



Australian Government

Cancer Australia

# Consumer participation guide





# Consumer participation guide

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# Preface

Cancer Australia believes that consumers, that is, people affected by cancer, can contribute significantly to its work agenda.

Your experience can provide us with a unique insight into how a cancer diagnosis has influenced your life and the lives of those close to you. Collectively, the views of consumers provide us with a valuable perspective on the impact of cancer, and the capacity of health services and the health system to respond to the needs of people affected by cancer. Your views and advice allow us to gain an understanding of what's working and what's not working within the health system, and you are able to contribute significantly to developing policies that will help reduce the impact of cancer on those people who currently have poor cancer outcomes.

This *Consumer Participation Guide* is one of three resources which have been developed to support you in your role within Cancer Australia. It provides you with some general information about Cancer Australia and some useful tips about participating as a consumer representative at a national level within Cancer Australia.

The three interrelated documents are referred to as the *Consumer Resource Kit* and include:

*Consumer Participation Guide*

*Consumer Resource Guide*

*Consumer Training and Mentoring Guide.*

It is not our intention that you are familiar with all the material in these guides, they are provided to you for your information only and to assist you with your role within Cancer Australia.

The *Consumer Resource Guide* provides you with a variety of reference material including information on the Australian health system, cancer in Australia, research and clinical trials and consumer participation. It may be useful information not only for your role within Cancer Australia but also if you are participating on other national or state cancer control initiatives.

The *Consumer Training and Mentoring Guide* is a resource developed to facilitate consumer mentoring of consumers as they develop in their role. Mentoring is a mutually beneficial relationship which involves a more experienced person helping a less experienced person to achieve their goals. It is a relationship that focuses on the needs of the mentee and aims to develop consumers to their fullest potential so that they become confident, active participants. Experienced consumers may be invited to assist with the training and mentoring of other consumers. *The Consumer Training and Mentoring Guide* has been developed to support you in this mentoring role.



# Section One: Cancer Australia

## Introduction

The aim of this section is to provide you with some general information about Cancer Australia.

Cancer Australia is a dynamic organisation whose role will evolve over time. Although we will try to ensure that this section contains the most up-to-date information about Cancer Australia we advise you to access Cancer Australia's website for information on our current priority areas.<sup>1</sup>

On completing this section, you should:

- have an understanding of why Cancer Australia was established
- know the roles and functions of Cancer Australia
- understand the structure, governance and consultative approach Cancer Australia has adopted
- have an understanding of the key activities that are being undertaken by Cancer Australia.

## Why Cancer Australia was established

Cancer Australia was established by the Australian Government in 2006 to improve health outcomes for all people affected by cancer; particularly those people whose survival rates or cancer experience is poorer. This includes Aboriginal and Torres Strait Islander peoples, people living in rural and regional areas, people from cultural and linguistically diverse backgrounds and people who are socially and economically disadvantaged.

Our aim is to improve cancer awareness, care and support for:

- people at risk of cancer
- people being treated for cancer
- people surviving cancer

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<sup>1</sup> For current information on Cancer Australia go to the Cancer Australia website at [www.canceraustralia.gov.au](http://www.canceraustralia.gov.au)

- ▶ people living with cancer
- ▶ people whose lives will be shortened because of cancer
- ▶ the families and friends who support all of these people every day around the country.

We work directly and in partnership with consumers, health professionals, cancer organisations, researchers and governments to improve outcomes for all people affected by cancer.

## CANCER CONTROL

‘Cancer control refers to all actions that aim to reduce the burden of cancer on individuals and the community’. Cancer control activities include education, research, early diagnosis and screening, specific cancer therapy, and support and care (including palliative care) of people affected by cancer. Cancer control involves hospital and community health care providers and also a strong voluntary sector led by the Cancer Councils. More broadly, cancer control involves the behaviour and lifestyle of every person in the community.

Clinical Oncological Society of Australia 2003, p.ix.

## Role and functions

Our role and functions as outlined in the *Cancer Australia Act 2006* are to:

- ▶ provide national leadership in cancer control
- ▶ guide scientific improvements to cancer prevention, treatment and care
- ▶ coordinate and liaise between the wide range of organisations, groups and service providers with an interest in cancer care and support
- ▶ make recommendations to the Australian Government about cancer policy and priorities
- ▶ oversee a dedicated budget for research into cancer
- ▶ help implement Australian Government policies and programs in cancer control
- ▶ undertake other tasks as directed by the Minister for Health and Ageing.

Our initial priorities in our first two years were to:

- enhance support, information and participation in decision making for people affected by cancer
- increase coordination and funding of cancer research, and actively support cancer clinical trials
- improve the quality of cancer care, and support and training for health professionals
- review current national cancer control and cancer research activities and identify priorities for action to further improve cancer outcomes in Australia.

Cancer Australia also has responsibility for the administration of a number of cancer control programs which have included:

- the Building Cancer Support Networks
- boost cancer research
- support for cancer clinical trials
- mentoring for regional hospitals and cancer professionals
- professional development for professionals providing care and support to people with cancer
- development of training courses for cancer nurses
- the National Centre for Gynaecological Cancers

In 2006, following the Senate Community Affairs Reference Committee Inquiry into Gynaecological Cancers in Australia, we were also given responsibility for the establishment and management of the National Centre for Gynaecological Cancers. The full report from this inquiry, *Breaking the Silence: a national voice for gynaecological cancers*, can be found at [http://www.aph.gov.au/Senate/committee/clac\\_ctte/completed\\_inquiries/2004-07/gynaecological\\_cancer/report/index.htm](http://www.aph.gov.au/Senate/committee/clac_ctte/completed_inquiries/2004-07/gynaecological_cancer/report/index.htm)

Cancer Australia does not have responsibility for all Australian Government cancer control programs. The Department of Health and Ageing has responsibility for a number of other cancer control programs including a number of screening and cancer prevention programs. You can obtain information on all the Department of Health and Ageing cancer control initiatives by accessing the following website: [www.health.gov.au](http://www.health.gov.au)

Cancer Australia, as a Commonwealth Government agency, does not establish or operate health services, or determine where services will be located, or how services will be configured or funded. It is also not responsible for the employment of health professionals in health services. You will find a more detailed account of the Australian health system in the *Consumer Resource Guide*.

## Vision and values

Our organisation's vision and values are listed in the box below.

### OUR VISION

To reduce the impact of cancer on all Australians.

### OUR VALUES

As an organisation, we value:

- ▶ improving outcomes in cancer control
- ▶ collaborating with our stakeholders
- ▶ working cooperatively
- ▶ being professional
- ▶ having personal and organisational accountability
- ▶ working as a learning organisation.

## Structure, governance and consultation approach

Cancer Australia is a statutory agency established through an [Act of Parliament](#) in 2006.

It is a small agency of approximately 18 people managed by the Chief Executive Officer, Professor David Currow.

It is a prescribed agency under the Financial Management and Accountability (*FMA*) Act 1997. The FMA Act determines how the organisation is established and outlines its organisational and reporting structures.

We are also accountable to Commonwealth Government financial management legislation and must adhere to Commonwealth Government procurement frameworks and guidelines.

### Advisory Council

The Advisory Council was established under the *Cancer Australia Act 2006* to “give advice to the Chief Executive Officer about the performance of Cancer Australia’s functions”. It comprises a Chair and up to 12 other members, all appointed by the Minister for Health and Ageing.<sup>2</sup>

Advisory Council members bring experience and expertise in areas including oncology, general practice, community cancer care, cancer research, academia and politics, and several have had a personal cancer experience. The inaugural members are:

- Dr Bill Glasson AO (Chair)
- Professor Sanchia Aranda
- Professor James Bishop AO
- Mr John Johnson
- Dr Megan Keaney
- Ms Meg Lees
- Mrs Janet McDonald AO
- The Hon Jocelyn Margaret Newman AO

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<sup>2</sup> For up-to-date information on the National Advisory Council go to <http://152.91.86.9/about-us/organisation/advisory-council.aspx>

- ▶ Professor Ian Olver
- ▶ Professor Christobel Saunders
- ▶ Dr Julie Thompson.

## Consultation framework

We aim to improve cancer outcomes in Australia through national leadership, collaborating with and adding value to the efforts of the many people who have an interest in cancer control.

We are looking at all cancers and all people with cancer, with an aim to improve cancer outcomes, survival and quality of life of those people affected by cancer.

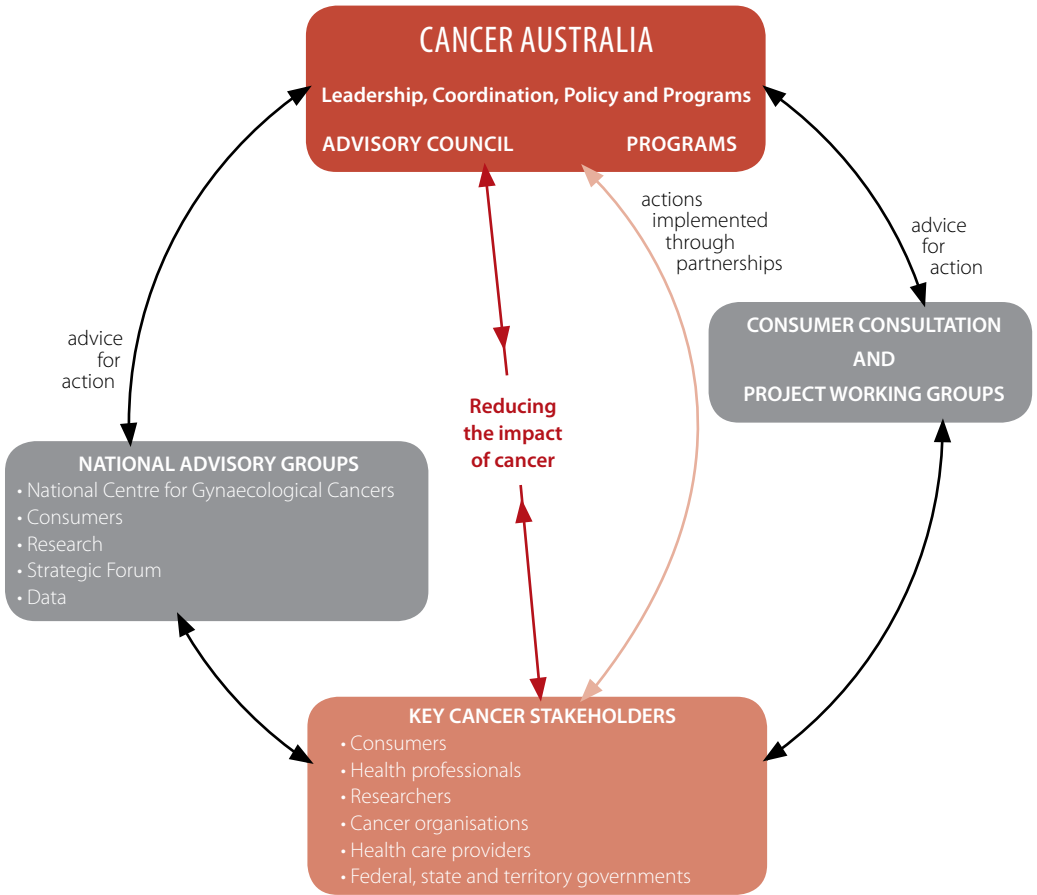
To maximise consultation with, and expert input from, the many people who we see as our key stakeholders, we established a number of advisory, reference and project working groups.

Cancer Australia reports to the Minister for Health and Ageing, and our key stakeholders are:

- ▶ people affected by cancer
- ▶ health professionals, including those in primary care
- ▶ cancer organisations
- ▶ researchers and research funders
- ▶ federal, state and territory government agencies
- ▶ the Department of Health and Ageing

Our consultative framework and the relationship between these groups and Cancer Australia have been illustrated in the diagram below.

# REDUCING THE IMPACT OF CANCER



We have a strong working relationship with the Department of Health and Ageing and other government agencies such as the National Health and Medical Research Council. We work together in a collaborative way to ensure that a coordinated approach to cancer control is adopted.

## Consumer representation

Over fifty consumers, with a range of experience and skills across the cancer care continuum, have been recruited to participate in our national advisory, reference and working groups.

Our aim is to involve at least two consumers in each group. Consumers have been recruited through three approaches: i) a national advertisement; ii) nominations from cancer consumer organisations, and iii) direct invitation to individuals with specific skills and experience. A selection panel comprising consumers from Cancer Australia's Advisory Council, Cancer Voices Australia and Cancer Councils selected the successful consumers through an open and transparent process.

### National advisory groups

Our national advisory groups provide advice and direction on a range of issues and activities undertaken by Cancer Australia. They recommend strategies and actions to improve cancer control and outcomes for people affected by cancer.

We have established a number of national advisory groups including advisory groups for:

- ▶ consumer interests
- ▶ research
- ▶ cancer data management
- ▶ quality and professional development
- ▶ the National Centre for Gynaecological Cancers.

We have also established an inter-governmental Strategic Forum, to bring together clinicians and senior health department officials from each state and territory government to provide us with advice on policy development and implementation, and to advance national cancer control activities throughout Australia.

Members of advisory groups have been selected from a wide range of relevant national groups and organisations to ensure a broad spectrum of expertise and experience, gender balance and geographic representation across Australia. Some members were invited directly due to their particular



experience or expertise. Each group includes people who have been affected by cancer, as well as medical and health professionals with expertise in research, prevention, early detection, diagnosis, treatment, care, support and other areas of cancer control related to a specific cancer, or the impact of cancer on people of a particular age group.

While members of advisory groups may have affiliations with a wide range of organisations, or may have been nominated by an organisation, members of Cancer Australia's national advisory groups are not invited to represent such specific organisations or professional bodies. Instead, members are invited to participate in their own right to provide leadership and expert input to the spectrum of cancer care.

### ***National Consumer Advisory Group***

The National Consumer Advisory Group was established to advise us on consumer needs, and helps us understand how the health care system can affect people with cancer. The group helps us to improve the quality of, and access to, information for consumers, and identify gaps in cancer prevention, early detection, diagnosis, treatment, psychosocial support, survival and palliative care. The advice received is incorporated throughout all of Cancer Australia's work.

Members of the National Consumer Advisory Group are mainly people who are affected by cancer—either as people diagnosed with cancer, or as carers or family members of someone with cancer. Three of the members of this group are health professionals, who have experience in cancer research or cancer service delivery.

Most of the members of this group have leadership experience in national or state consumer organisations, and collectively the group has enormous breadth of knowledge, skills and expertise in a wide variety of areas. All have come with a strong commitment to making a difference for people affected by cancer.

The members of this group serve terms of up to three years, with the period of appointment being determined by a ballot.

This group has identified the following three priority areas of work which it plans to address over the next few years:

- improving consumer access to nationally consistent and accurate information about cancer

- ▶ increasing involvement of consumers in all decision making throughout the cancer journey
- ▶ ensuring that quality psychosocial support is provided for consumers from diagnosis through to survivorship, and palliative and supportive care.

Many of the members of this group have participated in other working groups that we have established, or participated in other Cancer Australia activities, such as the assessment of funding grants.

### ***National Research Advisory Group***

Cancer Australia is implementing several initiatives to fund and better coordinate cancer research in Australia, and to build and support cancer clinical trials. The National Research Advisory Group was established to guide this work and to provide advice about:

- ▶ current and emerging issues in cancer research (horizon scanning)
- ▶ priorities for cancer research in Australia
- ▶ supporting Australia's representatives on the International Agency for Research on Cancer (IARC) councils.

### ***National Cancer Data Strategy Advisory Group***

Improved cancer data collection and management in Australia is considered an important issue by a wide range of stakeholders. Cancer Australia has contracted the services of an epidemiologist who works on developing and implementing a National Cancer Data Strategy.

The National Cancer Data Strategy Advisory Group brings together experts in health data reporting and data systems design, including consumers, cancer researchers, health policy makers and epidemiologists.

There are two consumers in this group.

## ***National Centre for Gynaecological Cancers Advisory Group***

The National Centre for Gynaecological Cancers is an Australian Government initiative established within Cancer Australia to improve outcomes for women affected by gynaecological cancers, their families and carers, and to lessen the impact of cancer on their lives.

The National Centre for Gynaecological Cancers Advisory Group was formally established in 2008. It provides support and advice to Cancer Australia on a complex and integrated work program for 2008–11, which has been agreed upon by the Minister for Health and Ageing. It is a multidisciplinary group from across Australia including consumers, health professionals and researchers from the entire cancer control spectrum, and with particular expertise in the area of gynaecological cancers. Members serve terms of up to three years, and at present there are three consumer representatives in this group.

For more information on the National Centre for Gynaecological Cancers go to [www.gynaecancercentre.gov.au](http://www.gynaecancercentre.gov.au)

### ***Reference and project working groups***

We have convened a number of reference and project working groups since our establishment to help us identify opportunities to improve cancer care and outcomes for people affected by particular cancers. These groups have provided us with expert advice on issues and activities related to particular cancers. As with the national advisory groups these groups included people who have been affected by cancer, as well as medical and health professionals with expertise in research, prevention, early detection, diagnosis, treatment, care, support and other areas of cancer control related to the specific cancer, or the impact of cancer on people of the particular age group.

We have established national reference groups for the following tumour- or age- specific groups:

- ▶ prostate and testicular cancers
- ▶ lung cancer
- ▶ upper gastrointestinal cancers
- ▶ head and neck cancers

- ▶ adolescents and young adults with cancer
- ▶ cancer of unknown primary site.

These groups were established because the evidence suggests that people affected by these cancers have poorer outcomes. In the future these groups will meet on an ad hoc basis depending on our workload and priority areas.

Project working groups have been established for all our main projects. Members of these groups provide advice to the project team on aspects of the particular project. Members may have expertise in the particular area or may represent an organisation that is crucial to the success of the project. It is our policy that at least two consumers are involved on these project working groups to ensure that where possible all projects funded by Cancer Australia maintain a consumer focused approach.

### **WORK OF THE NATIONAL REFERENCE GROUP FOR ADOLESCENTS AND YOUNG ADULTS WITH CANCER**

The Adolescents and Young Adults with Cancer Service Delivery Framework is an example of work completed by the National Reference Group for Adolescents and Young Adults with Cancer.

A key recommendation of the first meeting of this reference group was a need to develop a service delivery framework for adolescents and young adults with cancer to ensure that the special needs of this group were met.

Following this first meeting, CanTeen, a consumer support organisation for adolescents and young adults with cancer, approached Cancer Australia to work in partnership to facilitate this recommendation. Extensive liaison with consumers and key experts from across Australia resulted in the development of a national service delivery framework that identifies the needs of adolescents and young adults affected by cancer throughout the cancer journey, and describes the requirements of cancer services to meet these needs.

The framework aims to describe quality adolescent and young adult care, based on the best available evidence, and provides for states and territories to adapt it to their local circumstances.

## CONSUMER INVOLVEMENT IN THE NATIONAL SERVICE DELIVERY FRAMEWORK FOR ADOLESCENTS AND YOUNG ADULTS WITH CANCER.

As a survivor of Hodgkin's Lymphoma and an adolescent and young adult (AYA) 'cancer consumer' it is pleasing to be involved with Cancer Australia's Adolescents and Young Adult Reference Group to help develop the National Service Delivery Framework for Adolescents and Young Adults with Cancer.

It is important that consumers have the ability to use their personal experience, and those of their friends, to work with government to ensure that the system is continually improving. This is especially important in the area of adolescents and young adults, and the development of the National Service Delivery Framework for AYA Cancers, as this is a very unique stage of an individual's life.

As an adolescent cancer patient I have been part of the system and have invaluable personal knowledge on how the service delivery of my cancer care impacted on my life. This experience (and many other similar experiences of friends) has given me the background needed to ensure that consumers' views are considered in improving service delivery for AYA cancers. I am not a general practitioner, haematologist, radiologist or any other medical professional. However, it is a privilege to be at the table with these professionals and government to work together to develop the direction of AYA cancer care into the future.

I am a young man in the prime of my life who had cancer thrown into the mix. I did not and to this day probably still don't know what was best for me medically; however, I do know ways that many other aspects of an AYA cancer journey could be improved. Having the opportunity to feed this into a new service delivery framework gives consumers the ability to ensure that the system will be improved for AYA cancer patients of the future and tailored to the patients' needs.

Liam Hunt

Member of National Reference Group  
for Adolescent and Young Adults with Cancer

## **Aboriginal and Torres Strait Islander consultation process**

Engaging and consulting with Aboriginal and Torres Strait Islander peoples is very important to us. People affected by cancer in this population group have much poorer outcomes than the rest of the Australian population.

We understand that, if we are to make a difference to the cancer outcomes for this population group, we must effectively engage and involve Aboriginal and Torres Strait Islander peoples. We have sought the input of Aboriginal and Torres Strait Islander Community Controlled Health Organisations, councils and services throughout Australia on how best to engage and support Aboriginal and Torres Strait Islander people through their cancer journey. We have successfully recruited Indigenous representatives on the National Consumer Advisory Group, National Centre for Gynaecological Cancers Advisory Group and our Strategic Forum. We are continuing to look at ways to effectively engage this population group and to engage more Aboriginal and Torres Strait Islander consumers on all or advisory, reference and project working groups.

Supporting Aboriginal and Torres Strait Islander people with cancer has been a priority area for the Building Cancer Support Networks Grants Program. Five projects funded through the third grants round of this program will either directly or indirectly support Aboriginal and Torres Strait Islander people with cancer.

## **Priorities and programs**

Cancer Australia is a dynamic organisation that works within a government framework. Although its overall aim will not change, key priority areas and programs may change over time.

### **HINT**

For the most up-to-date information about our current activities, subscribe to the Cancer Australia newsletter, *Cancer Australia Connections*. Email Cancer Australia if you would like to be added to our mailing list or subscribe by visiting [www.canceraustralia.gov.au](http://www.canceraustralia.gov.au)

Cancer Australia's current (2009) priorities include:

- Improving outcomes for people affected by gynaecological cancers, through the work of the National Centre for Gynaecological Cancers
- Boosting cancer research through funding cancer research in priority areas and building capacity for multi-site, collaborative national cancer clinical trial groups
- Improving access to coordinated cancer services for those living with cancer or at risk of cancer, and using data to better inform planning of cancer control
- Supporting professional development for cancer professionals, including primary care doctors
- Engaging, supporting and informing consumers so that they can be fully involved in cancer control.

The following provides a brief overview of some of our key programs that will support the above priorities.

### ***The National Centre for Gynaecological Cancers***

The [National Centre for Gynaecological Cancers](http://www.nccgc.gov.au) was established by the Australian Government in 2007, under the auspice of Cancer Australia. It was established in response to the Senate Community Affairs Committee Report on the Inquiry into Gynaecological Cancers in Australia, *Breaking the silence: a national voice for gynaecological cancers*, published in 2006. This report can be found at [http://www.aph.gov.au/Senate/committee/clac\\_ctte/completed\\_inquiries/2004-07/gynaecological\\_cancer/report/index.htm](http://www.aph.gov.au/Senate/committee/clac_ctte/completed_inquiries/2004-07/gynaecological_cancer/report/index.htm)

The Centre is overseen by Cancer Australia's Chief Executive Officer who reports directly to the Minister for Health and Ageing. It works closely with all stakeholders, including the National Breast and Ovarian Cancer Centre.

The Centre aims to raise awareness about issues associated with gynaecological cancers, and improve the availability of quality information about gynaecological cancers. The Centre does not provide cancer services or advice about cancer issues for individuals

The diagram below shows the governance arrangement for the National Centre for Gynaecological Cancers.



In its first year an extensive work program was undertaken that included:

- a [review of currently available gynaecological cancers information resources](#)
- the [development of an on-line training module on the management of gynaecological cancers for general practitioners](#)
- the identification of areas of clinical practice in the management of women with endometrial cancer that would benefit from the [development of clinical practice guidelines](#)
- development of a minimum data set that will improve [cancer data](#) collection for gynaecological cancers
- development of a survey instrument that will measure the referral [patterns of care](#) for women with gynaecological cancers
- a review of the gynaecological cancers workforce.



In 2008–2011 the Centre will build on this work and implement the following work program:

- the establishment of a consumer fellowship and a clinical research fellowship for improved knowledge about gynaecological cancers
- the development of information resources on gynaecological cancers for consumers and health professionals
- the implementation of a national survey to establish the referral patterns of care by gynaecologists and GPs for women with gynaecological conditions
- professional development resources that will enhance the psychosexual care of women with gynaecological cancers
- the development and implementation of clinical guidance material for the management of women with endometrial cancer
- the implementation of a minimum dataset for gynaecological cancers
- the support of a sustainable and skilled gynaecological cancers workforce.

### CONSUMER INVOLVEMENT IN THE NATIONAL CENTRE FOR GYNAECOLOGICAL CANCERS

A number of consumers have been involved in the establishment of the National Centre for Gynaecological Cancers, and have provided advice on program areas and strategic planning for the Centre as a whole. Consumers have also been involved in the assessment of tenders for different aspects of the Centre's work and are included on all project reference or working groups.

#### ***Boost cancer research***

Cancer research and clinical trials are vital to increase our understanding of how to prevent cancer, to develop new approaches to detecting, diagnosing and treating cancers, and to improve support and care for people affected by cancer.

Cancer Australia administers funding for research and clinical trials support. We have developed new programs to better coordinate cancer research in Australia, and to build and support cancer clinical trials.

## CONSUMER INVOLVEMENT IN THE BOOST CANCER RESEARCH PROGRAM

Consumers have had input into the development of assessment guidelines to ensure that the research funded by Cancer Australia includes consumer involvement throughout the research process.

Consumers have also been involved with the assessment of research grants.

We are supporting consumers to undertake specific training to assist with their involvement in the research process.

The *Consumer Resource Guide*, the second resource within this *Consumer Resource Kit*, provides you with some additional information about consumer participation in research and information on clinical trials.

Further information about our key research programs and activities is available via the Cancer Australia website ([www.canceraustralia.gov.au](http://www.canceraustralia.gov.au)), including information on:

- ▶ increasing coordination and funding of cancer research, through the [Priority-driven Collaborative Cancer Research Scheme](#)
- ▶ actively [building capacity for cancer clinical trials](#) to be undertaken in Australia and [increasing the involvement of consumers in clinical trials](#)
- ▶ conducting an [audit of cancer research activity](#) in Australia.

### **Building Cancer Support Networks**

The Building Cancer Support Networks grants program provides seed funding to organisations to help develop or expand cancer support networks. These networks allow people to share their experience with others who have also been affected by cancer, and access information and resources to help them through their cancer experience.

A 'support network' is a group of people who provide each other with support (talking with others who may be having similar experiences), information, and advice on problems associated with a shared experience.

A support network may be a face-to-face group that is supported by a professional facilitator or a face-to-face group that is facilitated by a trained volunteer.

It may be a virtual support network that provides support to people either over the phone or via the internet.

We have added value to this program by collaborating with the Cancer Councils in each state and territory to ensure that there are support networks in each jurisdiction and to build strong relationships with key community organisations like the Cancer Councils. This partnership will build accessible, coordinated and quality support for people affected by cancer.

We have also [developed resources](#) that will support the development and maintenance of quality peer-support groups across Australia. These resources can be accessed through our website.

## CONSUMER INVOLVEMENT IN THE BUILDING CANCER SUPPORT NETWORKS

Consumers from our National Consumer Advisory Group were involved in the assessment of the Building Cancer Support Networks grants program applications.

### [Australian Cancer Trials Online website](#)

In collaboration with the University of Sydney and the National Health and Medical Research Council we are working to develop a web portal that will provide consumer-friendly access to information about cancer clinical trials.

We are currently working with consumers to identify the information that consumers require to make decisions about their treatment options, including clinical trials. Providing easily understood information on cancer treatment options will enable people affected by cancer to make more informed decisions.

## CONSUMER INVOLVEMENT IN THE AUSTRALIAN CANCER TRIALS ONLINE WEBSITE

Cancer consumer organisations are interested in helping to increase the awareness of clinical trials and to assist individuals, like ourselves, find the trials which are suitable to our needs.

Since the late 1990s, consumers have lobbied for a register of cancer clinical trials and a consumer-friendly website for easy access. The first aim was achieved by the establishment of the Australian and New Zealand Clinical Trials Registry and the second will be met by the development of a new website, funded in partnership by the University of Sydney, Cancer Australia and the National Health and Medical Research Council Australian and New Zealand Clinical Trials Registry.

As the Principal Researcher charged with bringing the consumer perspective to this project, a major part of my role has been to coordinate consumer views to inform the development of this work.

Sally Crossing AM  
Chair, Cancer Voices NSW

### ***Professional development***

Supporting health professionals, in their ongoing professional development, is an important component of our work. The treatment and management of people affected by cancer is an evolving field. Ensuring that all health professionals have access to the most up-to-date, evidence based information about cancer and the treatment of cancer is very important.

We have funded or are managing several targeted initiatives to support the cancer care workforce, and to promote the best possible care to people affected by cancer now and in the future.

Further information on these programs and activities is available via the Cancer Australia website ([www.canceraustralia.gov.au](http://www.canceraustralia.gov.au)), including information on:

- the development of a [national framework and effective continuing professional education modules](#). In partnership with Cancer Australia, the University of Sydney's Centre for Innovation in Professional Health

Education and Research (CIPHER) has led the development of [Cancer Learning](#). This information hub aims to consolidate the enormous variety of evidence-based learning activities, resources and information in cancer care available across Australia in one online location. Information on Cancer Learning can be found by visiting the Cancer Learning website at: [www.cancerlearning.gov.au](http://www.cancerlearning.gov.au)

- ▶ the development of a [national framework and training package for cancer nurses](#). This program started in 2005 in recognition of the need for people diagnosed with cancer to receive specialised cancer care. It has involved the development of a national framework and training package for cancer nurses (known as EdCaN). The Peter MacCallum Cancer Centre in Victoria is managing the [EdCaN](#) program, in association with other Australian cancer care institutions, universities and professional associations. Information on EdCaN can be found by visiting the EdCaN website at [www.edcan.org](http://www.edcan.org)

### CONSUMER INVOLVEMENT IN THE PROFESSIONAL DEVELOPMENT FOR CANCER PROFESSIONALS PROGRAMS

Consumers have been extensively involved in the EdCaN program. A number of consumer workshops were held during the development phase, to canvass the views of consumers and to ensure that the educational modules had a consumer focus.

General practice is usually the first point of contact for people with early symptoms of cancer, and the general practitioner plays a significant role in prevention, screening, follow-up after treatment, and palliative care. We have supported a number of [initiatives to better engage and support general practitioners](#) in the delivery of cancer care. This has included a review of the gynaecological cancers workforce, development of [training and resources for general practitioners](#), and the development of an [Education Program in Cancer Care](#) for medical practitioners.

#### **Service improvement**

Improving the way services are delivered, particularly the services delivered to rural and remote communities, and to groups with a poorer cancer outcome, is an important area of work.

Cancer Australia has developed the Cancer Service Networks National Demonstration Program ([CanNET](#)) to better link regional and metropolitan cancer services.

CanNET involves the Australian, state and territory governments working collaboratively with consumers of cancer services and primary, secondary and tertiary health professionals to improve outcomes through better coordination of existing services.

### **CONSUMER INVOLVEMENT IN THE CANNET PROGRAM**

Active involvement of consumers in the planning and establishment of the Cancer Service Networks (CanNETs) across Australia is pivotal to the success of this program.

In addition to consumers being involved at a national level, each of the seven project teams has recruited consumers to guide the development of their local cancer service networks. This strategy will help ensure that health care providers are focused on addressing the needs of people affected by cancer, particularly those in rural areas.

Consumer involvement is a key element of cancer service network development.

# Section Two: Consumer participation

## Introduction

In this section you will learn more about why Cancer Australia has adopted an approach that involves consumers.

After reading this section you should have:

- a clear idea of who we view as a consumer
- an understanding of why we think it is important to involve consumers in all aspects of our work agenda
- a clear understanding of your role as a consumer for a national government area.

Also included in this section are tips and hints on how to be an effective committee member.

## Who is a consumer?

By 'consumers' or 'people affected by cancer' Cancer Australia means people living with cancer, cancer survivors, carers and family members.

## What is consumer participation?

There are several ways of defining consumer participation. A definition used by the National Health and Medical Research Council (NHMRC) is:

*Participation* is about being part of the process. It is about more than observing and commenting on processes but actual involvement in forums, the authoring of solutions or the development of regulatory instruments. (NHMRC 2004, p. 9)

## A CONSUMER'S PERSPECTIVE

As a consumer, and having had my husband diagnosed with Glioblastoma Multiformae earlier this year, it has been a good thing to be involved with Cancer Australia. No-one would choose to become knowledgeable about cancer and its many and varied treatments but I am so pleased that the consumer is now considered to be an important contributor to the large picture of cancer treatment.

Helen Collyer  
Member of CanNET



## Rationale for consumer participation

We involve consumers in our activities because we acknowledge the current sound evidence that shows that a consumer focus is a powerful tool for driving system change, and for influencing policy development at a federal, state and territory level.

We have adopted consumer participation as a component of all our activities and we have demonstrated a unique and important commitment to consumer participation.

One of the first activities we undertook following the establishment of Cancer Australia was the recruitment of consumers who would be available to advise and work with us to gain a better understanding of the lived experience of having cancer. We saw that in order for us to fulfil the role outlined in the *Cancer Australia Act 2006* we needed to engage with a variety of consumers from a broad cross-section of the population. We also needed to ensure that Cancer Australia's ethos was firmly embedded with a consumer focus.

As outlined in Section One, we have established a consumer-focused national advisory group to provide us with advice on the specific issues faced by all consumers affected by cancer.

The National Consumer Advisory Group aims to improve the quality of, and access to, information for consumers, and to help Cancer Australia identify gaps in cancer prevention, early detection, diagnosis, treatment, psychosocial support, palliative care and issues of survival.

In its first year, the group identified three key priority areas of work:

- improving consumer access to nationally consistent and accurate information about cancer
- increasing involvement of consumers in all decision making throughout the cancer journey
- ensuring that quality psychosocial support is provided to consumers from diagnosis through to survivorship and palliative and supportive care.

It also developed a Consumer Values Statement identifying the issues which consumers affected by cancer saw as important.

## CANCER AUSTRALIA NATIONAL CONSUMER ADVISORY GROUP CONSENSUS VALUES STATEMENT

The following is an aspirational set of values that reflects what consumers of cancer services and other people affected by cancer see as important with regard to treatment support and involvement in cancer control. These values have been developed by Cancer Australia's National Consumer Advisory Group (NCAG). The values reflected in this document are significant at all levels of policy making, health service delivery and research. Consideration of these values by those involved in cancer care will help reduce the burden of cancer on the Australian community.

The NCAG fully supports the mission statement of the Charter of Paris Against Cancer (2000) and especially notes Articles VII and VIII which:

- (a) advocate the rights of people affected by cancer to be comprehensively informed and to be engaged in all phases of cancer treatment, research and policy making; and
- (b) stress the fundamental importance of the patient's quality of life regardless of the stage of the disease and its prognosis.

In particular, we urge that all people affected by cancer:

1. are respected, with key human rights such as freedom of treatment choice and acceptance of the cultural, sexual and religious background, socio-economic status, home circumstances and geographical location of people affected by cancer;
2. have the right to be fully informed and supported throughout their cancer experience;
3. are fully involved in the decision making around treatment and support and have access to a multidisciplinary treatment and support plan that incorporates the cultural, linguistic, emotional, social, physical, psychological, spiritual and sexual needs of people affected by cancer;
4. are informed of their ability to seek a second medical opinion around their diagnosis and treatment, and are supported whether or not they choose this option;

5. are given timely, appropriate information about treatment options and choices, that is communicated in a respectful, caring, compassionate and reflective way and that is in a mode and language that the consumer is most comfortable with (oral, in writing or recorded);
6. are entitled to be offered, in writing, detailed information (based on the best available evidence), about the type and staging of their cancer diagnosis;
7. where it is available and appropriate are given the opportunity to join cancer clinical trials;
8. are offered emotional and social support services;
9. have access to quality and safe treatment and support that, where possible, is delivered by a multidisciplinary treatment and support team; and
10. are viewed as important strategic partners by medical, research, industry, government and policy-making groups, in all aspects of decision-making across the cancer continuum of prevention, early detection, diagnosis, treatment, rehabilitation, survival and palliative care; and the direction of research

## The role of consumers

Consumers actively participate in all of Cancer Australia's national advisory and reference, and project working groups. In addition they have been asked to assist us in the evaluation of funding grants, tenders and research proposals.

The role of consumers in Cancer Australia's activities includes:

- participating in developing solutions that will reduce disparate outcomes
- providing advice to government through committee work
- influencing policy, cancer services and research
- building knowledge about the cancer experience
- mentoring and supporting new consumers
- advancing the understanding of cancer control and the role of Cancer Australia within the community.

Consumers can undertake these roles through a range of actions including offering experiences of care, suggesting improvements to care systems, commenting on new ideas and proposals from diverse consumer perspectives and asking questions about processes and approaches.

Most groups established will have clear terms of reference, which identify why the group was established and what its role is. It may also include information on when meetings are held and how long the group will be established for or how long members will remain on the group. Before accepting membership on any group, it is important that you read this document so that you are able to decide if you are able to effectively participate on the group within its guidelines.

## HINT

To assist effective representation on a committee or working group consumers are encouraged to:

- ▶ identify the boundaries of the issue being addressed within the context of the committee role
- ▶ look for options rather than single solutions
- ▶ do not expect to change funding allocations
- ▶ accept that Cancer Australia's role is to advise the minister—we can not make final policy decisions
- ▶ remember that the minister will probably be taking advice from others outside the committee

## How Cancer Australia can help you in your role as a consumer representative

We are keen to support you to carry out your role within Cancer Australia effectively. We recognise that your time is precious and that you may be involved in many other activities outside Cancer Australia.

### Financial support

Although your role within Cancer Australia is voluntary, we do not wish you to experience any out of pocket expenses if you are attending meetings or undertaking any committee work.

We will arrange all your travel and accommodation expenses if you are travelling interstate to a meeting, and we will also pay you a travel allowance prior to each meeting to cover additional expenses you may incur such as taxi fares, parking or the purchasing of meals.

In addition, if you are not receiving income from another source on the day of the meeting you can claim sitting fees. Cancer Australia bases payment of sitting fees upon the Tier 3 rate for Part Time Office Holders established by the Commonwealth Government [Remuneration Tribunal](#).

We have found that some consumers do not wish to claim these fees. It is important therefore that you notify Cancer Australia if you wish to claim a sitting fee prior to any meeting.

### Other support and training

We are keen to provide you with any training you may need in order to fulfil your role within Cancer Australia. If you are a consumer who has not previously been involved at a national level you may benefit from talking to a more experienced consumer. We have established a mentoring process that will assist new consumers become more familiar with their role within Cancer Australia. If you feel that you would benefit from this, please let us know.

In addition, if you feel that you may benefit from some specific training, such as the training you may require to be involved in the assessment of research grants or involvement on research projects, we are happy to assist you to find a course that you can undertake. A number of the Cancer Councils in each state and territory offer consumer training in research.

## How does my role in Cancer Australia differ from my role with advocacy organisations?

Many consumers involved with Cancer Australia are also involved in non-government cancer advocacy organisations. Your role within Cancer Australia is slightly different from your role within these organisations. As indicated in Section One, Cancer Australia must work within a legislative framework. When members are invited to participate within a government framework, their role is to provide advice that considers the benefits and risks of an issue, and recommends a best way forward based on the best available information.

Advocacy on the other hand is promoting or arguing for a particular issue. Advocacy organisations such as Cancer Voices play an important role in advocating for people affected by cancer. Because of their independence from government they are able to directly lobby to promote a particular point of view.

It is important that you understand the different roles played by the federal and state governments in the provision of health services. You may find it useful to read Section one of the *Consumer Resource Guide* (the second resource in this *Consumer Resource Kit*), on the Australian health system, to gain a better understanding of the overall system.

## AFFECTING GOVERNMENT POLICY: THE VOICE OF CONSUMERS

The key challenge in providing advice to government is engagement. An engaged government will help facilitate achievement of outcomes. This is done either emotionally (through hearing the patients' stories), intellectually (through listening to advice) or through a personal connection.

Consumers need to deliver to the government something that benefits it either directly or indirectly as a contribution to policy outcomes that both parties value. These can be:

- ▶ improved outcomes for people affected by cancer
- ▶ identifying monetary benefits of a policy proposal
- ▶ demonstrating that a proposal will deliver improved policy outcomes
- ▶ electoral betterment
- ▶ emotional satisfaction
- ▶ something that is consistent with existing policy
- ▶ demonstrating how our proposal will 'make a difference'.

John Stubbs

Executive Officer

Cancer Voices Australia and Member of CanNET

## References

Australian Commission for Safety and Quality in Health Care 2005, *Partnerships in Health Action: Promoting consumer and community involvement in health care improvement*, Commonwealth of Australia, Canberra, viewed 11 Jan 2008, [http://www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/C06811AD746228E9CA2571C600835DBB/\\$File/consumrept0705.pdf](http://www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/C06811AD746228E9CA2571C600835DBB/$File/consumrept0705.pdf).

Consumers' Health Forum of Australia 2007, *Consumer Representative's program*, viewed 13 February 2008, [http://www.chf.org.au/consumer\\_reps\\_program/about\\_rep\\_program.asp](http://www.chf.org.au/consumer_reps_program/about_rep_program.asp)

National Health and Medical Research Council & Consumers' Health Forum of Australia 2004, *A model framework for consumer and community participation in health and medical research*, NHMRC/CHF, Canberra, viewed 14 Jan 2008, <http://www.nhmrc.gov.au/publications/synopses/files/r33.pdf>.



# Section Three: Skills for effective consumer participation

## Introduction

This section offers a series of tips, skills and resources that may help you in your role within Cancer Australia. It also offers techniques to help you manage the role, and strategies to help you cope with demands that may be placed on you.

## Self-care

We cannot stress enough how important it is for you to look after yourself. Self-care is a highly relevant issue for consumers participating in Cancer Australia's national advisory, reference and working groups. From time to time the role may be quite overwhelming for you, and you may experience many competing demands on your time. You need to manage your physical and mental health to ensure that you do not become overwhelmed, tired or frustrated.

The Mental Health Council of Australia has produced a valuable resource for consumers of mental health services and family carers called *The Kit*. This resource is cited extensively in this section as it contains some very valuable and helpful material. This resource can be found at [www.mhca.org.au/Resources/CommunityDevelopment/TheKit-part1\\_AdvocacyandtheIndividual.pdf](http://www.mhca.org.au/Resources/CommunityDevelopment/TheKit-part1_AdvocacyandtheIndividual.pdf).

Included in *The Kit* is a pro forma that will allow you to undertake a stocktaking exercise of your commitments and to assess your personal physical, social, emotional, intellectual and spiritual fitness.

It is recommended that this exercise is completed once a year as a review of personal care needs and goals. *The Kit* also provides an example of a personal résumé, which would be useful for responding to requests for information about you, or for preparing a personal introduction before giving a presentation.

## HINT

### *Strategies to cope with stress*

- ▶ Have a way of distracting yourself. Read a book, draw, meditate.
- ▶ Actively take a break. Walk around the block, pull up weeds. Visit a friend.
- ▶ Pace yourself. Know when you are usually not at your best and when your energy is at its lowest. Organise your activities and establish routines around your knowledge of your own capacities. Stop rushing.
- ▶ Focus on the task. Sort out what you are going to do and when you are going to do it. Put things in priority order.
- ▶ Value yourself. Think positive thoughts. Praise yourself for what you are doing.
- ▶ Look back and see how much you have achieved to reach this point.

Mental Health Council of Australia 1998, p. 2

## Personal care

'Personal care' is understood in the literature as a sub-set of 'self-care'. It refers to the specific actions a person takes to take care of themselves and their wellbeing. All consumer involvement on committees requires a level of personal commitment and effort. It is good to organise your time to create a balance between looking after yourself and participating in your activities. Set realistic goals and expectations for yourself and others. This is part of caring for your wellbeing. Sometimes the environment where a consumer works may be hostile, tense, or stressful. One of the main things to learn is not to burn out through your role, ensuring that your energy levels are high to face the demands of your work.

## HINT

You can take care of yourself by:

- ▶ maintaining links with friends/family not involved in advocacy issues
- ▶ eating well
- ▶ obtaining sufficient rest and sleep
- ▶ exercising—for example, going for walks and swimming
- ▶ taking up a hobby and pursuing it regularly
- ▶ getting emotional support from individuals that you respect and trust
- ▶ taking time out occasionally—being self-indulgent
- ▶ understanding that, despite all your advocacy work, there will always be issues to deal with and you are not responsible for resolving all these issues—understand your own limits.

Mental Health Council of Australia 1998, p. 65

## Education and skills development

You can increase your effectiveness and establish the importance of the consumer perspective in committees in a number of ways. Firstly, it may be useful to participate in education and skills development sessions. These generally enable consumers to enhance their skills for committee membership work and allow you to interact with other consumers and establish networks. If we ask you to do a task that you do not feel you have the skills to do, please speak with the consumer team and we will see if we can organise some training for you.

## HINT

### **Training**

Cancer Councils and Cancer Voices groups in several states offer training sessions for consumer members of committees. For example, The Cancer Council New South Wales regularly hosts events to give consumers the skills and information they need to be involved in committee work including advocacy training, and training in research projects. For information on this training go to:

[www.cancerCouncil.com.au](http://www.cancerCouncil.com.au)

There is also the Breast Cancer Network of Australia (BCNA) —Seat at the Table program that provides opportunity for training on particular areas of consumer representation and involvement. For information on this training go to:

<http://www.bcna.org.au/content/view/723/1286/>

## **Mentoring**

Mentoring is a process where a more experienced person assists a less experienced person in his/her personal or professional development. The most common application of the mentoring process is when an experienced person helps a person new to his/her role adapt to the situation, or helps a person prepare to take on a new role.

The lifecycle of the mentor/mentee relationship is finite. Once the skills are developed, the mentor can retire. Mentoring relationships are about:

- ▶ developing people and increasing their capability to undertake a specific role
- ▶ a collaboration between the mentor and mentee, which provides opportunities for both to grow and develop
- ▶ focusing on shared wisdom and experiences.

You may be invited as part of your role with Cancer Australia, and the experiences you convey, to mentor new consumers and provide peer support and assistance to make them feel comfortable and confident to fulfil their role.

The third resource that forms part of the *Consumer Resource Kit* is the *Training and Mentoring Guide*. If you are asked to mentor a new member of a reference or working group please refer to this document.

## Participating on advisory, reference and project working groups

We have brought together a number of advisory, reference and project working groups that have been tasked by Cancer Australia to provide advice around a particular issue or approach that may improve outcomes for people affected by a particular cancer type. These groups may have representation from a variety of health professional groups, university researchers and academics, and federal, state and territory government officials. It is important that you do not feel intimidated by others on the group. Your contribution, as a consumer, is invaluable.

### CONSUMER PERSPECTIVE

By my becoming more directly involved with a group within Cancer Australia (The Upper gastro-intestinal Reference Group in my case), I have made an effort to read and learn about Cancer Australia. Survivors such as me often thirst for information and involvement. The only way to develop knowledge is to listen, look, read and become involved. The improved results are inevitable.

Graeme Hall

Member of the Upper Gastro-intestinal Tract Reference Group

## Dealing with your fears

You may experience fear when you first become involved in Cancer Australia's work, particularly if you are not familiar with committees or public speaking. You may benefit from acknowledging these feelings, instead of ignoring them. Many people face fear, be it fear of saying the wrong thing or being inappropriate; of stuttering and stumbling; of making a fool of oneself. You can manage your fear through self-appreciation and by paying attention to goals.

## HINT

### **Dealing with Fears**

When dealing with your fears:

- ▶ You may not be afraid of the whole situation, only a part of it. Focusing on what the exact fear is will make it easier to overcome.
- ▶ Plan and anticipate possible scenarios, assess the best and worst things that can happen, and consider possible strategies for achieving best outcomes.
- ▶ Prepare well—gain as much information as possible and discuss the situation with your peers.
- ▶ Be clear on the good things about yourself.
- ▶ Undertake activities you feel comfortable with.
- ▶ Be clear about the activity—name the purpose, set clear goals, plan what you are going to do.
- ▶ Rehearse your strategy with a trusted person.
- ▶ Start by being involved at a level that is comfortable to you—observe how others participate successfully.

Adapted from *The Kit*:

Mental Health Council of Australia, 1998

## Valuing your expertise

Do not underestimate the experience that you have, both as a person and as someone who has been affected by cancer. This experience is unique. Others may have similar experience but it will not be exactly the same and it is the combined experience of every committee member that brings power and knowledge. By valuing and respecting the perspective of everyone on a committee or group we are able to gather a broad and all-encompassing profile of the current situation within the health system. Through this we will gather an understanding of what needs to happen if we are to make a difference to the way cancer services are delivered in Australia and ensure that the disparate outcomes for certain groups are improved.

## Preparing for meetings

Before most meetings, you will be provided with meeting papers. These papers will provide background material for the meeting and will often present questions or concepts that we wish you to consider or provide us with advice on. It is useful to carefully consider these issues and come to the meeting prepared with your ideas. Reading the minutes of previous meetings may provide you with some context on some issues. If you attended previous meetings, make sure that you have actioned any agenda items that you may have been required to respond to. Members of meetings are usually asked to endorse the minutes of previous meetings.

Background papers may contain statistics on particular cancers or present information about particular cancers which you may not understand. The section on statistics in the *Cancer Australia Consumer Resource Guide* may help you understand statistics better.

### HINT

**Read everything carefully to inform yourself, highlight actual bits that you are unsure of or need clarification on. At a meeting use short-hand to write yourself good notes about questions you would like to ask or points you wish to raise at a meeting.**

## HINT

### **Questions are a powerful tool for consumers to use!**

As the 'new kid on the block' you can use your ignorance to your advantage as no-one expects you to know everything. Use the opportunity to ask basic questions such as:

- ▶ Would you mind defining that term for me?
- ▶ I don't know the background to that decision—could you fill me in briefly?
- ▶ Why didn't that plan work?
- ▶ What was the original intention?

Consumers' Health Forum of Australia 1999, p. 14

## Your role on committees and project working groups

You can play an active part on a committee or working group by preparing for the meetings and actively discussing issues, putting items on the agenda for a detailed discussion, and presenting papers for discussion. If you wish to raise an item at a meeting, ensure that the item is placed on the agenda before the meeting.

If you raise an item for discussion at a meeting you may be asked to prepare a brief background paper that will be distributed with the meeting papers. Think about how to introduce the issue, what facts and research do you need to present, when is a good time to raise a point, who is likely to support the proposition and discuss tactics with them beforehand.

The *Little purple book of community rep-ing* (Adelaide Central Community Health Service, 2003, pp. 23–25) provides practical advice to consumers working on committees, and offers this insight: "It usually takes several meetings before a new rep feels comfortable and familiar with meeting procedures or issues, and is thus able to speak up" (p. 24).

The Consumers' Health Forum of Australia advises that first impressions are crucial. It recommends that, to create a positive first impression, consumers should try to avoid:



- ▶ arriving late to the first meeting
- ▶ leaving agenda papers at home
- ▶ slinking-in timidly at a meeting
- ▶ talking at every opportunity, even when having nothing to say.

## HINT

If you wish to make a point at a meeting, make it strongly, and then leave it. Don't worry if it is not picked up straight away. Let it settle! If someone else picks it up later, then your point was made twice, and you have discovered an ally on that issue. Be confident that your perspective is relevant and valid!

Consumers' Health Forum of Australia 1999, p. 15

## Identifying issues that are important to people affected by cancer

As a consumer you will come with a variety of perspectives about your cancer experience. You may have had positive and negative experiences that you may wish to tell people about, and you may also have a clear view of what needs to happen to improve cancer services.

Remember, however, that your role in Cancer Australia is not to improve an individual service but to make recommendations on how we can change the delivery of services for all.

We ask you to think about the priority needs that people affected by cancer may have concerning specific issues such as access to services, information, involvement in decision-making, involvement in research, etc.

The Consumers' Health Forum of Australia 1999, p. 23, lists the qualities important in ensuring the effective work of consumers:

- ▶ analyse an issue, and judge its effects on consumers
- ▶ move away from a personal opinion to a viewpoint that takes account of the diversity of experiences and needs of consumers
- ▶ present an argument rationally and convincingly

- ▶ imagine the consequences of decisions, in the short- and long-term
- ▶ negotiate
- ▶ identify who you are representing.

## Assisting with stakeholder engagement

As a consumer you will come across a wide variety of people, many of whom may belong to one of Cancer Australia's key stakeholder groups. When an opportunity arises, you can enhance your representation of consumer interests by canvassing what consumers see as important. This will allow you to gain a broader understanding of the views of consumers. Think about the issues that have been raised and ask yourself if the issue can be addressed at a national level by Cancer Australia. Some issues are more appropriately addressed by advocacy groups or at a state level.

There may also be occasions where you can promote the activities and role of Cancer Australia so that people are aware of our aims and objectives.

Some simple strategies for building stakeholder relationships include:

- ▶ keep up-to-date with current issues affecting stakeholder groups
- ▶ where appropriate provide information regularly to stakeholder groups about Cancer Australia activities (in accordance with the Confidentiality Agreement signed with Cancer Australia)
- ▶ develop regular activities with some groups
- ▶ consult regularly
- ▶ where applicable actively involve groups in Cancer Australia activities
- ▶ collaborate with groups by actively responding to their initiatives.

# Communication skills

## Oral communication skills

As a consumer representative you may be asked to communicate your experience or present the consumer perspective at meetings or other gatherings, and you will need to feel confident and relaxed in order to communicate your ideas clearly and effectively. You will already have some of these skills, but this section provides you with some tips and guides on enhancing oral communication skills.

### HINT

#### *Rules to good listening*

- ▶ Don't talk
- ▶ Show that you want to listen
- ▶ Remove distraction
- ▶ Empathise with the speaker
- ▶ Be patient
- ▶ Control your emotions
- ▶ Selectively moderate your argument and criticism
- ▶ Ask questions
- ▶ Summarise, review and reflect
- ▶ Look for areas of interest
- ▶ Don't let the speaker's personality or mannerisms overpower the message
- ▶ Listen to both verbal and non-verbal cues
- ▶ Actively concentrate on the meaning of the message
- ▶ Take notes where appropriate
- ▶ Relate new information to what you already know

Mental Health Council of Australia 1998, p. 54

## ***Interpersonal communication skills***

Interpersonal communication involves not only the passing of information from one person to another, but also receiving or listening to information. This information may include facts, feelings, attitudes, opinions, instructions, or desires. Sometimes people do not receive information the way it was intended. There are several reasons why this may happen, but generally it is because the receiver is not listening attentively.

Effective listening is vital in negotiation and facilitation, which are essential components of the work that a consumer may often do (Mental Health Council of Australia 1998, pp. 42–49).

### ***Talking about your experience***

As a member of an advisory, reference or project working group you may be asked to talk about your experience, or be asked to utilise your knowledge to identify issues or solutions to identified problems. Contributing your experience in a meaningful way can be difficult and at times painful. It can also be difficult to find the right balance between divulging too much information, and just enough information to ensure that the message you wish to highlight is taken up and responded to by the group.

To find the right balance, speak for yourself and use your experience to illustrate the point. Share how the issue impacts on you, or how you think the proposal would work from your perspective. Share what your experience has been in similar situations or what might have happened if you had been in that position. Start your contribution with “from my perspective, giving out pamphlets is less effective than being told in person”, or “in my experience, travelling long distances between various services adds to the stress”. You do not need to go into more detail than that unless asked.

Your experience is valuable. The most important person to recognise this is you. When you realise how important your experience is, not just to yourself but to others, you will gain confidence in sharing it with others.

## HINT

Reliving your experience can be painful for both yourself and others: it is useful to practise telling your story before a meeting—If you do not feel comfortable telling your story at a meeting, for whatever reason, it is important for you to inform the chair or facilitator before the meeting.

### ***Public presentations***

Effective presentation is about communicating, learning and relationships. A good presentation begins with the recognition that each of us is different and, while no formula exists, there are some guiding principles. These principles for public presentations include:

#### ***1. Convey a positive attitude***

It is important that you convey a positive attitude when you present your experience, even if your experience of the health system was negative. An audience is far more likely to take home important messages if they are conveyed in a positive, constructive way. Thoughtful organisation and preparation can convey a positive attitude.

## HINT

### ***Communicating a negative experience to convey a positive attitude***

If you have a complaint about a certain aspect of care which you wish to convey as an example of what could be done better, reflect on the experience and present the experience in a objective rational way, highlighting what went wrong, and what you think could be done that would improve the outcome for others.

#### ***2. Know your audience***

Knowing your audience is essential. A presentation aims to convey a message to a particular group or a mixed group of individuals. Audience members will have different reasons for attending. Those members with a greater interest in the topic are likely to be more receptive and motivated.

### 3. Motivate your audience

Motivate your audience by identifying something to which members can relate. Emphasise how the information or issues addressed in your presentation directly affect or benefit them.

#### HINT

##### ***Tips for Power Point presentations***

- ▶ Slides need to be clear and simple
- ▶ Slides should not contain too much information
- ▶ Slides should be used to emphasise your main points
- ▶ Power Point is a very useful tool if used sparingly

Mental Health Council of Australia 1998, p. 131

### 4. Plan your terminology

Use terminology your audience understands. Knowing your audience will help you to select and use appropriate language. Consider your use of jargon and colloquialisms. Clearly explain new concepts and terms.

#### HINT

##### ***Using jargon***

Try not to use too much jargon (technical or professional terms which may be unfamiliar to many people). If you do use terms which may be unfamiliar to the audience, explain their meaning briefly and simply.

Mental Health Council of Australia 1998, p. 127

### 5. Be yourself

Be your *real* self when presenting. Present in your own style, rather than in someone else's. Humour can be effective in presentations but, as with any technique, humour should be appropriate.

## 6. Be enthusiastic

Conveying a genuine interest in the topic and confidence in the message is likely to enthuse and convince your audience.

### HINT

#### ***A good presenter***

- ▶ knows how to establish conditions conducive to learning
- ▶ takes a complex notion and explains it clearly and concisely
- ▶ incorporates a range of ideas and strategies
- ▶ understands principles of adult learning
- ▶ listens actively, feeds information and ideas back to check understanding
- ▶ monitors what is happening within the group (eg, boredom, confusion, excitement)
- ▶ knows when to intervene and when to be silent
- ▶ separates from group activities and discussions when necessary
- ▶ prepares to confront or support, be serious or light, depending on the situation
- ▶ 'slips into the shoes of others', knows his or her audience
- ▶ addresses the needs of the audience
- ▶ shares thoughts, feelings, experiences and reactions if and when appropriate
- ▶ is flexible so that the presentation framework can be adjusted to devote more or less time to a particular point or to take the presentation in a direction more relevant to the needs of the audience.

NSW Department of Education 1999, p. 10

## ***Storytelling***

Stories are seen as meaning-making activities. This is the idea behind consumers sharing experiences through stories, and explains their value to health services, clinicians and other members of committees. Capturing the meaning that people affected by cancer assign to the diagnosis, treatment etc will be valuable to the consumers' work in collaboration with health services and others (Bruce 2007; Elwyn & Gwyn 1999; Hurwitz 2000).

Storytelling has been a major part of consumer and carer participation in educating service providers and others. People's stories help to bring theoretical problems to life, and can be extremely effective in promoting greater understanding and appreciation of consumer/carers concerns. Part of preparing for a storytelling session is knowing which story to tell and why (Mental Health Council of Australia 1998, p. 134).

One of the most important things to remember when planning story telling is that **preparation is important**. Story telling is about you, and about sharing personal pain with other people. It is not something that everyone can do.

### **HINT**

**Write down your story. This is a good way to keep the story 'under control'.**

**Believe in the value of your story. This is a good way to keep the story 'under control'. This happened to you and you are the 'expert' about your own experience.**

Mental Health Council of Australia, 1998, p. 141

## ***Parable***

A parable is a story with a message. The story is told in a way that encourages audience members to think about their own feelings and responses to that message. Consumer and carer stories carry important messages and they have greater effect when their message stays with the audience, even when the details of the actual story are forgotten.



## Written communication skills

Consumers in Cancer Australia's national advisory, reference and other project working groups may be asked to comment on policy papers, project reports or deliverables or provide input into a policy issue. Should you be requested to prepare a report for a meeting or group, you will benefit from good writing skills. Below are a few tips about writing in general, and specifically about preparing a policy brief.

### ***The writing process***

The writing process is sometimes described as pre-writing, writing, and revising. Here are the steps in the plain language writing process:

#### ***Planning***

1. Determine your purpose
2. Identify your audience
3. Plan the writing project
4. Research or gather information
5. Focus the content
6. Organise the information
7. Visualise the final product
8. Identify the constraints
9. Recognise obstacles.

#### ***Writing***

1. Compose a first draft.

#### ***Editing and designing***

1. Revise the content
2. Check for accuracy
3. Organise the structure
4. Edit for style
5. Design the lay-out
6. Add graphics.

## *Evaluation*

1. Get feedback from peers
2. Try out on an audience
3. Revise or redesign.

## *Editing*

Here are some tips for revising your own writing, or editing the writing of others:

- Organise clear sentences: keep the subject and verb close together at the beginning of the sentence.
- Explain only one idea in each sentence.
- Keep sentences to less than 35 words; 25 words on average.
- Use verbs instead of nouns for your action.
- Use the active voice: make sure the actor is identified as well as the action.
- Use passive voice when appropriate and necessary.
- Use positive words and sentence constructions, avoiding negatives.
- Use a tone that suits your audience and avoid unnecessary formality.
- Simplify your words; choose everyday language.
- Cut the jargon and avoid acronyms.
- Use technical words with care: define or provide descriptive examples.

Practice Development Group 2002

## HINT

### ***Writing Tips***

- ▶ Write with personal pronouns: you, we, I.
- ▶ Be direct; eliminate any ambiguities.
- ▶ Use a logical pattern and make the links between ideas obvious.
- ▶ Use titles and subtitles that are informative or summarise the text.
- ▶ Cut out any information that is not essential to your purpose.
- ▶ Prioritise the information and put the most important information at the beginning.
- ▶ Use graphics, charts, and pictures to reinforce crucial facts and points.
- ▶ Use a formal table of contents for long documents, or a summary introductory paragraph for shorter ones.

Practice Development Group 2002

### ***Writing a policy paper***

A policy paper or brief is a document that outlines the rationale for choosing a particular policy alternative or course of action in a current policy debate. Although as a consumer representative of Cancer Australia you may not be asked to write a policy paper, you may be asked to comment on a policy paper or provide advice on a particular policy position.

## HINT

### ***Key questions before writing a policy paper or report***

- ▶ What is the central theme you are addressing?
- ▶ Every report has a purpose: What are you trying to do?
- ▶ Who is the audience?
- ▶ Has someone asked you to write this report?

Mental Health Council of Australia 1998, p. 155

The most common elements of a policy paper are as follows:

- ▶ title of the paper
- ▶ executive summary
- ▶ context and importance of the problem
- ▶ critique of policy option(s)
- ▶ policy recommendations
- ▶ appendices
- ▶ sources consulted or recommended.

(Based on material obtained from Young & Quin 2007).

### ***Title of the paper***

The title aims to catch the attention of the reader and compel the reader to read on, so it needs to be descriptive, punchy and relevant.

### ***Executive summary***

The executive summary aims to convince the reader further that the paper is worth in-depth investigation. It is especially important for an audience that is short of time to see clearly the relevance and importance of the paper by reading the summary. An executive summary of one to two paragraphs commonly includes:

- ▶ a description of the problem addressed
- ▶ a statement on why the current approach/policy option needs to be changed
- ▶ your recommendations for action.

### ***Context and importance of the problem***

The purpose of this element of the paper is to convince the target audience that an urgent problem exists which requires them to take action. The context and importance of the problem is both the introduction and first building block of the paper. It usually includes:

- ▶ a clear statement of the problem or issue in focus
- ▶ a short overview of the root causes of the problem

- a clear statement of the policy implications of the problem, which should clearly establish the current importance and policy relevance of the issue.

### ***Critique of policy option(s)***

The aim of this element is to detail shortcomings of the current approach or options being implemented, and therefore illustrate both the need for change and the focus of where the change needs to occur.

The critique of policy options usually includes the following:

- a short overview of the policy option(s) in focus
- a balanced argument illustrating why and how the current or proposed approach is failing. It is important for the sake of credibility to recognise all opinions in the debate of the issue.

### ***Policy recommendations***

The aim of the policy recommendations element is to provide a detailed and convincing proposal of how the failings of the current policy approach need to be addressed. This is achieved by including:

- a breakdown of the specific practical steps or measures that need to be implemented
- a closing paragraph re-emphasising the importance of action (if needed).

### ***Appendices***

Although a policy paper is a short and targeted document, authors sometimes decide that their argument needs further support and so include an appendix. Appendices should be included only when necessary.

### ***Sources consulted or recommended***

Many writers of a policy paper decide not to include any sourcing of their evidence as their focus is not on an academic audience. However, if you decide to include a short bibliography, then place it at the end. Many writers prefer to lead their readers to further reading, and may include a recommended readings section.

(Young & Quin 2007).

## Personal administration and organisation

It is very important to be organised so that you can cope with the many demands of your personal life. Consumers sometimes feel sick or tired because of the illness or the impact that certain treatments may have on their physical health. Carers, on their part, may feel tired because of the many demands of caring for the person affected by cancer and other demands and commitments in their lives. Keeping a diary or developing a personal plan may assist you to manage your time effectively, ensuring that you maintain a balance in your life.

### HINT

#### ***Prioritising tasks and writing a personal plan***

A plan may include:

- ▶ how much time you can make available for work activities
- ▶ the amount of time needed for tasks in relation to the number of tasks you are attending to
- ▶ a priority list of the work that has to be done
- ▶ a place to work in (an office or a place to put your things).

Mental Health Council of Australia, 1998

## HINT

### ***Managing Paperwork***

- ▶ Handle the paper once and deal with it immediately. For example, if you are asked for certain information, collect it and get it ready for mailing.
- ▶ If you need to comment on a short document, do it immediately after reading it.
- ▶ Do the things that you least like doing first. For example, do the not-so-pleasant things first and then reward yourself with the enjoyable material.
- ▶ Keep chipping away at big (and possibly boring) jobs like reviewing long policy documents.
- ▶ Distinguish between what is 'urgent' and what is 'important'. Base this decision on what you listed as a priority in your personal plan.

Mental Health Council of Australia 1998, p. 41

## **How to be an effective committee member and not become 'burnt out'**

The following are some hints about being an effective committee member and not becoming 'burnt out' or stressed about your role.

### ***Assertiveness***

Assertiveness is viewed as the "open and appropriate expression of thoughts and feelings with due regard to the right of others" (Mental Health Council of Australia 1998, p. 29). Some people find it difficult to confront others even if facing disruptive or disrespectful behaviour. Being assertive is about standing up for your rights but not necessarily about getting things your way.

As a consumer, you may need to be assertive, particularly about your time and other commitments. Remember it is OK to say no and clearly state what you can and cannot do.

If someone asks you to do a task that you do not feel confident in doing or do not have the skills to do, it is important that you say so. We are happy to provide you with training or to put you in touch with someone who can assist you in gaining the necessary skills to complete a task confidently and effectively.

## HINT

### **Managing Tasks**

- ▶ Clarify or reconsider your goals and priorities.
- ▶ If you are unable to do a task or need further skills to complete the task effectively, be honest and say 'no' to the request or state clearly that you would like to have further training in this area before you agree to do the work.
- ▶ Identify work that you are avoiding.
- ▶ Where possible, delegate work to others.
- ▶ Have breaks and give yourself a reward when tasks have been completed.

Mental Health Council of Australia, 1998

### ***Building a relationship with the Chair of a committee or working group***

Building a relationship with the meeting Chair can be an important strategy to assist you to manage the group's expectations of you and to ensure that your voice is effectively heard.

Having a discussion with the Chair before a meeting helps the Chair understand your situation. You may choose to divulge personal information about your experience or current position that may help the Chair to avoid asking you to do tasks that you may not be ready to do. Providing the Chair with some of your strengths and personal experiences will assist them to actively draw you into discussion. Some consumers have said that they deliberately sit opposite the Chair, so he/she is always conscious of them, and so they can catch his/her eye whenever they wish to speak.

According to the Consumers' Health Forum of Australia (1999, pp. 25–26), as a consumer on a committee, you can be a positive force by:

- ▶ bringing the discussion back to the relevant issue
- ▶ initiating new discussion
- ▶ summarising major points
- ▶ thinking laterally when discussion is not getting anywhere



- blending various people's comments together
- connecting two points
- diagnosing a problem
- inspiring others
- relieving tension, or creating useful tension
- remaining active even when the issue does not have consumer implications.

### ***Identify allies***

The Consumers' Health Forum of Australia (1999, p. 24) suggests that it is important to identify any potential allies for specific critical issues. Some allies may support you on some issues, and not on others. Anyone on the committee is a potential ally depending on the issues discussed. It is recommended to first sound out issues with other committee members and then decide if these issues are worth raising with the full committee.

### ***Network***

The Consumers' Health Forum of Australia (1999, p. 25) states that it is especially important to talk with any other consumers on the committee, and on related committees, to see what their opinions are on a particular issue. It is vital to share ideas on important issues, discuss why they are important, and what outcomes are desirable.

If you are ever a consumer on a committee that is part of a structure with many levels of sub-committees and working parties, it is extremely important to have a good set of contacts with other consumers within the structure. You could ask the nominating organisation or the committee secretary to provide a list of names of other consumers and a chart of the committee structure.

#### **A CONSUMER'S PERSPECTIVE**

I used to worry about sounding dumb when I asked questions. Then I realised that half of the rest of the committee didn't understand the answers either. When everyone is an expert in different areas, each of us on the committee has things we don't know or understand.

Consumer quoted in Consumers' Health Forum of Australia 1999, p. 14

## ***A word on influence***

Do not underestimate the impact you will have just by being part of a committee. Your very presence will influence how the committee considers issues and will raise awareness of thinking about consumer perspectives on all issues. So worrying about ‘winning’ on every issue is probably misplaced and anxiety provoking. You will not persuade people on every issue. So be strategic and save your strongest pitches and determination for the important issues.

## **Solution-focused approach to problem solving**

The solution-focused approach to problem solving implies an orientation towards fixing rather than blaming. A simple process before pointing out a problem is to stop and ask yourself, “But what would fix this?” In this way, a person can point out what is not working but also have a constructive suggestion for making it work better. For example: “I find it very hard to get to meetings on time because of the early starts and because the train I currently catch is unreliable. If we started 15 minutes later, I would be able to get a later train that I know is more reliable. Would that inconvenience anyone if we started later?”

Stating the problem in ways that it affects you rather than in general terms also gives more scope for solutions to arise. “I find it hard to concentrate when mobile phones go off in meetings”. This will provoke a better response than “people who leave their phones on are inconsiderate!” The process can be summarised quite simply—say what you want, not what you don’t want.

The process also works well in considering broader issues. It encourages people to look for the best alternatives within the constraints that are operating. Everyone wants limitless money. Given that this is not feasible, what else is possible? A simple strategy for turning negative discussions or comments around is to listen and ask quite genuinely, “So what would work?” It turns people’s attention away from what isn’t working.

## ***Negotiation***

Negotiation is defined as an interactive process between two or more parties seeking to find common ground on an issue or issues, of mutual interest or dispute, where the parties involved seek to make or find a mutually acceptable agreement that all concerned will honour (The Negotiation Experts 2007).

### **A CONSUMER'S PERSPECTIVE**

**I had a very successful cancer journey. Now on every occasion I can, I outline the positive elements of the health system. I find that cooperation and the involvement of multiple parties provide the best means of achieving policy change in the long term.**

**John Stubbs**

**Executive Officer**

**Cancer Voices Australia and member of CanNET**

Rose (1987) identifies six steps in negotiation, which he has labelled:

- ▶ Preparation
- ▶ Wants
- ▶ Propose
- ▶ Bargain
- ▶ Agree
- ▶ Follow-up.

Rose puts forward a very simple formula for prioritising wants:

- ▶ Could get (what would be good but not necessarily reasonable);
- ▶ Should get (what is reasonable)
- ▶ Must get (bottom line).

The negotiation may start with each party expressing their 'could get', but it will not progress until both parties work from the point of 'should get'.<sup>3</sup>

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3 A list of common negotiation strategies and steps for addressing these strategies can be found at the following link: <http://www.negotiation.net.au/docs/colbook2005ed1.pdf>

Fisher and Ury (1991, p. 11) also outline clear steps to negotiation. They counsel against bargaining from positions and instead suggest negotiating from interests. They propose using the 'principled negotiation' process and identify four main principles:

1. Separate the people from the problem.
2. Focus on interests rather than positions.
3. Generate a variety of options before settling on an agreement.
4. Insist that the agreement is based on objective criteria.

Your adherence to principled negotiation, even when the other side is being unprincipled, should be unbending. Fisher and Ury claim that principled negotiation is contagious and is always the best alternative.

## HINT

When negotiating separate the people from the problem. Even while retaining a clear sense of the differences in positions, and an understanding that there are often real conflicts of interest, consumers should avoid projecting an 'us' and 'them' feeling. It is important to maintain a good working relationship in a committee as this is often more important for future decisions than the outcome of one particular negotiation.

Consumers' Health Forum of Australia 1999, p. 28

### ***Problem solving and conflict resolution***

Most interactions will be smooth and you may find that your current communication skills are appropriate, enabling you to function well as a consumer on an advisory, reference or project working group. Nevertheless, some communication skills are required when the processes of interaction with others are not running smoothly. This is when consumers would benefit from some knowledge and techniques for conflict resolution and problem solving, addressed in this section.<sup>4</sup>

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4 A conflict-resolution training manual can be found at the following link:

<http://www.crnhq.org/>

The principles of good conflict resolution have not changed over the years. There is still no substitute for using empathy, listening more than talking, managing your emotions and those of others and focusing on the problem rather than on the person or their behaviour.

A very important part of conflict resolution and problem solving is to be certain you are clear about the precise problem. Often people focus on the effect rather than the cause. They will get upset with the person who is acting out their frustration rather than trying to see what is causing the frustration in the first place.

## HINT

**Listen. Put yourself in the other person's shoes. Discuss each other's perceptions. Ask questions so that you understand, and could explain, the other's point of view.**

Consumers' Health Forum of Australia 1999, p. 28

The Conflict Resolution Network talks about 'mapping the conflict'. By this, they mean looking at the issue to see what is going on and working out how to address it. This can involve trying to determine what needs or fears are motivating the other person or group of people. If you can at least guess what these motivations are, you have something to work with. People appreciate someone who is attempting to understand how they are feeling and it is quite difficult to keep being angry or obstructive under these circumstances.

Silence and reflection are also very effective tools in conflict resolution. If a meeting is getting heated, requesting the group remain silent and reflect on the conflict for two minutes can often produce the clarity that was missing in the midst of the struggle.

Conflict is often the source of growth and change, and should not be viewed as something negative. Approached with curiosity rather than fear, creativity rather than stubbornness, and optimism rather than pessimism, conflict can create some wonderful opportunities for growth.

## HINT

The Conflict Resolution Network makes available resources and material on conflict resolution skills, strategies and attitudes. It can be found at the following website: [www.crnhq.org](http://www.crnhq.org)

### **Reflection**

Reflection involves the reconsideration or recontemplation of an idea or issue.

Our reactions, especially at a deep emotional level, can interfere with our ability to see beyond the immediate event or issue. Quiet reflection allows us the distance to see the bigger picture. That is why we so often wake up in the morning with a fresh perspective, or a new idea for solving a problem we went to sleep with.

The value of 'reflective practice' is increasingly acknowledged in education, business and industry. Donald Schon (1983) argues that reflective practice is a process that enables us to critically analyse and plan in a structured way.

### **Summarising and clarifying**

These two skills require the ability to retreat from the immediate situation and to look at the bigger picture, seeking connections or emerging trends and themes.

Clarifying is usually a process of enquiry and most often expressed as a question. Clarifying requires curiosity: "So do you mean ...?" or "Are you saying that if we ...?". It is not the same as asking a rhetorical question though the questions can often start the same way. The answer to a rhetorical question is already obvious to the questioner and it is frequently used to make a point. A question of clarification is an information-seeking question; the answer to which will build on knowledge or put a situation in sharper focus.

Often a person will summarise their understanding of a situation before asking for clarification by saying: "As I understand it, the situation is ... So when you say ... do you mean...?"

## **Critiquing**

Critiquing is not the same as criticising. Criticising is pointing out faults and is often a negative process. Critiquing is the process of looking at something from all angles, not just from a person's own point of view. It is harder to critique than to criticise because to critique something well entails trying to understand and weigh up all aspects of a problem not just a personal perspective. The process is very objective, fair and thorough and involves weighing up the strengths and weaknesses of an issue and making a judgement based on the best available information to hand. It is often formal, and requires presenting written findings and arguments to an audience. Offering a thoughtful critique to a committee is a significantly influential contribution.

## **Where to find more information**

### **Power Point presentations**

Worsley School 2008, Using POWERPOINT effectively, viewed 26 March 2008, <http://www.worsleyschool.net/science/files/powerpoint/page.html>

Helmer J 2006, Using Power-Point effectively in an oral presentation, viewed 26 March 2008, <http://academics.hamilton.edu/occ/UsingPowerPoint.pdf>

### **Consumer participation**

Adelaide Central Community Health Service 2003, *The little purple book of community rep-ing*. 3<sup>rd</sup> edn, Adelaide Central Community Health, Adelaide, viewed 15 Jan 2008,

<http://www.participateinhealth.org.au/clearinghouse/Docs/littlepurplebook.pdf>

Consumers' Health Forum of Australia 1999, *Guidelines for consumer representatives*, 4<sup>th</sup> edn, Consumer's Health Forum of Australia, Canberra, viewed 14 Jan 2008,

[http://www.chf.org.au/consumer\\_reps\\_program/chf\\_guidelines.asp](http://www.chf.org.au/consumer_reps_program/chf_guidelines.asp)

### **Presentation skills**

NSW Department of Education and Training 1999, *The art of presentation*, viewed 15 Jan 2008,

[http://www.schools.nsw.edu.au/media/downloads/adminsupport/traindev/art\\_of\\_present.pdf](http://www.schools.nsw.edu.au/media/downloads/adminsupport/traindev/art_of_present.pdf)

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