Australian and New Zealand

CONSUMER GUIDELINES for ANOREXIA NERVOSA 2001

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Section One

1. Background

The development of Consumer Guidelines for Anorexia Nervosa was a major element of the Project to develop Clinical Practice Guidelines for Health Professionals involved in the treatment of Anorexia Nervosa, and also Guidelines for Consumers, as commissioned by the Royal Australian and New Zealand College of Psychiatrists, and successfully tendered by Professor Peter Beumont.

In early 1999 I accepted the invitation from Professor Beumont to join the Guidelines Committee, and be the Convenor and National Coordinator of the Consumer Guidelines for Anorexia Nervosa. As this appeared to be the first set of Consumer Guidelines for Anorexia Nervosa, world-wide, I decided to work from first principles and consult as widely as possible with Consumers in the preparation of this document.

As the National Coordinator I invited the Consumer Eating Disorders Support Organisations in each state and New Zealand to participate, and each State Organisation was given a specific Objective to consider. These Objectives corresponded to the Objectives in Professor Beumont's Tender Brief. Each State Organisation has prepared Guidelines relevant to their designated Objective, and these have been refined and collated into the final document.

The Tender Brief gave a broad definition of Consumers and stated ***"the Consumer Guidelines would be directed not only at Patients and their Family/Carers, but also others who should be suitably informed such as school counsellors, teachers, ballet mistresses, gymnastic and sport coaches, leaders of support groups, and lay persons who present themselves as therapists."*** After consultation with Consumers it has been found necessary to broaden the Target Audience even further, to include Health Professionals themselves, Treatment Centres, Professional Organisations and Educational Institutions for Health Professionals, in order to fully express the recommendations and wishes of Consumers. This has led to a much lengthier document than originally anticipated.

The process to obtain these Guidelines and Recommendations has included a wide consultation with Consumers, including input from Patients, Family Members and Carers, and some professionals, from both city and rural areas throughout Australia, with input also from New Zealand.

The Consumer Eating Disorders Support Organisations that have participated have done so in a professional manner, and this has included a full documentation of their involvement and methodology. The consultative process with Consumers has varied in each State Organisation, and this process has included comprehensive surveys, focus groups and one to one interviews. In NSW the National Co-ordinator was also Chairman of the NSW sub-committee, and obtained an Ethics Approval form the Central Sydney Area Health for both a Patient and Family/Carer Questionnaire as well as for conducting Focus Groups and One to One Interviews. The other State Organisations were then requested to work under the Ethical Guidelines of this Ethics Approval.

In the preparation of the Consumer Guidelines there has been an equal input from both Patients and the Family/Carers, and the Guidelines have given an equal weight to the needs of both parties.

It is one of the fundamental principles of these Consumer Guidelines, that recognition has been given to the fact that Anorexia Nervosa is an illness where the lives of all of the family members can be greatly affected. In principle the Family/Carer also has a legitimate and pressing need for reliable information, quality support and respect, and thus also becomes a "Consumer" for many of the services common to the Patient. This document has endeavoured to cover the interests of Patients and Family/Carers in a single document, which in itself has been a considerable challenge.

It should be recognised that the needs of the Patient and Family/Carer may sometimes be different and even conflicting on some issues, one example being the issue of Patient Confidentiality. However, these Guidelines attempt to give assistance to Consumers by offering Consumers a common pathway to follow on such complex issues.

I would particularly like to bring to the attention of the reader that during my research for the preparation of this document, it became very clear to me that Patients and their Family/Carers shared many common issues and much common ground. Both parties articulated and commented on similar issues and problems, and gave very similar responses to these issues and problems.

Therefore, I concluded that I could write a **single document** to cover the interests of both parties, and I also adopted a single terminology of **"Consumer"** to cover both Patients and their Family/Carers. So throughout this Document when the term "Consumer" is used in a Guideline, then that Guideline should be considered applicable to both parties. When not applicable to both, especially in situations when it is important not to infringe on Patients' rights, the separate Patient or Family/Carer terminology is used.

As the National Coordinator I would now like to acknowledge and briefly report on the contributions made by the following organisations in the development of the Consumer Guidelines for Anorexia Nervosa.

The Eating Disorders Association of NSW Inc

The Eating Disorders Association of NSW Inc formed a working sub-committee under the chairmanship of the National Co-ordinator to prepare Consumer Guidelines relevant to the following Objective:

To provide a guide for patients and carers of what they should expect of treatment and of the involvement of the various health professionals.

This Committee consisted of Family/Carer and Patient representatives and held its first meeting in May 1999, meeting regularly, sometimes twice monthly over the next thirteen months.

The Committee decided that its approach would be to collect a broad record of people's history and personal experiences, which encapsulated their main issues and problems relevant to the above objective. In order to obtain this information, the committee decided to conduct a survey of Consumers, and for this purpose designed two very comprehensive questionnaires, one for Patients and one for Family/Carers. It took a number of meetings to design the questionnaires, and some outside expertise was sought for this purpose.

The Committee considered core areas and issues that it thought were most important. The Committee decided to concentrate on issues surrounding vital times in the illness, because it was felt that Guidelines based on these issues would be of greatest benefit to Consumers. These vital issues included the Diagnosis, early Treatments, Hospitalisation and Discharge from hospital. The important issue of Patient Confidentiality was also discussed, and questions were incorporated into both questionnaires to cover all of these issues.

The final questionnaires were piloted on a small sample of people, and the Committee then applied and obtained an Ethics Approval from the Central Sydney Area Health, and the Northside Clinic, a private hospital with an Eating Disorders Unit. The questionnaires were distributed to Patients and Family/Carers towards the end of 1999 through Treatment Centres which provided specialised treatment for Anorexia Nervosa, which included the Royal Prince Alfred Hospital, the Northside Clinic, the Waters Clinic, the Wesley Private Hospital, Rivendell Hospital and the Day Centre at Carlingford. The questionnaires were also posted to members of the Eating Disorders Association of NSW (Inc) including the ACT, and distributed by the Eating Disorders Support Network of NSW, as well as given to other Consumers who had responded to an advertising brochure inviting people to participate. Approximately 245 questionnaires were distributed with 75 returns from both metropolitan and rural areas of NSW as well as the ACT, with 40 returns from Patients and 35 returns from Family/Carers.

The Committee then held four Focus Groups and invited those who had returned their questionnaires as well as others who had responded to a "flyer" and expressed an interest in attending a Focus Group. There were four Focus Groups held during March & April 2000, with a total of 15 attendees at the two Family/Carers Focus Groups, and a total of 14 attendees at the two Patient Focus Groups. The Chairperson facilitated the two Family/Carer Focus Groups and one Patient Focus Group.

The agenda for the Focus Groups arose from analysis of the results and comments from the returned questionnaires, and the NSW Committee determined some key questions to be put to the attendees. The Focus Groups were structured in such a way that the Consumers present were asked to articulate problems and issues of importance to them, on some key issues as determined by the Committee, & then the group was asked to present some positive solutions to these matters. At each Focus Group these solutions were recorded and incorporated in a separate document as draft Guidelines for the Committee to consider.

In all, nine draft documents were prepared by the Committee starting with the first draft document prepared by the Chairperson after analysis of the questionnaire. The Committee met after each Focus Group and collated and consolidated the Guidelines in a thorough and methodical manner, until the final NSW draft of 83 Guidelines was prepared.

Eating Disorders Foundation of Victoria (Inc)

The Eating Disorders Foundation of Victoria utilised their Community Development Worker to co-ordinate their part of the Project, and prepare Guidelines relevant to the following Objective:

To provide health information about the illness of Anorexia Nervosa, its dangers and the distinction of its behavioural features from healthy practices.

The Eating Disorders Foundation of Victoria formed a sub-committee which decided on a strategy to consult with the following three Consumer groups:

- Group 1 those directly affected by Eating Disorders, that is carers and people with an Eating Disorder,
- Group 2 those in contact with people with Eating Disorders and carers through the course of their work, ie teachers, coaches, youth workers, support group leaders etc, and
- Group 3 those who may be involved in treatment, ie GP's, Therapists, Dieticians etc

Although the guidelines clearly stated that it was expected to consult with Consumers, the sub-committee felt it was important to also gain a professional perspective on Consumer's needs.

The sub-committee agreed to use Focus Groups as the main consultative strategy, with the goal of gathering information from participants. The major issues were identified as follows:

- what the general level of understanding of Anorexia Nervosa is amongst Consumers,
- what the need for information is, ie what would be useful for Consumers to know,
- where and to whom Consumers would go to find the information,
- in what form the information would be most accessible

The sub-committee held 6 Focus Groups during February 2000, 4 in Metropolitan Melbourne, 1 in Geelong and 1 in Wodonga, with 31 participants in Group 1, 3 participants in Group 2, and 15 participants in Group 3. There were also 6 postal responses from people who were unable to attend the Focus Group but elected to fill in a survey.

The focus groups were recorded on audio tape and later transcribed and analysed, and a comprehensive summary of the main issues was prepared. A

total of 16 recommendations that related to the major issues above were prepared and forwarded for incorporation into the Guidelines Document.
These were incorporated into the NSW document by the National Co-ordinator and sent back as a draft document to the Eating Disorders Foundation of Victoria(Inc) for comments and approval. This Document then became the first National Draft Document.

Anorexia Bulimia Nervosa Association Inc South Australia

The Anorexia Bulimia Nervosa Association Inc of South Australia employed a Project Officer to co-ordinate their part in the project and prepare Guidelines relevant to the following objective:

To facilitate the involvement of patients and carers in treatment planning and delivery.

The Association formed a project management team which determined the goals and strategies. There were two major aims of the project, one of which was to prepare a series of recommendations based on consumer consultations related to the stated objective. The other was based on adding value to the experience of the participants by providing them with the opportunity to facilitate an involvement in both the planning and delivery of their treatment.

Two research strategies were decided upon, one a short questionnaire designed by the management team, and the other being in-depth interviews. The detailed surveys prepared by the NSW sub-committee were also made available. The Association's data base of members was used as the source of consumer contact.

The questionnaire was developed with consideration of the ethical guidelines of the NSW survey, and 90 questionnaires were posted with comprehensive information on the project and an invitation to attend an interview. There were 23 questionnaires returned, and a total of 5 in depth one to one interviews were conducted.

In relation to the planning of treatment consideration of the questionnaire and interview findings showed that many people were unaware of their options and prerogatives when it came to treatment planning, and the project management team prepared 13 recommendations related to this matter. On consideration of the results around treatment delivery, the research revealed the most successful programs focussed on the patient, with involvement from both patients and carers, taking place in a supportive, nurturing and positive environment. This resulted in the preparation of 12 recommendations.

These 25 recommendations were incorporated into the Draft National Document by the National Co-ordinator and sent back to the state Association for comments and approval. This Document then became the second National Draft Document.

The Eating Disorders Association Inc QLD

The Eating Disorders Association Inc QLD was asked to prepare Guidelines relevant to the following Objective:

To assist those in rural, remote and disadvantaged areas in respect both to the identification of the illness and the strategies of use in getting well.

The Co-ordinator of the Association prepared 5 recommendations based on her extensive experience dealing with Consumers over her years working with the Association, as well as a comprehensive Questionnaire, “Review of Services for People Affected by Eating Disorders.”
The National Co-ordinator incorporated these recommendation into the draft national document, and this Document became the third National Draft Document.

Eating Disorders Association NZ Inc

This Association looked at the problems and issues related to Anorexia Nervosa in the school community. The Association utilised the resources of their full-time field worker to prepare a questionnaire of 14 questions .This person had excellent liaison with schools and school counsellors in the area as she was employed to give presentations to intermediate and secondary school children on body image and self-esteem issues. 73 questionnaires were sent out to school counsellors in the Auckland and greater Auckland areas. There were 27 replies and a report was prepared.

Whilst the information contained in this report was very valuable, the National Co-ordinator decided it was beyond the present scope of this particular Document. Some of the issues were already covered by recommendations in the National Draft Document.

Other Input

There has been a number of further National Draft Documents as a result of input from other parties. After comments from Emeritus Professor Little of the Centre for Values, Ethics and Law in Medicine at the University of Sydney, the Document was divided into two sections, the second of which consisted of the Consumer Recommendations for Other Parties.

There were also some changes in language after input from Professor Carney of the Law School of the University of Sydney. These changes reflected advice to change the tone of the language from that of “Consumers expect (more of a “must” or demand) of Health Professionals “ to that of “what Consumers have a right to expect or should expect.” These language changes were not welcomed by some Consumer representatives, and this was evidenced in the comments in some of the evaluations of the draft document that were returned to the National Co-ordinator. The reader should be aware of these sentiments, and the fact that there was a number of Consumers who wanted a more pro-active and demanding document.

In late 2000 The National Coordinator invited Consumers and the Consumer Eating Disorders Support Organisations to participate in an Evaluation of the final Draft Document. This led to some further small refinements to produce the final Document. The comments from Consumers validated the fact that Consumers considered the section containing the Consumer Recommendations for Other Parties to be an important and integral part of the Consumer Guidelines.

Summary

In the preparation of this document I have tried to maintain the intellectual integrity of the recommendations from the various states. There were times when some overlap in recommendations occurred, and I have endeavoured to eliminate duplication where possible.

The final document represents a true reflection of the issues, sentiments and matters expressed by the Consumers themselves. The process has been faithful in keeping an accurate record of their problems, issues and their own solutions, which form the backbone of these Guideline recommendations.

I would like to extend my sincere thanks to the Eating Disorders Associations that participated, and to all of the committee members who so willingly gave their time for this Project. I believe that those who participated have found this a valuable experience, and should take great pride in the fact that this document should be of real benefit to future Consumers whose lives have been affected by this illness.

I commend the document to Health Professionals as essential reading, and it is my hope that they will work closely with Consumers following all of the Guidelines. Such a close liaison should bring significant benefits to the health of those Patients receiving treatment for Anorexia Nervosa.

Lastly I give my thanks to those Patients and Family/Carers who showed both courage and trust when they opened their hearts to share in honesty their personal experiences.

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2. Definitions

a/ Consumer

Throughout this document the word Consumer refers to those people whose lives have been personally touched by Anorexia Nervosa and includes both the Patient and the Family/Carer.

The word Consumer is used when the issue is common to both the Patient and the Family/Carer, and implies that there is a consensus viewpoint on this issue that does not infringe on the rights of the Patient.

b/ Patient

The Patient is any person who currently has Anorexia Nervosa or has had past treatments for Anorexia Nervosa, and is currently undergoing treatment or requires further treatment for the illness.

The word Patient when used in the Document should alert Consumers to the fact that the issue under consideration may require the consent of a Patient over the legal age, before discussions can take place with the Family/Carer.

c/ Family/Carer

Family/Carer refers to the person or persons who have a close relationship with the Patient that also involves an element of responsibility and caring for the Patient's health and well-being.

d/ Treatment Centres

This includes Public and Private Hospitals that provide Inpatient services for Anorexia Nervosa, or any other facility that provides Formal Treatment Programs such as Day Programs, Evening Programs, Part-Time Inpatient Programs or such.

e/ Health Professional

This includes all Health Professionals involved in the provision of treatment, such as the Psychiatrist, Psychologist, General Practitioner, Dietician, Nurse, Occupational Therapist, Family Therapist, Social Worker, Medical Specialist, and Counsellor. They can be based in a Treatment Centre, private practice, in a community service or mental health service.

3. Objectives

The main Objectives of the Consumer Guidelines for Anorexia Nervosa are
To prepare a set of Guidelines for Consumers that:

- Are informative and instructive to Consumers
- Assist Consumers to become empowered to take a greater participation in treatment planning
- Help Consumers to understand the value of appropriate interventions, especially at critical times in the illness such as Diagnosis, Admission and Discharge from a Treatment Centre
- Give guidance to Consumers to enable them to better discern the standard of services provided by Health Professionals and other service providers
- Give guidance to Health Professionals and other service providers on the expectations of Consumers
- Improve awareness in the general community about matters that impinge on the lives of those Consumers affected by Anorexia Nervosa

Section Three of this Document which contains the Consumer Recommendations to Other Parties has the Objective of giving specific recommendations to these Parties to help lead to improvements in the services provided to Consumers, as well as improvements to other matters that affect the quality of life of those Consumers affected by Anorexia Nervosa.

Section Two

Australian and New Zealand
Guidelines for Consumers for Anorexia Nervosa

DIAGNOSIS

Illness suspected but not diagnosed

Guideline 1

Consumers need to act and seek an immediate intervention with a qualified Health Professional such as a GP to obtain a professional diagnosis and commence treatment. Treatments should be commenced following Guidelines 23 and 24.

Guideline 2

Consumers should contact their State Consumer Eating Disorders Support Organisations to obtain information about the illness, its treatments and support available to Consumers, as well as a copy of the Consumer Guidelines.

Making the first appointment

Guideline 3

The Family/Carer believes it may be of assistance for a Family/Carer to make prior telephone contact with the Health Professional to-

- Give a history from a Family/Carer perspective
- Obtain some information about the illness and its treatment
- Take the opportunity to release emotions and seek advice

Guideline 4

It is advisable to book a long appointment for the Patient's first consultation to allow sufficient time for the diagnosis and exploration of the issues.

First Consultation with a Qualified Health Professional

Guideline 5

The Family/Carer believes it is strongly advisable that a Family Member or Carer travels with and supports the Patient at the first appointment.

Initial Consultation with a General Practitioner

The GP has an important role in the diagnosis of Anorexia Nervosa, and is often the Consumer's first point of contact. Consumers have an expectation that GPs should be able to provide an accurate diagnosis of Anorexia Nervosa, and be competent in understanding the treatment needs of the Patient.

Guideline 6

The Patient should expect the GP to give the following information at the initial consultation. If the Patient is below the legal age or gives permission, then this information can be shared with the Family/Carer.

- A summary of the Patient's general state of health
- Types of tests that may be required

- Information on the medical problems and potential complications of the illness
- Information & explanations about the illness itself- can be verbal or written
- Explanation of the aspects of the illness that need treatment
- Role of the different Health Professionals in provision of treatment
- Aims and duration of treatments
- Cost implications of treatment
- Discussion and referral options if Patient is not returning to the GP

Guideline 7

Patients should expect the GP to discuss all relevant treatment options with them and then be referred to the option or options of their choice. When the Patient is below the legal age, or gives consent, then the Family/Carer should expect to be included in these discussions.

Guideline 8

If the Patient requires a second appointment with the GP, then this consultation should follow promptly. Matters to discuss should include the following

- Results of any tests
- Re-affirm diagnosis
- Clarify comprehensive referral options
- Cover issues from Guideline 6 not dealt with during the initial consultation

Initial Consultation with another Health Professional.

Guideline 9

Consumers have a right to expect any other Health Professional who provides an initial diagnosis, to also provide the Patient with a broad range of information covering aspects in Guideline 6.

Guideline 10

At the initial appointment Consumers should be given some useful written material from their Health Professionals.

Confidentiality and Legal Issues

Rights of the Patient

Guideline 11

Patients at all times have some basic rights, which include-

- A right to confidentiality which includes a right to know what is divulged to others
- A right to an active involvement and decision making in their treatments.
- Being treated by Health Professionals with respect and dignity, and not be stigmatised as “anorectic”.
- Having their treatments managed by Health Professionals in a discreet manner that maintains the Patient’s privacy & dignity.
- Being treated by Health Professionals in a respectful and non-judgmental manner that is sensitive to the nature of the illness

- Having their age taken into account by Health Professionals so they are treated appropriately for that age.
- As Patients make progress with treatment, then they should expect attitudes of Health Professionals to reflect and acknowledge this progress.
- Being acknowledged for trying with their treatments, even when the outcome is not as predicted.
- Being provided by Health Professionals and the Family/Carer with an encouraging, sincere, compassionate and positive environment.

Guideline 12

Consumers have a right to expect that Health Professionals will discuss with them at the beginning of the Professional relationship the issue of Patient Confidentiality. This includes what information is confidential between the Health Professional and the Patient, and what information can be discussed with the Family/Carer.

Guideline 13

Family/Carers have a right to expect that Health Professionals will be proactive in initiating and seeking the Patient's informed consent to discuss issues with Family/Carer, and including them in the treatment process.

Guideline 14

It is recommended that the amount of information about a Patient the Health Professional discloses to the Family/Carer depends on the age, individual circumstances of the Patient, and the family's contact with the Patient. If a Patient of legal age gives permission for a fuller disclosure to the Family/Carer, then such a disclosure should **not** be considered a breach of Confidentiality.

Guideline 15

Consumers should note that some items can be discussed between Health professionals and Family/Carer without breaching Patient/Health Professional Confidentiality. These include:

- General information on the illness and its complications
- Advice or Carer instructions to help support the person with the illness
- Notification of clear suicidal intent
- Informing Family/Carer of a crisis
- Discussion of social issues that create a risk for the Patient

Guideline 16

Consumers should be aware that communication between Health Professionals and the Family/Carer should be done in a way to aid understanding of the illness, and to assist the Family/Carer to better help and support the Patient.

Guideline 17

It is recommended that Family/Carers should be given an understanding on whether there is progression or regression of the Patient, medically, nutritionally and/ or psychologically.

Guideline 18

It is recommended that if there is a clear risk of suicide then the Health Professional should discuss the issue fully with the Patient, and inform the Patient that the Family/ Carer will need to be involved in the discussions.

Guideline 19

Family/ Carers should be proactive in seeking information in regard to their legal rights when the Patient is refusing the appropriate treatment options. This extends to obtaining information from a Health Professional or other appropriate person about the right to obtain a Legal Order over the Patient.

Guideline 20

It is recommended that the Patient's Therapy discussions should be confidential.

Guideline 21

Whenever the Patient's health is at serious risk, Consumers should be aware that options may include treatments not consented to by the Patient. The Health Professional should fully explain to Consumers issues such as their Duty of Care to the Patient, rights of the Patient and Family/Carer, and any appropriate legal channels to be pursued.

Guideline 22

The option of a written agreement in the form of an "Advance Care Directive" could be explored by Consumers and Health Professionals. This agreement would be reached by consultation between the Patient and the Health Professional and would specify what steps should be followed in the situation where the Patient's health may deteriorate at some future time.

TREATMENTS

Guideline 23

Consumers need to be aware that Anorexia Nervosa should involve a multiple of Health Professionals & that **all** of the following aspects of the illness need attention

- Medical & general health issues, including complications of the illness
- Dietary issues
- Psychological issues
- Social development issues of the Patient
- Family social issues

Guideline 24

Consumers should endeavour to choose sufficient Health Professionals to provide treatment so that **all** of the above aspects of treatments are included in the overall treatment and care of the Patient. Consumers should expect Health Professionals to provide guidance with this matter**.**

Guideline 25

When Consumers choose a Multi-Disciplinary team of Health Professionals, it should be expected that that one of the aims of treatment is that all Health Professionals work together on commonly agreed goals, sharing a common understanding of the Patient.

Guideline 26

Consumers should expect to be given the option of choosing a multi-disciplinary team of Health Professionals for the extent or part of the treatment.

Guideline 27

It is in the Patient's best interests to commence formal treatments as soon after diagnosis as possible.

Guideline 28

Consumers should ask Health Professionals about their qualifications and experience in treating Anorexia Nervosa.

Guideline 29

It is advisable that Consumers endeavour to seek help from those Health Professionals and other professionals who have appropriate qualifications and registration for their profession, specialised training, understanding or specific expertise with treating Anorexia Nervosa.

Guideline 30

It is advisable that Consumers consider alternative treatments and natural remedies only after consultation with their Health Professionals. Such treatments are best considered supplementary to their treatments by appropriate Health Professionals.

Guideline 31

Consumers should inquire from Health Professionals about their treatment regimes and services and the expected effectiveness of such.

Guideline 32

Patients should discuss their own treatment goals and the treatment goals of the Health Professional at initial stages of treatment, to enable a more collaborative and achievable set of goals to be predetermined.

Guideline 33

Patients should continue to discuss and evaluate treatment options with Health Professionals during the course of treatment. Participation in planning at different junctures within treatment should be achieved in a way that is not intimidating and is sensitive to the Patient's state of health.

Guideline 34

Consumers should recognise that one of the aims of treatment should be to see that treatments are structured around the Patient as an individual person, and structured so there is flexibility to include the Patient's changing needs and circumstances.

Guideline 35

Consumers should recognise that treatment goals should be open to change, and new goals added once old ones have been reached.

Guideline 36

There should be an active and continual input into treatment planning, and the Patient should tell the Health Professionals what is helpful and not helpful.

Guideline 37

Family/Carers should understand that the pace at which the Patient feels comfortable with in the recovery, should be acknowledged and that this will vary from Patient to Patient.

Guideline 38

Consumers should be aware that an explanation of the recovery process should also include discussions around possible Patient setback times, to remove feelings of failure.

Guideline 39

Consumers should expect that treatments should be focused not only on food but also on other issues significant to the Patient.

Guideline 40

Consumers should recognise that support from Health Professionals and Family/Carer needs to be maintained or even increased once weight has increased, as weight gain is only one aspect of recovery.

Guideline 41

During treatment should a crisis occur then treatment plans and goals should be re-explained once the crisis is over, as many Consumers may not be able to absorb information at a time of high emotional stress.

Guideline 42

Consumers should expect that their concerns and suggestions are listened to by health providers, and should be responded to in some way.

Guideline 43

The Patient should expect to have the option to collaborate in meal planning.

Guideline 44

The Patient should expect to be introduced and guided through social and "real" situations to better manage life outside the clinical environment.

Guideline 45

Patients should be aware of the need to be taught strategies for recognising times of vulnerability, and expect to be shown strategies for coping with these times.

Guideline 46

Consumers need access to an up-to-date referral directory of Health Professionals and treatment services specialising in Anorexia Nervosa. This referral directory should ideally be provided by an independent source such as a State Consumer Eating Disorders Support Organisation.

Guideline 47

In order to provide continuing and ongoing treatments and support to Patients, then Consumers should be aware that the treatment options include-

- Hospital In-Patient treatments
- Comprehensive Day Programs or other Non-Residential Programs
- Outpatient treatments
- Outpatient Support Programs

Guideline 48

When a Treatment Centre cannot provide the appropriate treatment service the Consumer should expect a referral to an appropriate service.

Guideline 49

The Patient should have the option to obtain a second opinion before hospitalisation occurs unless the Patient is in imminent danger.

Long-Term Patient

It is important for Consumers to understand that some Patients with Anorexia Nervosa will have a chronic and long-term illness which may respond poorly to treatments.

Guideline 50

In the case of a Patient with a chronic, long-term illness, it is important that both Consumers and Health Professionals maintain realistic goals which aim to improve the quality of life of the Patient, and stabilise the Patient’s health.

ROLE of the FAMILY/CARER

The potential impact of Anorexia Nervosa on a family is often enormous and consequently the illness is very much a family issue.

Family/Carers have a valuable perspective that can be of benefit to Patients and Health Professionals. They can play a vital role by working with both parties.

Guideline 51

Family/Carers have an expectation that their perspective must be given consideration, taken into account and respected by Patients and Health Professionals.

Guideline 52

When Patients are non-compliant with their treatments by being irrational, secretive or dishonest about their illness, the Family/Carers are of the opinion that the Family/ Carer should take the initiative in seeking or facilitating continuance of the Patient's treatment.

Guideline 53

The Family /Carer should endeavour to provide appropriate support to the Patient throughout the illness. This may include:

- Discussions about what support would be helpful to the Patient
- Unconditional love and emotional support to the Patient
- Financial support when applicable
- Communication with Health Professionals when appropriate
- Maintaining a caring home environment
- Support after discharge from a Treatment Centre
- Encouraging Patients to keep appointments with Health Professionals
- Upgrading their own knowledge & understanding of the illness
- Contacting their State Consumer Support Organisation for Eating Disorders for information
- Having and showing faith in the Patient's ability to recover
- Being mindful of the illness and its impact on the Patient

Guideline 54

Family/Carers have a right to expect Health Professionals to acknowledge their needs separately to the needs of the Patient, and to provide assistance appropriate to their needs.

Guideline 55

Family/Carers should seek from Health Professionals and other service providers, education and information around practical strategies for dealing with the Patient's Eating Disorder, as well as supporting, caring and nurturing strategies for themselves and the Patient.

Guideline 56

If the Patient is above the legal age and excludes the Family/Carer from involvement, then the Family/Carer may find it helpful to seek other involvements, such as attending Support Groups, Educational Seminars and programs.

ROLE of the HEALTH PROFESSIONAL

The treatment of Anorexia Nervosa requires a multidisciplinary or multi-faceted approach by Health Professionals, and therefore Health Professionals need to work as a TEAM in order to provide the best possible treatment to the Patient. This is important especially in an Outpatient's scenario, where Health Professionals may be separated geographically from one another. Good communication between Professional Colleagues and with Consumers is an essential element of treatment.

TREATMENT ISSUES

Guideline 57

Consumers have a right to expect Health Professionals to explain what their particular health roles are in the treatment of Anorexia Nervosa.

Guideline 58

Consumers have a right to expect Health Professionals to work as a Team when providing services to Patients.

Guideline 59

Consumers expect Health Professionals to recognise that the Patient’s treatments need to address the medical, nutritional, psychological, social and emotional needs of the Patient, and be flexible to the changing nature of the Patient’s needs during the time in treatment.

Guideline 60

Consumers have a right to insist that Health Professionals are prompt in referring to other specialised Health Professionals so that **all aspects of treatments** are covered.

Guideline 61

Consumers have a right to expect that a Health Professional with a limited experience or expertise in Anorexia Nervosa should either refer the Patient on where possible, or liase closely with experienced colleagues.

Guideline 62

Consumers should expect or arrange if necessary for one of the Health Professionals to take on the role of coordinating the care and treatment of the Patient.

Guideline 63

The Health Professional has an important role to support the Patient, and Consumers should expect Health Professionals to meet the needs of the Patient promptly when specific issues arise.

Guideline 64

Consumers have a right to insist that Health Professionals never refuse to help a Consumer without offering an alternative referral or some additional type of help or support.

CONSUMER ISSUES

Guideline 65

Consumers expect Health Professionals to be mindful of the guilt and stress sometimes experienced by them, and be sensitive and non-judgmental when exploring causation of the illness.

Guideline 66
The Family/Carer should seek counselling when appropriate, and expect Health Professionals to recognise and inform them when such a need is appropriate.

Guideline 67
Consumers expect Health Professionals to be aware of the Health Professionals' Clinical Practice Guidelines, and provide services according to these Guidelines.

Guideline 68
Consumers should expect that Health Professionals will refrain from stereotyping or demeaning Consumers both in a public and private forum.

CONSUMER INFORMATION

Consumers believe that the point of **initial diagnosis** is a crucial time for the dissemination of detailed information to them. Consumers also believe that it is part of the Health Professional's role to provide adequate and relevant information to them at all times when providing treatments.

Guideline 69
Consumers expect Health Professionals to provide information that is-

- Practical rather than theoretical
- Relevant to the individual Patient
- Non-judgmental and presented in a sensitive fashion
- Sensitive about weight matters
- Positive in outlook

Guideline 70
During treatment Consumers have a right to expect Health Professionals to provide them with a full range of information some of which may be provided as written information, and includes-

- Information about the illness and its complications
- Explanations of the various treatment options and different forms of treatment/therapy
- Explanations of the desired aims and outcomes of such treatments
- The costs of treatment, including the difference between the public and private systems
- Information about the recovery process and the chronic nature of the illness, sometimes necessitating lengthy treatments
- Where to seek additional help and support
- Information about Support Organisations and their services
- Practical advice to help the Patient and the Family/Carer
- Specific information to the Family/Carers about how they can and can't help the Patient, the setting of boundaries and other responsibility issues.
- Information about legal orders.

COMMUNICATION

Consumers have a right to expect a satisfactory level of communication between the different Health Professionals who are providing treatment, to ensure a collaborative & consistent treatment plan.

It is also a very important element of treatment that Health Professionals and Consumers have an effective communication with one another. Good communication between the Patient and the Health Professional is crucial to building a trusting relationship between the Patient and the Health Professional.

Guideline 71

Consumers have a right to expect that communication between Health Professionals and Consumers encompass –

- Open, respectful and effective communication
- A compassionate, caring, and encouraging attitude with the Patient
- A procedure in place to contact the Family/Carer during an emergency or crisis.
- Sufficient and regular time put aside for Family/Carers to discuss matters with the Health Professionals who provide treatments

Guideline 72

It is recommended that when a misunderstanding or dispute arises between a Consumer and a Health Professional, both parties should set aside some mutually agreeable time to discuss the matter. If unable to settle the matter, consideration should be given to bringing in an agreed third party such as another Health Professional colleague, or another family member, or a neutral party such as a Social Worker or representative from the State Consumer Support Organisation, to aid the conciliation process.

Section THREE

Consumer Recommendations For Other Parties

Consumer Recommendations to Treatment Centres

Guideline73

Consumers recommend that Treatment Centres for Anorexia Nervosa should have their own specific Information Package which is readily available to Consumers both prior to admission and on admission. This Information Package should include:

- Information about the Treatment Program and its rationale
- The Treatment Centre's ethos and Mission Statement
- Services offered in that Treatment Centre
- Other relevant Patient information such as costs of services
- Availability on a Treatment Centre web page

Guideline 74

Consumers insist that each Treatment Centre must have a Formal **Admissions Procedure** which must be followed for all admissions at all times. Such a procedure should be personalised so it is appropriate for the age, gender, ethnicity and state of health of the Patient.

The **Admissions Procedure** to include:

- Outlines of the Treatment Program given verbally to both Patient and Family/Carer
- Written information on the above
- Explanations of the treatments and when they will be followed
- Explanations of any treatment choices and alternatives that may be available
- Explanation of the roles of the different Health Professionals
- Explanations of how the treatments work to the benefit and best interest of the Patient
- Information about the facility and its rules and policies
- Information about legal orders
- Grievance procedures
- Costs of all services including extra and hidden costs and rebates available
- Explanation of a "Buddy System" if in place and appropriate to the Patient
- Providing a warm and respectful greeting
- A tour of the facility for the Patient and the Family/Carer

Guideline 75

Consumers expect Treatment Centres to nominate a Health Professional or suitable person who is responsible for the communication between the Treatment Centre and the Family/ Carer, about the Patient's treatment, general health, progress and other matters. In the case of a hospital environment this service could well be provided by a specialised social worker or expert nurse.

Guideline 76

Consumers expect Treatment Centres to have a procedure in place so that the above nominated person can respond quickly to the Family/Carer's inquiries, and communicate immediately with the Family/Carer during an emergency or crisis.

Guideline 77

Consumers expect that all Treatment Centres will endeavour to engage specialised or experienced Health Professionals to look after Patients with Eating Disorders. The role of the hospital nurse is particularly important in an Inpatient environment.

Qualities of such Health Professionals should include-

- A caring manner
- Awareness of the issues relating to Eating Disorders
- Ability and willingness to listen to the Patient
- Being up-to-date in their knowledge about the illness & its treatment options
- Being responsive to the Patient's needs and concerns.
- Feeling comfortable working with Patients with Anorexia Nervosa

Guideline 78

Consumers expect Treatment Centres to maintain a roster that always includes a Health Professional who is knowledgeable about Anorexia Nervosa and sensitive to Patients' needs.

Guideline 79

Consumers insist that Treatment Centres provide a multidiscliplinary staff team and multifaceted team approach that looks after all the Patient's individual needs, including the nutritional, psychological, medical & emotional needs of the Patient.

Guideline 80

The Treatment Centres' Policy and Procedures manuals should cover the following, and the Treatment Centre should practise the following**,**

- Addressing the Patient's environment to promote a humane experience for the Patient
- How to actively promote and encourage contact with the "outside" world
- How to provide opportunities for Patients to develop skills to manage daily living and to maintain the gains after discharge

Guideline 81

Consumers request the Treatment Centres have a policy that allows suitable Health Professionals on some occasions to maintain a therapeutic relationship with the Patient during a hospital stay.

Guideline 82

Consumers have a right to be informed about what is expected of them during treatment, and the expected outcome of treatment services.

Guideline 83

Patients should be encouraged to provide feedback on aspects of their treatments at the Treatment Centre.

Guideline 84

Treatment Centres that provide Inpatient treatments for Anorexia Nervosa must have a Doctor on call, especially for emergency situations, or when the duty Doctor is unavailable.

Guideline 85

Treatment Centres providing Inpatient treatments, should employ a Social Worker to look after the interests of Patients and Family/Carers, and take on the role of advocate for these Consumers.

Guideline 86

Consumers recommend that Treatment Centres have a policy on Tube Feeding and other invasive practices. This policy should be included in the Information Package, and where applicable explained and discussed on admission of the Patient.

Discharge from the Treatment Centre

Guideline 87

Consumers insist that Treatment Centres have a **Discharge Procedure** involving discussions with the Patient, Family/Carer and Health Professionals. Matters for discussion should include the following-

- Explanations of further treatments needed
- The diet plan
- Tests that need follow up
- Discussion about where to obtain further help
- Referrals to appropriate Health Professionals, Services and Support Agencies
- Follow up appointments made with the nominated Health Professionals
- Explanation of the danger signs of relapse and appropriate response to these
- Specific and comprehensive guidance to the Family/Carer on what to do to support and help the Patient manage recovery

Guideline 88

Treatment Centres should prepare a **Post-Discharge Report** which includes information on treatments received by the Patient and general information on the Patient's progress. This report should be available and given to a nominated Health Professional, who will be in charge of the continuing care of the Patient.

Guideline 89

Consumers recommend that Treatment Centres should provide post discharge treatment services so as to provide a smooth transition and maintain a continuity of care to the Patient.

Guideline 90

Consumers require that Treatment Centres be proactive in following up Patients after discharge by providing a **Post Treatment Centre Follow-up Service**. Such a service could include-

- Follow-up by telephone contact with both the Patient and the Family/Carer for an agreed period of time
- Contacting the referred Health Professionals to ensure appointments have not been missed by the Patient

Guideline 91

Consumers recommend the development of an **Acute Care Service for Patients** that includes services provided **in the home**, especially post hospitalisation.

Guideline 92

Treatment Centres should consult with the State Consumer Eating Disorders Support Organisations, or other relevant consumer representatives, to have an input from Consumers when developing Protocols or Guidelines for their facility.

Consumer Recommendations on Information Issues

Guideline 93

Consumers recommend that information about possible early warning signs of Anorexia Nervosa and intervention techniques be developed and widely distributed to community health centres, fitness centres, schools, Universities, Defence Organisations and other suitable organisations, and be on public view in these locations.

Guideline 94

Consumers require information to be developed and presented in an appropriate way and made specific to the needs of identified target groups including-

- Family
- Friends and other Carers
- Partners
- Patients- including chronic Patients, adolescents and males

Guideline 95

Detailed information should be developed for Consumers about

- The process of seeking treatment and recovery
- Predisposing characteristics, warning signs, and nature of the illness
- Personal coping skills specific to the difficulties faced by Consumers
- How the Family/Carers can learn to live with Anorexia Nervosa in the family

Guideline 96

It is recommended that detailed information, including practical strategies, be developed for Consumers about difficulties in communication and general useful communication skills.

Guideline 97

Information that is developed should be made widely accessible in different formats, for example, written, audio visual, audio etc.

Guideline 98

Information Workshops should be developed for Family/Carers, and be held in city and regional areas.

Consumer Recommendations for Professional and Educational Organisations

Guideline 99

Professional Organisations of those Health Professionals involved in treating Patients with Anorexia Nervosa, should provide special education and training about Anorexia Nervosa and other Eating Disorders to their members in city and regional areas.

Guideline 100

These Professional Organisations should also develop and implement Clinical Practice Guidelines, Standards of Practice and consider production of a specific policy and procedure manual about the treatment of Anorexia Nervosa and other Eating Disorders.

Guideline 101

These Professional Organisations should develop specific resources and information packages to assist their members with the treatment of Anorexia Nervosa. These organisations could also assist with the production and distribution of suitable Consumer information.

The Role of the GP

Consumers believe that GPs have an important role in the diagnosis and ongoing care of Patients with Anorexia Nervosa, and therefore must have sufficient training and the proper resources for these services.

Guideline 102

Consumers ask that an educational module on Eating Disorders be incorporated into all current university study requirements in order to qualify as a General Practitioner.

Guideline 103

GPs should receive regular in-service training on Eating Disorders, and a widely accessible educational program about Eating Disorders should be developed and made available to GPs.

Guideline 104

GPs should have access to a list of GPs and other specialist Health Professionals with expertise with Anorexia Nervosa, as well as Treatment Centres for Anorexia Nervosa.

Consumer Recommendation to Health Professionals for Good Communication

To help facilitate a Team effort, particularly in an outpatient's scenario where Health Professionals may be separated geographically, Consumers request that Health Professionals implement the following-

Guideline 105

Communication between Health Professionals should encompass

- Professionalism and Duty of Care requirements
- Prompt referral to other Health Professionals when required
- A formal reply to the referring Health Professional
- Appropriate feedback to one another during the treatment period
- Direct communication to other Health Professionals involved in treatment during a Crisis situation
- An Agreed Procedure for the line of communication especially during a crisis situation
- Recommendation of another Professional colleague to consult when the existing Health Professional is unavailable to provide treatment.

Consumer Recommendations on Social Issues

Most Consumers agree that the level of understanding about Eating Disorders in the general community is minimal, and that many myths still exist about Anorexia Nervosa. This level of ignorance can often lead people in the community to act in an inappropriate manner contrary to the best welfare of those Consumers whose lives are affected by Anorexia Nervosa.

Guideline 106

Consumers recommend that those industries associated with an increased incidence or risk of Anorexia Nervosa develop as a matter of urgency, their own Guidelines for people with Anorexia Nervosa who participate in these activities. These Guidelines should be developed through their own Professional Associations and Organisations with input from recognised experts and Consumer Eating Disorders Support Organisations.
Such industries include:

- School and Tertiary Counsellors
- Gym instructors and Fitness Centres
- Ballet, Gymnastic and Athletic teachers, coaches and clubs
- Modelling and Acting Schools and Agencies
- Defence Forces

Guideline 107

When industries employ or involve people in any of the above activities then Consumers insist there is an obligation to provide a safe environment for those employed or involved. Pertaining to Anorexia Nervosa this safe environment should not compromise or put at risk the health of those employed or involved in these activities.

Guideline 108

It is recommended that both Health professionals and Consumers should be mindful of the **social** consequences of Anorexia Nervosa for the Patient and the Family/Carer. Consumers should seek extra advice and professional assistance-

- To help the Patient cope with school, University or employment
- To help the Patient with social activities and daily living
- To attend family or relationship counselling if these relationships come under too much strain
- To attend Support Groups for Patients or Family/Carers when under stress or in need of emotional support.
- To seek expert financial advice when costs of treatments are a burden.

Guideline 109

Consumers recommend that the Media changes some ways it portrays Anorexia Nervosa. The focus should be on providing accurate information about recovery and useful tools to help support people with Eating Disorders, rather than specific details about the lives of people with Anorexia Nervosa and sensationalising the illness with before and after photos.

The Media should consult with expert Health Professionals and Consumer Eating Disorders Support Organisations.

Guideline 110

Consumers encourage the Media and public organisations to support awareness raising in the community about Eating Disorders in general and Anorexia Nervosa in particular.

Consumer Recommendations to Government

Guideline 111

Consumers insist that the Public Health System should provide specific Eating Disorders Treatment Centres to adequately service the needs of Consumers in each state.

Guideline 112

Consumers recommend that general public awareness campaigns and widely accessible information about Anorexia Nervosa be developed by Government Health Authorities to aid prevention, early detection and effective intervention and support in the general community. These should be developed in consultation with Anorexia Nervosa experts and Consumer Eating Disorders Support Organisations

Guideline 113

Consumers recommend that a widely accessible educational program about parenting issues including Eating Disorders, life skills and coping be developed.

Guideline 114

Consumers recommend that Government gives financial support to the State Consumer Eating Disorders Support Organisations to help them further develop services and implement recommendations in these Guidelines.

Consumer Recommendations to Consumer Eating Disorders Support Organisations

Guideline 115

It is desirable for Consumers in city, regional and rural areas to have access to Support Groups. State Consumer Eating Disorder Support Organisations should be encouraged to set up Support Groups, developing and utilising their own Guidelines.

Guideline 116

Consumers should have access to a 1800 (toll free) information, referral and telephone support service, especially to give equality of access to information to Consumers in rural areas**.** It is recommended that Consumer Eating Disorders Support Organisations seek funding to establish this service.

Guideline 117

Consumer Eating Disorders Support Organisations have an important role in the development of Consumer information and resources, and have the potential to work in partnership with other parties in the development of such. Consumer Eating Disorders Support Organisations should seek funding to develop and provide these valuable Consumer and community resources.

Availability of Guidelines

To ensure that Consumers have a good awareness and ready access to the Consumer Guidelines for Anorexia Nervosa, it is important that these Guidelines are always readily available to Consumers.

Guideline118

It is recommended that the Consumer Guidelines and Recommendations for Anorexia Nervosa be readily accessible to Consumers, and should be widely available in the community including Public Libraries, University Libraries, School Libraries, at the State Consumer Eating Disorders Support Organisations, suitable Government Agencies, all Eating Disorders Treatment Centres, GP's surgeries and on the World Wide Web/Net.

Consumer Eating Disorder Support Organisations should help to promote and publicise the Guidelines to Consumers and service providers. Literature given to Consumers should refer them to the Consumer Guidelines and where they can be obtained.

Health Professionals should also have ready access to the Consumer Guidelines to understand and fulfil Consumer expectations of their role. Access could be provided through promotion in professional journals and their respective Professional Organisations, as well as through contact with the Consumer Eating Disorders Support Organisations.