returns are made.

If your cancer support service is a registered company, the secretary is also responsible for annual returns being made to the Companies Registration Office, accurate records of the names and addresses of directors being kept with the Companies Registration Office and informing the Companies Registration Office of any changes made to the company's Memorandum and Articles of Association.

The treasurer is responsible for managing the finances and sources of funds for the service. The treasurer provides financial information to the board, signs off on the annual audit if one is required, ensures prudent management of the organisation's finances, presents the accounts at the annual general meeting and oversees the appointment of the organisation's bankers and auditors.

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Delegation

In general, the role of a Board is to give direction, formulate strategy, acquire and allocate resources, and set policies, while the role of the manager is to manage the operational aspects of the cancer support service. However, there are occasions when the Board and management often have to work together to come to a decision on big issues. The Board can delegate power and authority to the manager, employees or sub-committees but it cannot delegate its responsibility.

It is important that the Board ensures that it is not delegating something that:

- Is illegal
- Creates a risk for the organisation
- Breaches confidentiality
- Conflicts with professional standards
- Is morally wrong

Clear job descriptions and frameworks for the manager and staff to work to, such as a strategic plan, business plan, annual objectives, policies and procedures, assist the process of delegation.

When delegating authority, the Board should set clear guidelines on who it is delegating to, within what limits decisions can be made and within what timeframe. The levels of financial delegation should be clearly recorded in the Board minutes.

Succession Planning

Succession planning has been defined as: *'A deliberate and systematic effort by an organisation to ensure leadership continuity in key positions, retain and develop intellectual and knowledge capital for the future and encourage individual advancement'* (Rothwell 2001).

Leadership is a critical component of the success of any organisation and those that engage in succession planning tend to perform better. Succession planning can help an organisation to adapt to a changing environment, to plan for key personnel leaving the organisation and to assist in changing an organisation's direction or culture.

Because succession planning often relates to the manager or chairperson in situ, it can be a sensitive topic and frequently does not get addressed. It should be discussed at Board level and with the people involved and it should form part of your strategic plan. In this way, it will not be forgotten and it is a task that will be built into the manager's work programme.

You should also develop an emergency succession plan to cover such situations as the manager or chairperson retiring early, or having a long-term illness, or passing away.

Strategic planning (forward thinking)

Strategic planning is essentially thinking and planning for the future in order to give your cancer support service a direction. It sets out the future you envisage (your vision), the purpose of your service (your mission), the specific changes or benefits you are hoping to achieve (your aims), the activities or actions that need to be carried out (your objectives) and the detailed operational plan to achieve this. A strategic plan also sets out the belief system or values of your cancer support service, e.g. openness, equality, respect, empowerment, etc.

A strategic plan gives your cancer support service a unity of purpose and a direction or pathway to follow. It helps you to prioritise activities. It helps you to build credibility with the outside world. It may be a requirement for certain streams of funding, e.g. grant aid. It should help you to assess what your service has achieved when you look back and review its implementation.

Managing money

A company will need to have its own bank/credit union account. Any money raised from members, donations or any external funding should be lodged and dispensed from this account. Two people should sign cheques. Someone will also need to be responsible for day to day bookkeeping and budgeting.

Companies will have to produce an Annual Report and set of Audited Accounts. An accountant should be appointed by the members of the company to do this. A record of money coming in and money spent will need to be kept along with receipts (where possible) in order to assist the auditors complete the accounts each year.

Even if the cancer support service is not incorporated, the treasurer should keep a simple record of what has been raised and what has been spent. This will help to prevent misuse, fraud or theft and demonstrate accountability. An unincorporated service might need some money (a 'kitty') to provide light refreshments or even to pay for room hire. Members need to agree how much they will contribute to this kitty, e.g. €5 each week. If a cancer support service needs a kitty, then one person should become responsible for holding the kitty and for paying money out of it.

When the relevant sections of the Charities Act (2009) come into force, all charities will have to provide an annual report to the Charities Regulatory Authority. Different levels of reporting will be required depending on the size of the charity (see section on Annual Report).

Some simple rules about money include:

- Have bank accounts in the name of the cancer support service, not an individual's name
- Pay by cheque rather than cash
- Get receipts if at all possible
- Keep a record of all money coming in and going out
- Have two signatories for cheques
- Have a form for claiming expenses
- Do not leave cash or cheques lying around. Put cash or cheques received into the bank account as quickly as possible
- Examine financial reports in detail and ask questions
- Have an annual budget

Bank accounts

Your cancer support service should have its own bank account, separate from the accounts of its members, in order to receive funding (e.g. donations, grants, fund raising) and to make payments.

One person should be given responsibility for managing this account and they should keep a record of receipts, lodgements and payments into and out of the account.

Two people should be required to sign any cheques on behalf of the cancer support service. Similarly if your service uses electronic funds transfer mechanisms.

Blank cheques should never be signed and the persons with responsibility for signing cheques should see relevant invoices and approve every item of expenditure.

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Managing assets

Your cancer support service should maintain a list of the assets it owns, e.g. furniture, computers, motor vehicles, buildings, etc. These assets should be periodically inspected to see if they need repairs, maintenance or replacement. This will enable you to plan for sourcing funding to carry out necessary maintenance or replacement. Whenever an asset is changed or upgraded, you should check that your insurance cover continues to be adequate. If you do not replace an asset, your insurance cover may even come down.

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Sources of funding and applications

Irish Charities Tax Research (ICTR) has developed good practice principles for fundraising by the charity sector in response to the *Charities Act*. The *Statement for Guiding Principles for Fundraising 2008* can be obtained from the ICTR web site (www.ictr.ie). The core messages from the guidelines are summarised below:

- Act honestly and truthfully, and answer all reasonable questions about fundraising
- Give information about the status and authority of those soliciting funds including visible ID for public fundraising
- Have a policy for the activities of volunteer fundraisers
- Ensure third party fundraising conforms to the organisation's own standards and practice – put a written agreement in place if possible
- Provide clear, unambiguous communications that do not contain any misleading information. Include name, logo, address, telephone number, email, web site and CHY number

- Images should be appropriate, relevant and respect the dignity of the individual and should avoid stereotypes
- There should be clarity over the purpose of fundraising and where all of the proceeds will go, e.g. is it for the organisation in general or for a specific purpose?
- No undue pressure to contribute should be put on anyone
- Fundraising activity should not be a nuisance or cause disruption
- Donations should be used solely to further the work/mission of the organisation
- Donations made for specific purposes should be honoured
- Plan to handle any shortfall or excess when fundraising for a specific purpose
- Have a complaints procedure in place
- Have systems to ensure all funds are used effectively and to minimise the risk of misuse
- Take care when fundraising from children or young people
- Comply with the Data Protection Acts (1998 and 2003) and the Data Commissioner's guidelines on direct marketing

Before embarking on fund raising you should:

- Be clear what you need to raise the money for and how much you need to raise
- Check if there are other alternatives to meet the needs of the cancer support service (e.g. free venues)
- Decide who will be responsible for fund raising
- Work out what makes your service special – why people should support it?
- Plan ahead

There are a number of ways of fund raising for your cancer support service and all require some investment of time and energy. These include:

- Fund raising from the members of the cancer support service
- Applying to a statutory body such as the Health Service Executive for a grant
- Carrying out local fund raising events or street collections
- Seeking private donations from individuals or philanthropic organisations

If you seek grant aid or funding from statutory bodies there will be an application process that you will have to go through. There will be specific terms and conditions about what you can use the money for and what type of reporting you will have to provide to the funders. Many philanthropic organisations have similar application and reporting requirements to those of statutory bodies.

You must apply to the local Garda Division for a permit to collect cash in public places and in the future, when the relevant section of the *Charities Act* comes into force, you will also need a permit for non-cash collections from the public. Cash collection boxes must show the charity's name prominently and in the future, when the relevant section of the *Charities Act* comes in force, you will be required to seal collection boxes unless prior permission is granted by the Charities Regulatory Authority.

Your cancer support service should provide ID (for public fundraising) or letters of authority (for private fundraising) for fundraisers. You should also ensure that you have adequate insurance cover in place to cover fundraising activities. Make sure that your fundraisers know to make people aware of what you are raising money for and to thank them.

When private donations are received you should record the donation and acknowledge its receipt. You should record if the donation was made for a specific purpose. You should keep donors informed about what the money has been used for. If it is not possible to use the donation for a specified purpose your cancer support service should have a procedure in place to communicate this to the donor and to deal with the donation in a manner that is satisfactory to the donor, including the return of the gift.

In order to minimise the risk of fraud, loss or theft when your cancer support service receives cash contributions [2], the sum of money should be counted by two representatives of your organisation. A record of cash received should be kept and cash should be banked as soon as possible. If this is not possible immediately, it should be stored in a secure place. Expenses should not be deducted from cash. You should bank it first then pay agreed expenses out of the bank account.

If you get money from private donations you should keep your donors informed about what the money has been used for.

Contracting to third parties

If your cancer support service needs to use the services of third parties, e.g. consultants, trainers, web designers, plumbers, etc, and the contract is sizeable (e.g. €3,000 or more), you should put the contract out to tender. For amounts under this but over a certain threshold (e.g. you might decide the threshold should be €500 or €1,000) you should seek at least three quotations before contracting the service. Contracts with third parties should be in writing and include a fixed price, an agreed time scale and an agreed payment schedule.

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2   Cash includes cash, cheques, bank drafts, postal orders, credit card or gift card donations.

Health and safety

An organisation has a duty of care to its staff, volunteers and members/clients. The *Safety, Health and Welfare at Work Act, 2005* obliges an employer to have a safety statement for the work place. The statement has to:

■ Identify any hazards

■ Assess the risks from such hazards. Different types of risk and how to manage risk are explored in the next section

■ Identify the steps to be taken to deal with the risks

■ Provide details of the person in the workplace who has responsibility for health and safety

All staff and volunteers should be made aware of this statement. One way to ensure this is to have each person sign a compliance form when they join your cancer support service. This should acknowledge that they have had the safety statement explained to them, have had any questions answered and that they understand it.

If you prepare food in your service, you will need to develop a Hazard Analysis Critical Control Point (HACCP) to which all food handlers will have to adhere. Further information about food handling can be obtained from www.fsai.ie or www.safefood.eu.

Managing risk

Risk is an everyday feature of our lives and of the job of running any group, service, company, event or charity. There are many types of risk. The most important for your cancer support service are reputational, physical, legal, financial and technological. Some of these are important in the context of health and safety, e.g. physical risks.

Reputational risks can happen when something is done to give your service a bad reputation, your activities harm someone or someone 'bad mouths' your service (even if not true).

Physical risks can happen if someone falls or has an accident while on your premises or taking part in one of your events.

Legal risks can happen if you do not meet your obligations under various legislation (e.g. Employment, Equality, Companies Acts), or if someone sues your cancer support service (e.g. arising from injury).

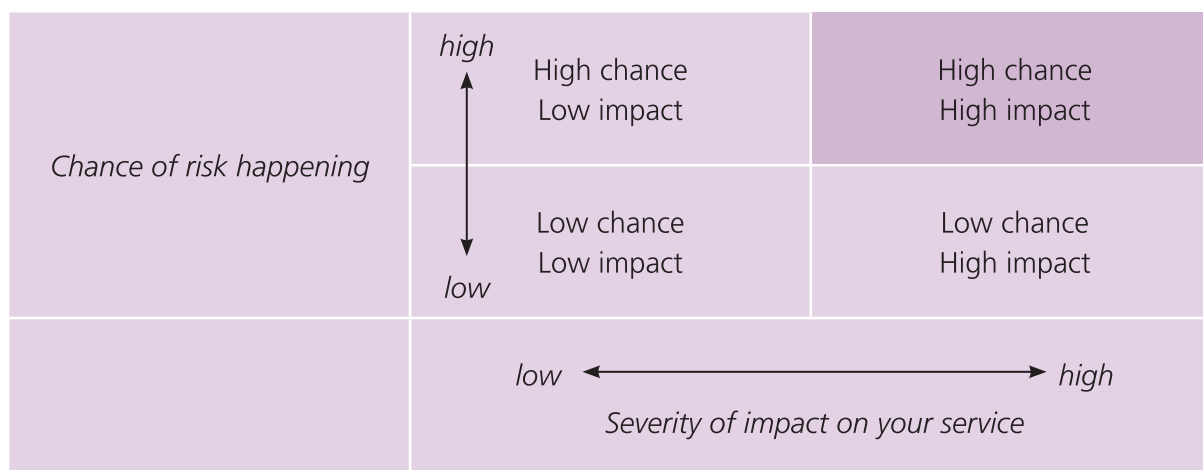**Financial risks** can arise if you do not manage the finances of the service adequately, if you incur debts that cannot be repaid, if you cannot raise enough funds for your activities or if there is fraud or theft of the service's assets or cash.

Technology risks in the context of cancer support services relate mainly to information technology such as computers dying without an alternative back-up system, hacking into files, etc.

It is important that you identify 'major risks'. These are risks that have a high likelihood of occurring and if they occurred would have a serious impact on your cancer support service and its ability to continue or that would prevent you achieving your aims.

The diagram below gives a visual aid for identifying the level of risk. The coloured box is where 'major risk' lies.

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Risk Management

	high	High chance Low impact	High chance High impact
Chance of risk happening			
	low	Low chance Low impact	Low chance High impact
		low ←——————————————→ high *Severity of impact on your service*	

There are three aspects to risk management:

■ Prevention – how can risks be prevented or at least minimised?

■ Compliance – what must we comply with legally (e.g. employment legislation)?

■ Strategic management – how will the risk, if it occurs, impact on our ability to achieve our aims and continue in business and what will be our response?

Once major risks have been identified, you need to assess and manage them. The first steps are to decide:

■ What high risk activities will be avoided

■ What levels of risk are inherent to the service and have to be accepted if the service's activities are to continue

■ What risks can be assigned to third parties, e.g. through insurance, outsourcing

■ What your public relations (PR) plan will be if something happens

The next step is to establish some basic ground rules (policies and procedures) and what level of risk can be handled by staff/volunteers/members on a day to day basis and what level of risk needs to be referred to the board/higher management (if this exists).

Finally, you need a system to monitor and review your risk management so that new risks are identified and assessed, any failures in controls (policies or procedures) are identified and rectified and there is an understanding of individual responsibilities for implementation and monitoring.

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Insurance

There are a number of different types of insurance that might apply to your cancer support service. No matter how small your organisation or cancer support service, always check your insurance status and cover.

If you employ staff you will need employer's liability. If you use volunteers you will need to check with your insurance company that they are covered. In most cases volunteers are covered by employer's liability but you may have to pay an extra premium. The general public should be covered through public liability insurance.

If your cancer support service owns assets such as a premises or vehicles you will need cover for the asset and contents. If you own assets such as buildings, vehicles, etc., make sure they are properly assessed for insurance cover and the adequacy of this cover is checked each year. If you have to make a claim, insurance pay-outs are based on the current value of an asset so it is important to ensure that you are not over-valuing (which will result in you paying too much insurance) or under-valuing (which will result in inadequate cover).

If you have the use of a building, check that the insurance policy covering the building will also cover your members/clients using the building.

Professional services should be covered under professional indemnity insurance. Board directors and officers can also obtain liability insurance.

If you meet in someone's home, the homeowner should check with their insurance company that their home insurance will cover gatherings of the group in the event someone has an accident or a fall. If additional insurance cover is required for public liability, external funding should be sourced. Public liability insurance is not expensive. You should have public liability insurance for any event organised and run by your cancer support service. For insurance purposes, volunteers are considered staff when the event is within your control. Independent events run by third parties are not in your control and you are not responsible for insuring them.

Child protection

If your cancer support service works with children or young people you should familiarise yourselves with the *Children First: National Guidelines for the Protection and Welfare of Children, 1999* (www.hse.ie). If you work with children then you must:

■ Develop a policy on child protection for your cancer support service including procedures for handling allegations of child abuse (see the sub-section below on handling complaints/allegations of abuse)

■ Designate a member of your organisation (staff or volunteer) to have responsibility for ensuring that child protection procedures and arrangements are in place

■ Implement training, supervision and support on child protection

Criteria for, promotion of and information about your service should clearly state whether or not you support children. Even if you do not specifically deal with children it is still good practice to develop a child protection policy.

If you have volunteers or staff who work alone with vulnerable adults or directly with children, they may require Garda clearance.[3] This can take some time to obtain, so you need to plan ahead.

Ideally, a minimum of two adults should be present when working with children. This is both for the protection of children and for the protection of staff or volunteers. The publication, *Our Duty to Care*, is a good practice guide for those working with children and is available from the Department of Health & Children (http://www.dohc.ie/publications/our_duty_to_care.html).

Children should never be transported in private cars unless there are two adults present and the insurance policy on the vehicle covers this type of activity.

Listen to what children have to say – they have a right to be taken seriously and to be heard. Parents/carers also have a right to be consulted and kept informed in relation to all matters concerning their family.

The child's welfare should be paramount. Do not keep the problem to yourself or assume that someone else will raise concerns or deal with the matter. Other concerns should not get in the way of your responsibility to the child. Keep notes of your concerns and any concerns should be discussed immediately with a senior colleague (e.g. manager, supervisor, chairperson) – do not investigate the matter or confront the alleged abuser on your own. Notify the Health Service Executive Community Care or Gardaí of your concerns.

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3   The Garda Central Vetting Unit deals with requests to vet prospective employees who work with children or other vulnerable groups. Currently, it only covers prospective full-time employees of the HSE or HSE funded agencies but the Department of Health & Children plans to extend the vetting arrangements to cover all organisations.

If you work with groups of children, e.g. camps, establish basic ground rules for group activities including use of language, physical conduct, bullying and sanctions that is communicated in age appropriate language to all participants (children and parents/carers, volunteers and staff). Ensure that all activities are supervised by at least one qualified adult. The box below[4] provides further guidance for working with children.

Child Protection

Do	Don't
• Listen to what children have to say • Give children information in age appropriate language • Be respectful of the child's choices and preferences and their development needs • Ensure that activities are enjoyable and fun • Promote and protect the rights of children • Establish boundaries between a working relationship and a friendship	• Engage in or encourage games that can be construed as rough, physical, sexual or racially provocative • Touch the child in any way that could be construed as inappropriate • Do things of a personal nature that a child is capable of doing for themselves • Make comments to a child that could be construed as sexually suggestive • Let allegations of abuse go unchallenged or unreported

Elder abuse

Abuse of an adult has been defined as *'a single or repeated act or lack of appropriate action occurring within any relationship where there is an expectation of trust, which causes hurt or distress to an older person or violates their human and civil rights'*.[5]

The key principles that should guide the handling of allegations of elder abuse are set out in the box overleaf.[6]

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4   Based on Diabetes Federation of Ireland, *Holiday Camps – Guidelines for Staff and Volunteers*.

5   Department of Health & Children, *Protecting Our Future, The Working Group on Elder Abuse,* 2002. www.dohc.ie/publications/protecting_our_future.html?lang=en

6   Department of Health & Children, *Protecting Our Future, The Working Group on Elder Abuse,* 2002.

Principles for Handling Allegations of Elder Abuse

- Acting in a way that supports the rights of the individual to lead an independent life based on self-determination
- Recognising people who are unable to make their own decisions and/or to protect themselves, their assets and their bodily integrity, and ensure adequate protection for them
- Recognising that the right to self-determination can involve risk and ensure that such risk is recognised and understood by all concerned and is minimised wherever possible
- Although intervention may, in some cases, compromise the older person's right to independence and choice, the principle of 'least restrictive alternative' should apply at all times
- Ensuring that the law and statutory requirements are known and used appropriately so that older people receive the protection of the law and access to the judicial process

Allegations of abuse require particular attention. There are five main types of abuse: physical, sexual, psychological/emotional, neglect and financial.

Physical abuse is where an injury is known or suspected to have been deliberately inflicted.

Sexual abuse is where an adult is used by another or others for sexual gratification without their consent or a child is used by others for sexual gratification, including pornographic material.

Psychological/emotional abuse is where the needs of the person for affection, approval, consistency and security are not being met. It can also involve threats of physical or sexual abuse.

Neglect is where there is wilful or unintentional persistent or severe acts or omissions of food, clothing, entitlements, warmth, hygiene, intellectual stimulation, supervision and safety.

Financial abuse is where a person is not allowed access to their assets or finances, including social welfare entitlements, or is denied money for basic necessities. It also encompasses pressure to sign over assets when a person is elderly or not fully *compos mentis*.

Reasonable ground for concern would include the following:

- The older person indicating that they are being abused
- A statement by someone who has witnessed an incident or incidents of abuse
- Illness, injury or behaviour consistent with abuse, e.g. unexplained bruises, burns, eye injuries, tearfulness, depression, etc.
- Consistent signs of neglect over time

Any staff member or volunteer who receives information about or is aware of a member/client that is being abused or is at risk of abuse has a duty of care to report the matter as soon as possible to their manager or supervisor.

The key elements of policy and procedures for elder abuse are as follows:

■ Developing a written policy that is communicated to all staff and volunteers

■ Training for managers, staff and volunteers in elder abuse and the signs of elder abuse and the cancer support service's policy on elder abuse.

■ Ensuring that all reports of abuse are taken seriously

■ Establishing clear internal lines of reporting for cases of elder abuse

■ Noting and recording allegations of abuse factually and accurately

■ Keeping a record of all communications and interventions relevant to each case

■ Ensuring that staff and volunteers understand the importance of not delaying in discussing concerns with their manager or supervisor

■ Referring the allegation of abuse to An Garda Síochána immediately if the older person is at immediate risk of serious harm

It is important to respect the dignity, choices and self-determination of older people and not to put undue pressure on an older person to make a formal report. The older person should be given the choice of reporting the allegation and to allow them to decide what level of risk they can live with. The exception to this is cases of criminal assault or immediate risk of serious harm, in which instance the matter should be reported to An Garda Síochána. However, in all circumstances the older person must be made aware that the staff member or volunteer is making a report and to whom this report is being made.

Confidentiality should apply to all matters pertaining to an allegation of abuse as far as possible. It may be necessary to share information with other service providers such as Health Service Executive Social Work Departments or organisations providing services or care to the older person or the authorities such as An Garda Síochána. The older person should be made aware of this and their consent obtained to disclose the allegation to another organisation or agency. They should also be made aware of any allegations made on their behalf, but without their knowledge, by another person.

The staff member or volunteer who makes a complaint against another should be reassured that they will be taken seriously, they will be protected from any risk of reprisals or intimidation, and they will be kept informed of any action that has been taken or its outcome.[7] Confidentiality is maintained, as far as possible.

Ways in which you can protect your staff/volunteers from allegations of abuse are:

■ Rigorous recruitment and selection (see *Section 5: Recruiting, Training and Supporting Staff and Volunteers* for further guidance)

■ Proper induction of new staff members and volunteers

■ Communicating and training staff and volunteers in the standard of care/service expected from them in their dealings with member/client's

■ Having a code of ethics

■ Using probationary periods

■ Providing ongoing support and supervision

■ Having feedback mechanisms

Further guidance on elder abuse can be obtained from the Health Service Executive website (www.hse.ie).

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Complaints

Having a clear written policy on how complaints are to be handled is very important. It is important that this policy is communicated to members/clients, staff, volunteers, others you work with and people you are supporting. This can be done by providing an information leaflet which sets out how a complaint can be made and what action your cancer support service will take in the event of a complaint. It is very important that complaints, especially those about abuse, are addressed promptly.

The basic steps in handling any complaint are:

■ Acknowledge in writing receipt of the complaint

■ Notify any staff member or volunteer if a complaint has been made against them

■ Establish the facts and document the details

■ If a complaint is upheld, the matter should be referred to a senior member of the organisation for a decision on the course of action to be taken

■ Notify the complainant about the course of action

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7   Under the law, no person making an allegation of abuse can be penalised for making an allegation through official channels as long as the report is made in good faith and is not malicious.

- If a complaint is not upheld, the staff member/volunteer involved should be reassured that their reputation and career prospects would not be adversely affected
- Where there are reasonable grounds to suspect that a criminal offence has occurred, the matter must be reported to An Garda Síochána immediately

Evaluation and review

Evaluation is the term used to describe how we review and examine how a service or organisation came about and if this is still valid (its rationale); the resources and processes it uses to achieve its aims (its efficiency); the outcomes and impacts it has actually achieved (its effectiveness); and the cost of delivering its services relative to the benefits of that service (its value for money).

The process of evaluation can be used to look at a service as it is being rolled out (formative evaluation), when it ends (summative evaluation) or on an ongoing basis (continuous learning).

Evaluation is rarely an end in itself. It should inform good decision-making, planning and strategic development. It is also a mechanism for obtaining feedback from different stakeholder groups such as board members, staff, volunteers, organisations you work with, organisations who fund you and people you want to influence (e.g. policy-makers) and members/clients. Evaluation is often a requirement if you receive grant aid or funding from statutory organisations such as the Health Service Executive or Pobal or from philanthropic organisations. Evaluation can be a bit like detective work in order to provide evidence that your service works, is of benefit and of value and services that are funded by the State will increasingly be required to produce an evidence-base.

While evaluation can be very technical, it can be boiled down to a core set of questions as follows:

- What did we set out to achieve?
- Did we achieve it or parts of it?
- How did we go about achieving it?
- Did the benefits outweigh the cost/resources?
- What worked well and why?
- What did not work well and why?
- What do we need to improve or change for the future?

Legal advice

If your cancer support service is in doubt about any of its legal obligations, then seek legal advice.
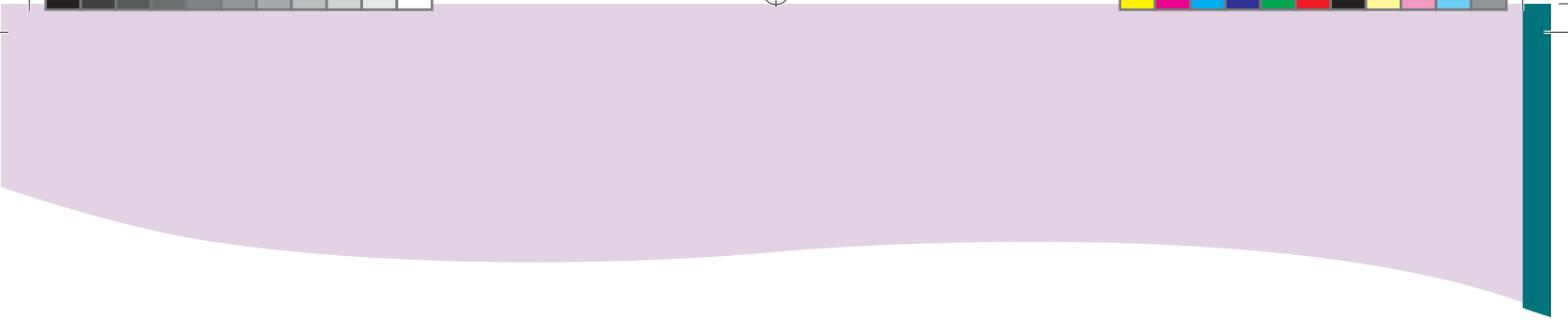
Section 11: Where to Find Further Information

What this section covers

This section provides some pointers to useful sources of information and covers:

- Irish Cancer Society
- Books and further reading
- Websites
- Useful organisations
- Centres of excellence
- Documents that informed these guidelines
- List of employment legislation

Irish Cancer Society

43/45 Northumberland Road, Dublin 4.
Phone: 01-2310500
Fax: 01-2310555
Website: www.cancer.ie
National Cancer Helpline: 1800 200700

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Books and further reading

Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer, 2003,
National Cancer Control Initiative and the National Breast Cancer Centre, Australia
www.nhmrc.gov.au/publications/synopses/cp90syn.htm

Moderator's Guide. Clinical Practice Guidelines for the Psychosocial Care of Adults, 2006,
The Cancer Council Queensland, Australia

Setting Up a New Voluntary or Community Group, 2009, Carmichael Centre for Voluntary
Groups, www.carmichaelcentre.ie

*Solid Foundations. A good practice guide for building strong and effective community and
voluntary sector organisations, 2007*, the Wheel, Dublin, www.wheel.ie

Our Duty to Care 2002, Department of Health & Children, Dublin, www.dohc.ie

Managing Volunteers: A Good Practice Guide, Citizens Information Board.

*Managing Better: A series on organisational and management issues for the community and
voluntary sector.* Combat Poverty Agency.

Good Practice Resource Pack for Cancer Help and Support Groups, Cancerlink (now known
as Macmillan).

Strategy for Cancer Control, Irish Cancer Society 2006.

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Websites

Activelink, www.activelink.ie

Carmichael Centre, www.carmichaelcentre.ie

Citizens Information Service, www.citizensinformation.ie

Citizens Information Board (formerly Comhairle), www.citizensinformationboard.ie

Department of Health & Children, www.dohc.ie

Equality Authority, www.equality.ie

Food Safety Authority of Ireland, www.fsai.ie

Fundraising Ireland, www.fundraisingireland.ie

Health & Safety Authority, www.hsa.ie

Health Service Executive, www.hse.ie

Irish Association of Palliative Care, www.iapc.ie

IBEC, www.ibec.ie

Irish Cancer Society, www.cancer.ie

ICTR, www.ictr.ie

Irish Hospice Foundation, www.hospice-foundation.ie

Macmillan Cancer Relief, www.macmillan.org.uk

Money Advice & Budgeting Service, www.mabs.ie

National Cancer Control Programme, www.hse.ie/eng/about/21c/cancer_services/nccp.html

National Employment Rights Authority, www.nera.ie

Oireachtas, www.oireachtas.ie or www.irishstatutebook.ie (useful for copies of legislation)

Philanthropy Ireland, www.philanthropyireland.ie

The Helplines Association, www.helplines.org.uk

The Wheel, www.wheel.ie

Volunteer Ireland, www.volunteer.ie

Useful organisations

Garda Central Vetting Unit, Thurles, Co. Tipperary, 0504-27300

Centres of Excellence

There are eight Special Cancer Support Centres that have been designated as centres of excellence. They are located in the four HSE administrative regions as follows:

NCCP East-Dublin North East:
> Beaumont Hospital
> Mater University Hospital

NCCP East-Dublin Mid Leinster:
    St. James' Hospital
    St. Vincent's University Hospital

NCCP South:
    Cork University Hospital
    Waterford Regional Hospital

NCCP West:
    Mid Western Regional Hospital
    Galway University Hospital

For further information go to http://hse.ie/eng/services/Find_a_Service/National_Cancer_Control Programme/Centres/Regional Cancer Centres.html.

Documents that informed these guidelines

American Cancer Society, *Man to Man. Prostate Cancer Education & Support Program. Group Program Guide and Trainer's Manual*, 1997.

An Bord Altranais, *Guidance to Nurses and Midwives on the Development of Policies, Guidelines and Protocols*, 2000.

Belfast City Hospital Trust, *Belfast City Hospital Macmillan Support and Information Centre Volunteer Policy*, 2006.

Belfast City Hospital Trust, *Cancer Support and Information Service Volunteer Core File*, 2006.

Belfast City Hospital Trust, *The Recruitment, Training and Supporting of Volunteers within Cancer Information and Support Services*, 2007.

Belfast City Hospital Trust, *Training Programme for Professionals working with volunteers in Cancer Information and Support Services. Guidance notes for Information & Support Centre Managers*, 2007.

Cancer Council New South Wales, *Cancer Support Groups: A guide to setting up and maintaining a group*, 2009.

Commonwealth of Australian, *Cancer support groups: A guide for peer facilitators*, 2009.

Complementary Therapists Association U.K., *Code of Practice & Disciplinary and Complaints Procedure*, www.complementary.assoc.org.uk/Code

Council for Children's Hospitals' Care, National Children's Hospital, Our Lady's Children's Hospital and The Children's University Hospital, *Child Protection Guidelines for the Children's Hospitals*, 2008.

The Cancer Council Queensland, *Moderator's Guide. Clinical Practice Guidelines for the psychosocial care of adults with cancer*.

The Charity Commission of England and Wales, *Charities and Risk Management*, 2007.

Citizens Information Board, *Managing Volunteers: A Good Practice Guide*.

Department of Health & Children, *Protecting Our Future – The Working Group on Elder Abuse*. 2002

Diabetes Federation of Ireland, *Holiday Camps – Guidelines for Staff and Volunteers*.

European Cancer Patient Coalition, *Code of Practice between Patients' Organisations and the Healthcare Industry*, 2009.

Family Support Network, *Good Practice Guidelines for Peer Led Family Support Groups*, 2010.

Fenlon D and Foster C. Care *After Cancer: Research evidence behind Macmillan's promotion and trialling of a new approach to cancer after care based on four key principles*. Macmillan Cancer Support, London, 2009. Available at: www.macmillan.org.uk/Documents/GetInvolved/ Campaigns/Campaigns/ Survivorship/SurvivorshipReport2009.pdf (accessed 12 July 2010).

Department of Health and Children, *Children First: National Guidelines for the Protection and Welfare of Children*, 1999.

Health Service Executive, *Trust in Care. Policy for Health Service Employers on Upholding the Dignity and Welfare of Patient/Clients and the Procedure for Managing Allegations of Abuse against Staff Members*, 2005.

Health Service Executive, *Implementing 'Protecting Our Future', a programme to raise awareness of elder abuse among healthcare staff*, 2008.

Health Service Executive, *Prevention of Abuse of Children by a Staff Member while in the Care of the Hospital*, 2009.

IBEC, *Preventing and Dealing with Bullying and Harassment in the Workplace*, 2008.

Irish Cancer Society, *Overview of Care to Drive. The Irish Cancer Society* and *St. Vincent's University Hospital Pilot Transportation Service*

Lance Armstrong Foundation, *Livestrong. Resource for Cancer Survivors*, 2004-2005.

Macmillan Cancer Relief, *Good Practice Guidelines. Cancer self help and support*, 2005.

Macmillan Cancer Relief, *Good Practice Resource Pack for cancer self help and support groups*, 2005.

Macmillan Cancer Relief, *A best practice guide to working with volunteers in information and support services*, 2009.

Macmillan Cancer Support, *Men and Cancer*, 2007

Macmillan Cancer Support, *The Cancer Guide*, 2007

North East Lincolnshire Compact, *Code of Practice on Community Groups*.

St. Luke's Hospital, *Elder Abuse Policy*, 2010

South Dublin County Volunteer Centre, *Data Protection Policy*, 2010

Telephone Helpline Association, *Quality Standard Workbook*.

Tosach, *Good Employment Practices. Management Committees*.

Tuam Cancer Care Centre, *Tuam Cancer Care Support Volunteer Manual*, 2009

University Hospital Birmingham NHS Foundation Trust, *Volunteer Vision and Venture: A Strategy for Volunteering at University Hospital Birmingham*, 2006.

U.K. Department of Health, *Confidentiality*. NHS Code of Practice, 2003.

Walters, K., Buszewicz, M, Weich, S., King, M., *Help-seeking preferences for psychological distress in primary care: effect of current mental state*, 2008, British Journal of General Practice.

The Wheel, *Solid Foundations. A resource guide for building strong and effective organisations in the community and voluntary sector*, 1997.

World Health Organization, *Guidelines on Developing Consumer Information on Proper Use of Traditional, Complementary and Alternative Medicine*, 2004.

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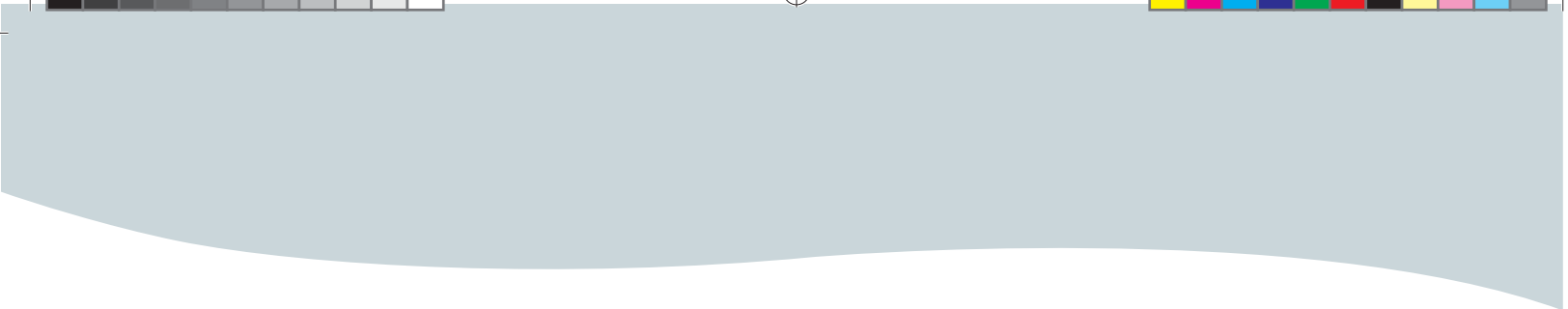
List of relevant legislation

The following is a list of the most pertinent employment legislation (it is not an exhaustive list) presented in alphabetical order:

Adoptive Leave Acts (1995 and 2005)

Carer's Leave Act (2001)

Data Protection Acts 1988 and 2003

Data Protection (Access Modification Health Regulations, 1989

Employment Equality Acts (1998-2008)

Equal Status Acts (2002-2004)

Freedom of Information Acts 1997 and 2003

Industrial Relations Act (1990)

Juries Act (1976)

Maternity (Protection of Employees) Acts (1981 and 1991)

Maternity Protection Acts (1994 and 2004)

Minimum Notice and Terms of Employment Acts (1973-2005)

Organisation of Working Time Act (1997)

Parental Leave Acts (1998 and 2006)

Payment of Wages Act (1991)

Pensions Act (1990 and amended 2002)

Protection of Young Persons (Employment) Act (1996)

Protection of Employees (Part-time Work) Act (2001)

Protection of Employees (Fixed-Term Work) Act (2003)

Redundancy Payments Acts (1967-2007)

Safety, Health and Welfare at Work Act (2005)

Terms of Employment (Information) Acts (1994-2001)

The Protection for Persons Reporting Child Abuse Act (1998)

Unfair Dismissals Acts (1977-2007)