

Coping with Mental Health Issues: A handbook for families and carers



ARAFMI Queensland Inc.

Coping with Mental Health Issues: A Handbook for families and carers

Published by ARAFMI Queensland Inc. – Brisbane 2014

Copyright © ARAFMI Queensland Inc.

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, transmitted in any form or by any means, electronic, mechanical, photocopied, recorded or otherwise copied without the prior written permission of the publisher.

National Library of Australia
Cataloguing-in-Publication Entry

Designed by ARAFMI Queensland Inc.

ISBN: 0 646 28495 9

First published: 1996

Copies available from:
Mental Health Carers Arafmi Queensland Inc.
PO Box 248
New Farm Qld. 4005
Phone: (07) 3254 1881
Fax: (07) 3254 1736
Email: info@arafmiqld.org

Contents

Foreword

The initial shock	1
Learning about mental illness	2
Telling others	3
Should you talk about the mental health issue?	5
Coping with some symptoms	8
Your part in the treatment process	18
Family relationships	21
Lack of energy and reduced motivation	26
Supporting independence	28
Ongoing support	30
Coping with aggression	32
Indications of suicide	35
Coping with grief	37
Caring for yourself	39
Recovery	41
Working for change	43
How to get help	44

Foreword

Since 1976, mental health carers had been meeting to share their experiences. In 1977, the group became ARAFMI. It was almost 10 years on when we became aware that we had accumulated a wealth of knowledge and skills for coping at home, learnt by trial and error.

At the time, there were no written words for carers, other than our own handouts and I had been toying with the idea of putting these together in booklet form. It was timely that a member offered a sizeable donation, but wanted us to specify what the money would be used for – so came the decision to produce our coping skills book.

To an organisation without any funding, the \$200 donation meant a lot. So, from my personal experience and that of other carers, work on the booklet began. The outcome was 500 copies of a 20-page '*Coping Skills for Carers*' book, the only publication of its kind helping carers to know that **THEY WERE NOT ALONE**.

In 1996 there was a revision of the content, with some changes made and extra issues included, resulting in 5,000 copies of a 38-page book.

In 2003, it was time for a reprint and we were aware that our knowledge and skills had increased. Now with some minor adjustments, the fourth edition is available from Arafmi Queensland Inc. Many thanks to those who have worked on this production and to all the carers who have shared their experiences and been part of Arafmi over the years.

Ailsa Whitehead AM
Life Member

The initial shock

When mental illness first occurs, each member of the family can be affected in one way or another. This is particularly so if there has not been any previous experience with mental illness. Most of us simply do not understand what mental illness really is or what to expect or how to act when we are confronted with some of the changes that may occur in someone that we care about.

Reactions commonly experienced by families and carers are:

- **GUILT: Where did I go wrong? Did I do anything to cause this?**
- **STIGMA: What will other people think?**
- **FEAR: of self-harm**
- **FRUSTRATION/ANGER: at being unable to do anything or not knowing how or where to get help**
- **HURT: by criticism from people who just don't understand**
- **GRIEF: at the loss of the person as you knew them**

These are normal reactions but there is help. Health professionals and community support programs can assist with information, education, strategies for coping and ongoing support.

You are not alone.

The Arafmi telephone support line enables you to talk to someone who understands what you are going through.

Arafmi's Carer Support groups allow you to meet with others in similar situations, to share your problems and learn new ways of coping.

Learning about mental illness

The first and probably the most important step in coping with a mental health issue is to find out as much as you can from those who know about the illness, its treatment and care.

Information on various mental health issues is available from your local hospital, community mental health service or Arafmi.

Read as much as you can about the illness. Arafmi and other community organisations can provide information. Arafmi also has a lending library for members and many books on mental health issues are available in public libraries.

Ask the health professionals involved in your family member or friend's treatment about:

- **Anything concerning the illness that you don't understand**
- **Medications and their side effects**
- **Possible warning signs of relapse and managing symptoms**
- **How the mental health system works**
- **What support services are available for the person and their carer or family.**
- **How best to support the person and their recovery.**

Staff at the mental health service can also provide information to you and your family. If there is something that you don't know or are unsure of - ask.

Learn all you can from the experience of other carers. Joining an Arafmi Carer Support group can help or phone the Arafmi telephone support line where you can talk to a support person about what is happening for you.

Telling others

Truth is usually better than avoidance or lies, so try to be as open as the situation allows. For the most part, people handle best what they can understand. They fear most what they don't understand. However, people often go through a process of accepting painful news in stages.

Some people can be really understanding, compassionate and comforting. Confide in them and let them help.

Other people just don't seem able to understand so avoid in depth discussions with them where possible.

The majority of people fall somewhere in between. If they seem unsympathetic, it may be due to lack of knowledge.

Wherever possible, share your feelings, explain something about the illness and explain what the person with the mental health issue may be experiencing and most likely, you will get their support. Only you can judge how much to share and with whom. Where appropriate, offer accurate, basic printed information such as that found in brochures. Arafmi can provide these.

Try not to allow yourself to become socially isolated by creating a barrier as a defence mechanism against being hurt.

This can happen very easily, and when you become aware of it, you will need to look at your own needs without feeling guilty. Improving your own self-esteem can benefit everyone involved.

Children can experience feelings similar to adults, such as guilt, shame and frustration. They may also be afraid of developing a mental health issue themselves and so may not want to talk about it. Compassionate understanding and loving support will help ease the situation over time.

When children and young people ask questions, it is best to tell them the truth about the illness - in words that they can understand. Tell them as much as you think they may need to know given the situation at the time and try to offer them reassurance. For example, it may be appropriate to say something like *'I know so-and-so is sometimes hard to take and at times you may wish that he/she would just go away. It's going to be hard but if we all try to help and offer support, in time things will improve.'*

There is information and support available for children and young people. It may also be helpful for children to talk to someone who is experienced in the area, either through a community mental health service or child and youth mental health service.

Should you talk about the mental health issue?

The answer to this question depends on the person and their health and well being at the time. Some symptoms can make it very difficult for a person to concentrate on long and detailed conversations. However, the more a person knows about the illness, the more likely they are to participate in treatment and care. On the other hand it can be very difficult for a person experiencing a mental health issue to understand what is happening due to the impact of the illness.

Different mental illnesses affect different people in different ways. A person experiencing mental ill health may not have full control of perceptual or thought processes or emotions, particularly during acute episodes of illness.

Mental illness can cause lack of motivation, reduced energy, inability to concentrate and vulnerability to stress. As a result, the person may find it more difficult to work, maintain relationships, mix with other people or do other things that most people take for granted in their daily life. Loss of confidence and self-esteem can follow, resulting in feelings of worthlessness and self-blame.

It is very important to try to get the message across that the illness is a **medical** one, that it's not their fault, that it is not a character defect or a sign of weakness.

Trying to 'normalise' the illness can help. For example, if you try to think about a mental health issue in the same way you would with any other illness, in time you will find it easier to talk about it and cope with.

If you are in doubt about any particular situation, ask yourself or the person, *'If this were any other serious illness, how would you/handle this situation?'* Comparing the illness to other major chemical imbalances such as diabetes, sometimes helps, for instance, *'If you had diabetes, would you be reluctant to seek help when you feel early symptoms?'*

Explaining the illness in a sensitive way may help people to understand the illness better. It will also convey the message that you have some appreciation of what they are going through. You could seek help from a health professional to make sure your information is accurate - you may not need to 'label' the illness.

Remember, when a person is unwell, concentration may be affected and they may be more vulnerable to stress so it's best to avoid long intensive conversations or debates. Be clear about what you want to say before you start talking. Use short sentences and don't switch from one topic to another and wait for the person to have time to process what you have said.

Timing is of paramount importance. For some people, mental health issues can impact on perceptions, thoughts or emotions and so reduce a person's capacity to understand what is happening to them. They may not share your understanding of the nature of the illness at that time – or even that they have an illness at all. They may not think that the situation is as you think it is and think that things will improve over time without clinical help.

Trying to explain details about the illness to a person who is unwell may only aggravate the situation. It may be best to wait until you are confident they are well enough to have a conversation about mental health issues.

Try to remain supportive and let things move at the person's own pace. Have information available for the time when they are ready to talk about issues.

People who experience mental ill health are people with feelings, hopes and aspirations like the rest of us. Remember that the illness does not render them less intelligent or less sensitive.

Coping with some symptoms

Many of the symptoms of mental illness are difficult to understand, so most people need some assistance to understand and cope with them effectively.

Everything I do or say is wrong sound familiar?

Many carers despair because they feel they are wrongfully accused or their words and actions are misunderstood.

It is natural to defend yourself in these situations. However, this rarely serves any purpose when the person who is accusing you is not in touch with reality. Sometimes, defending yourself will just reinforce the belief of the other person. To argue that you are right will make it more difficult for the other person to 'back out' with some dignity.

It is better not to force decisions. When accused or contradicted, **pause** and think before answering. This may guard against you being hurt. You can develop a plan for next time. If you practice how to withdraw – the final outcome could be worth it.

At this point, it is more important to avoid the situation getting out of hand rather than to 'win the point'. The person may be out of touch with reality and unable to control their feelings. If you detach emotionally and remind yourself that the illness is controlling what is happening for the other person, it can possibly make it easier for you to cope.

It may be that the other person is in pain, and they want others to hurt as much as they are hurting – especially those closest to them. For many people, this will pass when they are well again.

One of the most helpful ways of responding is by using what are referred to as 'I' statements.

This simply means **beginning** the sentence with 'I', by saying something like, 'I feel upset when you play loud music through the night because I lose a lot of sleep' rather than 'You wake me up when you play loud music through the night'. Starting the statement with 'you' sounds more confronting and accusing.

Using this skill enables you to get your message across by saying the same thing in a different way and with practise this can be an effective way of communicating.

Delusions

People who have a mental health issue may express ideas that to others, are strange and out of touch with reality. These delusions may be about relatively minor matters or may alternatively influence a large part of their thinking.

Delusions of ***persecution*** can be common, particularly if a person with a mental health issue is hearing voices coming from someone who is '*out to get me*' – such as the police, ASIO, a neighbour or a family member. The person may believe that the house is 'bugged' or that their food or drink is poisoned. Delusions of ***grandeur*** are also common – the person may believe that he/she is a great artist, Prime Minister or Jesus Christ.

It is not easy to keep calm when a person is threatening to 'go out and get them' or do something that others will perceive as foolish. However, nothing will be achieved by trying to convince the person who is experiencing delusions that their perception of the situation is wrong. On the other hand, you need to avoid

reinforcing the delusion. Acknowledge that the experience is very real for them but quietly explain that you are not experiencing things in the same way. Avoid confrontation. If possible, try to discontinue the discussion at this point without putting the person down.

Hallucinations

Hearing 'voices' is the most common hallucination and is particularly common for people who have schizophrenia or psychosis. However, hallucinations can affect any of the senses. A person who is experiencing hallucinations may hear, see, feel, smell or taste things that are not there or experience things in a distorted way. For example, food may taste different – often the reason why a person experiencing the hallucination thinks they are being poisoned. For many people the voices can be unpleasant – accusing, condemning, criticising or urging the person to do something. Hearing voices can be a torment and may be a terrifying experience. If a person with a mental health issue is hearing voices, it may be take some time before they are prepared to admit it. If they do, try not to over-react and don't try to convince them that the voices don't exist.

Remember: The voices are real to the person who experiences them. Acknowledge they are hearing the voices, reflect the person's feelings about it, and if it seems appropriate, indicate that you and others don't share the same experience. For example, it may be appropriate to say 'It must be frightening for you to hear that voice, but I can't hear it'.

One of the most important things to remember is that medication can be effective in dealing with hallucinations and delusions, sometimes even more than the most well-meant and carefully

orchestrated talk. If these symptoms are not being adequately controlled, it may be an indication that the person's treatment program needs reviewing or that they have stopped taking medication.

'Odd behaviour'

Unusual forms of behaviour such as giggling, laughing or crying for no apparent reason, conversing with the 'voices' and even meaningless 'word salad' talk are all common symptoms for people who have schizophrenia. What can you do when you are out together in public? Surprisingly, simply asking the person to 'stop it' often works. It's certainly worth trying. It is important for all the family to recognise that changes in behaviour for a person with a mental health issue is a symptom of the illness – not a character defect. If the family as a whole does not understand this basic fact, it can easily lead to conflict and disruption to family life.

Swearing can also be a problem for some people with a mental health issue. It can occur in people who, under normal circumstances, may not use this language. Mental illness can remove or lower the usual inhibitors that stop a person swearing. Don't take it personally – just try to ignore it where possible. If it occurs when you are out in public – again, try asking them to 'stop it'.

Social withdrawal

People who have a mental health issue find that they are unable to cope with the usual interpersonal contacts of day-to-day life and withdraw into their own private world. Try not to interpret this as rejection, but rather as a symptom of the illness, a sign that the person cannot handle the level of stimulation involved.

Sometimes a quiet, private space is needed so they can withdraw whenever they feel overwhelmed – preferably their own room. It is usually best to leave the person alone during such periods, apart from making sure that the necessities to maintain their wellbeing are available. Try to minimise demands and pressure placed on them. When they feel ready they will renew contact at their own pace and in their own way.

On the other hand, it is important to discourage social withdrawal becoming a habitual way of life. This can happen all too readily with the loss of confidence and self-esteem that often results from mental health issues.

A continual low level of stimulation can be just as detrimental as over stimulation. Some people who are actively delusional can build a fantasy world that has little contact with the reality of the world around them and spend most of their time in that state.

Gently encourage the person to participate in family life as much as possible, to maintain contact with friends and neighbours and to continue with any social and hobby interests they may have.

Mood swings

Some people who have a mental health issue are prone to excessive variations in mood – extreme ‘highs’ (mania) or ‘lows’ (depression), or fluctuations from one extreme to the other, as in bipolar disorder.

Depression: episodes of depressed mood are not confined to people who have a diagnosis of depression or bipolar disorder. Whatever the diagnosis, people can become depressed when they realise that they have a mental health issue.

How can we best help a person who is experiencing depression?

- **No useful purpose is served in trying to ‘jolly’ them out of the depression by saying things like ‘pull up your socks’. Rather, acknowledge the distress they are experiencing and let them know that you are available to help and provide support.**
- **Encourage them to have a medical examination, including nutritional and environmental assessment. These factors can underlie depression.**
- **Encourage them to take an interest in things and people outside themselves – hobbies, social or physical activities.**
- **Discourage preoccupation with past problems or failures.**
- **Don’t rush them, but do encourage them to set positive, attainable goals and to take small steps towards achieving them.**
- **Be alert to any indications of suicidal thoughts (see Indications of suicide on page 35).**

Mania: occurs most commonly in bipolar disorder but can be a symptom of other mental illnesses. In bipolar disorder, a person may swing between the extremes of major depression to a ‘high’ or manic phase.

It can be difficult to persuade a person experiencing a manic phase to seek or accept treatment. They may be on an all time high and feel great with little understanding that their ideas and actions are inappropriate and appear reckless and irrational to others. They may be seeing the world as a wonderful place and feel they are brilliant, powerful or irresistibly fascinating.

Common symptoms of mania include increased energy and over-activity; reduced need for sleep; irritability – particularly when

others oppose their ideas; rapid thinking or speech (flight of ideas); over friendliness; overspending; reckless driving; gambling; high risk sexual activity; grandiose beliefs and plans; hallucinations and delusions.

Be aware that in this acute manic stage a person can be at risk of harm due to their behaviour and the belief that nothing can go wrong. When this happens, hospitalisation may be the only way the illness can be managed.

If lack of financial responsibility is one of the symptoms, do what you can to protect yourself and your family as soon as you see evidence of this. Separate bank accounts may be an option and it may be necessary to place a caveat on the sale of property. Trying to reason with a person when they are in a manic state is usually impossible.

Obsessions and compulsions

These are repetitive thoughts and actions that the person is unable to control – continual hand washing, checking and re-checking that doors are locked or gas and appliances are turned off and performing certain rituals. The person often fears that something dreadful may happen if these repetitive actions are not carried out. Although they may be aware that the behaviour serves no useful purpose, trying to resist may cause unbearable anxiety for them.

There is no point in telling the person to stop, because the behaviour is not within their capacity to control. However, try not to become involved in the obsessions by ‘helping’ – understand that this is their problem and that you see it differently. There are types of therapy that can be quite helpful in controlling obsessive-

compulsive disorders; it may help if you can encourage the person to seek appropriate professional help.

People who have a mental health issue can feel very isolated and may be vulnerable when approached by people offering 'love' or 'salvation'. This may not be unconditional love and if the person is particularly vulnerable they may find themselves under strong pressure to become part of a religious sect or cult, which they may be unable to resist.

Some religious sects and cults hold strong fixed beliefs about mental illness that may be contrary to the clinical support being provided.

Arguing about these beliefs with the person is usually ineffective and may open up a gap between you and them. It may be best to calmly let the person know that you do not share their belief and leave it at that, while making it clear that they continue to have your love and support, and that you are available when needed.

On the other hand, it is important to recognise that religious faith can be a source of great support and comfort to some people with a mental health issue.

Self-medication

The effectiveness of medications used to control symptoms of mental illness can vary from one person to another and they may also produce some unpleasant side effects. People with a mental health issue may stop taking their prescribed medication and resort to various forms of self-medication such as:

- **taking more or less than the prescribed dose**
- **buying over-the-counter medications from pharmacies**
- **‘doctor shopping’ – going around to different doctors to get prescriptions**

Try to encourage the person to avoid these forms of self-medication. The interactions between different types of medication without proper medical supervision can produce adverse effects and may even aggravate the illness. Also, addiction can creep up or an accidental overdose may occur.

Vitamins and other nutritional supplements are generally safe to take in moderate doses and can often be helpful, particularly if the person’s diet is poor. If the person would like to try nutritional medicine, a nutritionally oriented doctor or skilled naturopath should be consulted as it is not just a matter of taking a few vitamins on a trial and error basis.

This does not mean that regular prescribed medication should be discontinued. Ideally, both methods may be used to complement each other and under the guidance of a health practitioner.

Drugs and alcohol

Alcohol or drugs can tend to make the symptoms of mental illness worse or even may trigger a relapse – so, without ‘nagging’, do whatever you can to discourage their consumption. Some people find that they are able to take alcohol in small amounts – one or two drinks at the most - but drugs such as amphetamines (speed), marijuana, LSD and PCP (angel dust) can be like a poison for someone with a mental health issue.

If a person is using drugs or alcohol:

- **set firm rules about drug taking and excessive alcohol consumption in your home**
- **set an example by not drinking heavily or using drugs yourself**
- **explore other ways of reducing tension – walking, special interests or other activities**
- **discuss the problem with a doctor or mental health worker**
- **seek support for yourself to cope with the situation**

Cigarette smoking is very common amongst people coping with a mental health issue – no doubt because they find it helps reduce stress. The habit is usually very difficult to break but encourage and support them in their efforts to quit if possible. However, don't nag about it - as much as you may be tempted to!

Your part in the treatment process

The chances of effective treatment and care for a person with a mental health issue are optimised when there is a 'therapeutic alliance' between the individual, their family and the clinicians in the treatment team.

When a person is living with their family, one or more family members may assist with care and support. Families and carers can make a valuable contribution to the medical and psychiatric assessment of their family member's condition.

Medications

Anti-psychotic medications often have side effects that can be unpleasant and sometimes even stressful. This could be one of the reasons why a person may refuse to take medication. In some instances, the symptoms of the illness may be preferable to the side effects of the medication. Other people may decide that now they are feeling better they do not need the medication, not realising they are much improved because they are taking the medication.

If the person rejects the medication, encourage them to discuss it with their doctor. Try to resist saying things like '*you must take your tablets*'. You could perhaps point out that people with epilepsy or other forms of illness need regular doses of specific medication to remain well. Similarly, people who have a mental health issue need medication to maintain their health and wellbeing.

A tablet organiser (available from pharmacies and supermarkets) could be helpful. You may start by setting out each day's supply together until the person feels able to manage this alone.

Certain vitamins and minerals that have an anti-oxidant action if taken in appropriate doses, may give some protection against the side effects of the drugs. If the person's GP or psychiatrist is not knowledgeable in this area you could consult a nutritionally oriented doctor or skilled naturopath.

Talking to health professionals

Carers often have vital background information about the condition of the person experiencing a mental health issue which may not be available from other sources – particularly if the person is out of touch with reality. It seems reasonable to expect to be given the opportunity to share this information with the health professional involved in the treatment. This does not always happen.

It also seems reasonable to expect the treating psychiatrist to explain the illness to carers and to inform them about the treatment plan; what the carers could do to help and also what may be unhelpful. This also does not always happen. If you do not know what to expect, even with the very best of intentions, you may say or do things that are unhelpful.

Ask to speak to the psychiatrist. If you are unable to do so, don't be put off. If the person is receiving treatment in the public health system, ask to make an appointment with another member of the treatment team.

Alternatively, you could write a letter to the doctor. Assure them that you understand the doctor/patient relationship and that you

are not expecting any confidences to be disclosed. At the same time, ask the psychiatrist or doctor to respect your confidences and not repeat your conversation to your family member.

Be concrete about what you are seeking, such as asking for general information about the illness, recommended books, guidance on what to expect in the way of medication side effects and clarify any details that you are not sure about.

You could give the psychiatrist any relevant background information that is not likely to be available from other sources. You could tell them how the person is coping or not coping, at home. **Be brief.** Don't write a novel!

It may be useful to describe the person's present behaviour patterns and indicate how this differs from what it was previously. Amongst other things, this may help the doctor to determine if they are covering up and presenting an entirely different picture from what is happening at home.

You may feel nervous about an interview with the doctor and forget the things you want to say or ask. This is natural, so make a list. Once again, just the facts – not too much detail.

Don't be afraid to say *'I really don't understand. Could you explain that again?'* or *'There doesn't seem to be any response to the medication. Is that usual? How can I help?'* On the other hand, people may be over-medicated and this can cause unpleasant side effects. If you feel this may be a problem, discuss this with the doctor as well. Above all, don't be afraid to speak up if you feel it is necessary in the interests of the person for whom you are caring, your family or yourself.

Family relationships

Relationships between a person experiencing a mental health issue and the rest of the family can sometimes become difficult. During periods of comparative wellness, the person may seem close to their 'old self' and be able to participate in the usual day-to-day activities of the household. This may change rapidly, often for no apparent reason, and suddenly they may be unable to think clearly, show affection or relate to what is going on around them.

We may not always realise how much our interpersonal relationships depend on the signals that we are receiving from the other person involved. When a person has a mental health issue, these signals can become distorted by the illness. You may find that when the person is unwell they may be unable to relate to you and other family members or to express their emotions. This could be due to the illness and should not be taken personally.

Love and understanding need to be tempered with some degree of detachment and objectivity. This will enable you to cope with the stresses involved in the relationship.

Try to provide a supportive environment that minimises stress and try not to over-react to highly charged emotional situations that can arise from time to time. It is useful to remind yourself at critical times that – *'It's the illness talking'*.

Give some thought to how you communicate. The person you care for may have difficulty in handling complex statements because mental illness often affects a person's concentration. This may also vary depending on the person's state of mind. When they are clearly unwell, try to make questions and answers

brief and unambiguous – one brief statement at a time, allowing them to process what is being said.

Mental illness may also affect a person's sense of humour, so when they are unwell it's probably best to avoid using humour unless you have good evidence to the contrary.

Avoid arguments and confrontation wherever possible – these only raise the emotional temperature and provoke stress for everyone involved.

Try to provide some structure to home life. Where possible establish a simple, predictable routine. Encourage them to participate in family activities, to share in their usual routine household chores and to take regular exercise – but realise that the illness may prevent them from doing these things at various times.

As in any household, some clear, concrete rules are essential. When a person has a mental health issue it may be necessary to spell out some rules that would normally be taken for granted or make other rules that are specific to the situation, such as:

- **we all take daily showers**
- **we do not smoke in the house**
- **we all eat meals at the dining table**
- **doctor's appointments must be kept**
- **loud music will not be played after 10pm**

When the person is well enough, try discussing with them how situations can be handled in the future so as to make things easier for everyone involved. A written plan can be used, for instance –

If I become unwell and I am unable to recognise early symptoms, I give permission for my family to contact my case manager/service provider to try to intervene early in the episode’.

These agreements can cover a range of important issues both for the family and the person who experiences the illness.

It is important to realise that a person’s capacity to adhere to rules may vary according to the severity of the illness, so you must be prepared to be flexible. During periods of acute illness for instance, they may be quite unable to maintain their usual routines of personal hygiene or other aspects of self-care. They may remain unwashed and untidy for some time. They need support and assistance at such times, not pressure to conform. As they improve, you can encourage them to return to the normal standards expected of all members of the household.

If the person has a source of income they should be expected to contribute to household expenses – just like any other member of the family.

Some people with a mental health issue do have difficulty managing their money. Some can be easy prey for other people ready to relieve them of what little money they have and others may need protecting against themselves. If your family member or friend needs help and guidance in money matters, you will need to work out with them what is the best way of handling their particular problems.

It is important to allow the person to retain as much dignity and autonomy over their own life and decisions as they are able to handle. Loss of control over their own thoughts, emotions and

actions is one of the most disturbing aspects of mental illness and can undermine their self-confidence and self-esteem. Support them in taking as much responsibility for their own affairs as they can handle at the time – and remember that this may vary over time, depending on their mental health. Be prepared to help where necessary and then step back – be guided by their needs at any given time. Try to avoid encouraging dependency or taking over completely.

Advocating for your family member or friend

Some people in an acute stage of mental illness may lose track of what is happening to them and may be unable to communicate their needs to the treatment team. Mental illness can undermine a person's confidence so completely that they may need someone to speak up for them and ensure they get the treatment and support they need.

You may need to act as an advocate in dealing with the clinicians providing treatment, care and support services if the person is unable to effectively represent their own interests. This is particularly so if treatment and support services are inadequate.

For example, medical investigations may be required to ensure that any physical or environmental factors related to the mental health issue are identified and treated. A GP may refer a person with psychiatric symptoms to a psychiatrist without thorough medical investigation. The psychiatrist may then proceed to treat the psychiatric symptoms, assuming that all possible medical factors have been investigated before referral.

Several research studies have shown that, when thorough medical examinations are carried out and any medical disorders are

identified and treated, psychiatric symptoms may be substantially alleviated. So, if you have any reason to think that the person has not had a thorough medical examination, don't hesitate to speak to the treating psychiatrist and be persistent about it.

Likewise, if you think any aspect of the treatment, care or support provided to the person is less than adequate, don't hesitate to take the matter up with the person involved and, if you don't receive satisfaction on the matter, take your concerns to a higher authority – the Regional Director, Mental Health Unit, Health Rights Commission or the Minister if necessary.

After all, carers and families are the ones who are left 'carrying the can' if the treatment, care or support the person receives is less than adequate.

Lack of energy and reduced motivation

Loss of motivation and energy should be understood as symptoms of the illness, **not** as perverse laziness. Physical exhaustion and fatigue are common symptoms of mental illness. Many anti-psychotic medications have little effect on these symptoms – in fact, some medications may aggravate this problem.

Fatigue and lack of motivation can be so extreme as to leave the person with little or no interest in hygiene, self-care or other basic routines of day-to-day life. Sometimes there can be very little interest in anything other than eating and sleeping – and even these may be disrupted by the illness.

Energy and motivation levels may fluctuate considerably from one stage to another – particularly with bipolar disorder where mood swings can be extreme.

You will need to adjust your expectations to suit your own assessment of what the person is likely to accomplish. If energy and motivation levels are low, the person may need a great deal of help and encouragement to tackle routine personal and household tasks. Try to jointly agree on set tasks and goals that are within limits **at the time**. You will need to be very patient and allow the person to do things in their own time. Try not to harp on things that don't get done or don't get done as you would like.

Encouragement and support, not criticism, are what the person needs. If they are not bathing, offer encouragement such as, '*I know these are your favourite clothes, so while you hop in the shower I'll wash them and have them ready for you tomorrow*' or '*Why not take a shower, it'll freshen you up*' or '*Lunch will be ready after you have a shower*'.

When energy and motivation levels improve, you can adjust your expectations accordingly. You could then encourage the person to be independent and to participate more in family activities.

Flexibility and sensitivity to the person's condition and support needs are the keys to success in the carer's role.

Supporting independence

‘What will happen to our relative when we are no longer able to care for him/her?’ This is one of the greatest concerns for family carers – particularly ageing parents.

Encouraging a son or daughter who has a mental health issue to live away from home, ***providing they are ready for it and suitable accommodation can be arranged***, should be viewed as a loving approach rather than rejection.

This could be the first step towards independent living for the person. For other family members, it may provide the chance to resume social and recreational activities that may have become disrupted.

Quality time spent together could be increased, resulting in less stress for everyone. You may also find that separation can improve your relationship with your family member. This remains a very personal decision and depends on you and your family member’s relationship.

It is always difficult to ‘let go’, but doing so gradually could be the beginning of the person accepting an increased measure of personal responsibility for his or her own life.

It is often a good idea for the person to try living away from home on a trial basis for a start. If it doesn’t work out, returning home for a short period before beginning another trial at living independently may work. Another option may be for them to have their own accommodation but to make the move gradually by staying, say three nights with the family and the remainder of

the week in their own home, until they are confident living alone. Be sure to make it clear that this is not a failure – it is learning.

Some guidance on financial management may be helpful. This is available free of cost from outside agencies if family guidance is not acceptable. It is important to arrange backup support, other than that provided by close family members.

The degree and type of support required will vary from one individual to another. Supported accommodation is available at various levels of care according to individual need. Some types of accommodation have lifestyle support to assist people to get their lives back on track.

There are some options for both supported and unsupported accommodation. Arafmi may be able to help with information on supported accommodation options available.

Ongoing support

The onset of a mental health issue can result in a person relying on other family members and friends for support and assistance in meeting the demands of day-to-day living.

This support can then become routine, with the person and the carer or support person continuing with the same level of support even though the treatment has been effective enough to enable the person to resume doing things for themselves.

The question is: how do you know when to step back and let the person resume their independence?

This issue can be important because it may affect every aspect of your relationship with the person. If you continue doing things that the person is able to do for him or herself, you may lose control of the situation and become a slave to the illness. On the other hand, refusing assistance and support when the person is genuinely unable to cope is likely to undermine their self-esteem and/or bring on a stressful confrontation, which may aggravate the situation.

Your best guides are:

- **your knowledge of the person's personality and behaviour prior to the illness; for example, what did you assist them with prior to them becoming unwell?**
- **a good understanding of the illness and its likely effects on life skills and performance**
- **careful observation of the person's condition and response to treatment**

- **your assessment of the particular situation, including your own feelings**

When faced with these issues, stop and take time to think. Ask yourself – *‘Is it me and the way I am feeling now?’* Look carefully at the context of the situation.

- **What was happening for the person before this situation arose?**
- **Just how important is this particular issue?**
- **Is there some underlying issue? For instance, is the person feeling worried or insecure about something that has just happened or is about to happen; such as an impending visit to the doctor?**

If, after considering all these factors, you feel fairly sure that the person’s requests for support are not justified by their circumstances at the time, you will have to consider how to handle this particular issue. If you decide to insist on the person doing things for themselves, the situation is probably best handled in the same way as you would with any other person. If this is different from the way you have previously been dealing with these situations, try to make any changes **gradually** so as to prevent undue stress and allow the person to take one step at a time and to retain some dignity.

Whatever your decision, be as consistent as you can but also be prepared to allow some flexibility when necessary. A certain degree of give and take is necessary when handling sensitive interpersonal situations.

Coping with aggression

Aggression is no more frequent among people with a mental health issue than in the general community. However, if violence occurs it often receives dramatic media coverage because of the unusual nature of the behaviour involved.

It is important to realise that aggressive behaviour in a person with a mental health issue can be related to the illness rather than being a sign of 'bad character'.

However, in a potentially dangerous situation, how do you look after yourself and avoid doing anything to aggravate the situation?

There are no hard and fast rules, but there are some basic do's and don'ts that may be useful:

- **Try not to over-react.** Take time for a deep breath and try to remain calm. Remember that the aggressive behaviour is related to the illness. This is not easy but it is worth working at as your reaction is likely to be reflected in the other person. Your self-control in the first few moments could defuse the situation and completely alter the direction that the episode takes.
- **Do not argue.** You will need to judge from your knowledge of the person whether to stay and talk calmly, or leave the situation as quickly as possible. If you stay (and you may have no choice), do what you can to let the person know that you are *trying* to understand how they are feeling. Showing fear to an aggressive person may spur them on. On the other hand, there is a chance that making you fearful is just what the other person is trying to do. If that is the case, then admitting your

fear could well calm the situation. Only you will know what is likely to work best in the situation – to hide your fear or admit it.

- **Do not make promises that you may be unable to keep.** It is important to retain the person's trust. Aim towards having the person to decide to 'cool it'.
- **Do not say things like** – 'Now don't do anything silly' or 'Everything will be alright'.
- **Allow the person to retain some dignity.** The person may be hoping the incident will end, but is unsure of how to go about it - give them opportunity to save face. Once again, try to concentrate on the person's feelings rather than the action. This is time consuming but well worth the effort if you can encourage a decision to refrain from threatened violence.
- **Do not attempt to remove a weapon** from anyone threatening to use one. Delusions and hallucinations are very real to the person experiencing them. There is a need to acknowledge this without agreeing to believe in it. **Firstly**, validate their experience as being real for them. **Then** explain that you do not see it the same way, therefore acknowledging 'your reality'. However, it is important to realise that the person may not, at that moment recognise you as *you*: they may believe that you are someone who could harm them.
- **Involve the police as a last resort.** Do not use the police as a threat to try and get control of the situation. However, if you feel your safety is threatened do not hesitate to call them.

If you are concerned about the possibility of violence it may be helpful to have a friendly chat with the local police officers about the situation before the need for their help arises. This will give the advantage of preparing the police about the possibility of needing their assistance and creating a more informed and

sympathetic approach should an incident occur. You will in turn, be more comfortable involving police officers with whom you have previously spoken.

Set up a plan of action for your own protection in the event of threatened violence. The plan may simply be to notify a friend to make a pre-arranged phone call on your behalf. To contact your friend, you could phone on the pretext of cancelling an appointment and mention a code word or phrase, so that your friend need not become involved, other than to pass on your pre-arranged message.

It is natural to want to keep any disruption quiet and not involve other people, such as neighbours and other family members. However, most people will be supportive and understanding if you share with them something about the illness, what the person may be experiencing and your own feelings.

A person who is sometimes aggressive at home may appear 'normal' amongst other people, or at hospital. If the person is refused admission to a hospital, or refuses to present for treatment, you will need to be assertive in giving accurate information about your concerns for yourself and the safety of your family member or friend.

You may need to put in motion the process for involuntary assessment under the Mental Health Act. You can obtain details of this process from your local Community Mental Health Service, hospital or courthouse.

Indications of suicide

Even the slightest hint of suicidal thinking should always be taken seriously. These thoughts may not always be expressed openly. Some veiled hints of suicidal thoughts may include:

- ***‘Nobody cares about me’***
- ***‘I’m no use to anybody’***
- ***‘You’d be better off without me’***
- ***‘You won’t have to put up with me much longer’***
- **Giving away personal possessions or tying up loose ends.**
- **Saying goodbye – not always a straightforward ‘goodbye’**

Below are some useful **Do’s** and **Don’ts**:

- **Do** listen intently and reflect the person’s feelings. Acknowledge that they must be feeling very depressed to consider such action. Talking about suicide is **not** likely to make a person do something they had not previously contemplated.
- **Do** let the person know that you are available and be supportive. Ask what you can do to help.
- **Do** try to talk to a professional person or someone with experience in this area. There is a lot of misinformation in the general community so do be selective about where you seek help. The Arafmi support line is available for carers.
- **Do** try to find out if they have developed a plan as to how they will suicide. If they are not with you, you will need to talk them through derailing the plan, e.g. *‘I want you to flush those tablets down the toilet while we speak’*. Once you have

achieved this, you need to arrange for some immediate support for the person.

- **Do** quietly notify any clinicians or treatment team who may be involved in their care.
- **Do** try and clarify what the person has said, such as,
‘What do you mean when you say?’
‘I want you to know that I do care. Tell me about how you have been feeling lately’
- **Don’t** panic – keep calm – take a deep breath.
- **Don’t** try to jolly the person out of it. Instead, talk about specific aspects of their life:
‘Have you seen (your friend) Michael lately? How is he?’
‘How is (your pet cat) Fred?’

In other words, try to direct the conversation onto things that they care about.

- **Don’t** give advice or say things like:
‘Cheer up, everything will get better’
‘Don’t talk like that – you have everything to live for’
‘Don’t do anything stupid’
- **Don’t** add to the stress by putting pressure on the person to ‘tell all’.
- **Don’t** change the subject, ignoring what the person has said.

Coping with grief

Grief is a natural reaction to the pain of any significant loss in our life. The major changes that a mental health issue can bring to the person and their family can cause them to experience a strong sense of loss and grief, even when they may not realise it. People can grieve for ‘what used to be’.

The grieving process tends to follow a similar course, whatever the loss. Once you understand the process, you can recognise the signs and deal with them.

The first reaction to the shock of loss is usually denial. *‘This can’t really be happening’*. *‘They have got it wrong’*.

Hard on the heels of denial is anger – a normal response to something you don’t understand. Anger and resentment are often directed at all and sundry and need to be expressed. Take time to work through the anger and channel the energy towards positive action: learn about the illness, do everything you can to ensure that your family member or friend gets the treatment, care and support they need.

Parents can often experience feelings of guilt and regret. *‘What did I do wrong?’* *‘If only ..!’* Again, it is important to remember that *you are not to blame*. Acceptance and hope are often slow to achieve. As your relative or friend improves, you tend to hope for a permanent recovery, only to be plunged into despair again if there is a relapse.

Loneliness and depression can take over if you let them. You need a friend who will listen and allow you to talk about what you are experiencing and feeling – without judging. Making contact with the Arafmi carer support line or joining an Arafmi carer support group will enable you to share your feelings with others who have similar experiences often helps on discovering *you are not alone*.

If you find you have not been able to work through your grief in these ways, a grief counsellor could possibly help. No matter how many years down the track, a trained counsellor can often help resolve the pain of grief.

Caring for yourself

There may well be a need to be constantly 'on duty' in times of crisis. When the crisis is over, however, be careful not to remain on 24-hour call. Doing so cuts down on your ability to think clearly, drains your energy and limits your effectiveness. No one can be physically and emotionally involved 24-hours every day without feeling the effects. Doing so risks 'burnout', at the expense of everyone's well being.

It will greatly add to your peace of mind if you equip yourself to handle the day-to-day demands of caring as well as crisis situations by:

- Informing yourself about every aspect of the illness.
- Formulating a plan of action before a crisis happens – wherever possible, involve the person you care for in this planning.
- Having the necessary phone numbers and other information on hand so that you can be confident and decisive, and feel secure in your preparedness. Knowledge and preparation will give you strength.
- Making sure that some of your own physical, social and emotional needs are met so you can cope with the extreme stresses that carers can experience over long periods of time.
- Taking regular exercise and eating nutritious foods are keys to a healthy lifestyle. Try to get both.

- Involving yourself in some interests or other activities that you find personally satisfying and rewarding.
- Maintaining a social life outside the home, however limited it may be. Above all, don't make yourself a slave to the illness. You have a right to a life of your own.

It will help you immensely if the person who has a mental health issue can learn as much about the illness as possible.

Mental illness does not interfere with a person's intelligence. It is possible that the other person could be feeling guilty for causing you stress. You need not add to that guilt by continuing to give your 'all'. If you burn out you will be of little use to anyone.

Recovery

Some people who develop a mental health issue recover after one or two episodes - with or without treatment. We usually associate treatment with a cure. However, at the moment, this is not so with most serious mental illnesses. Certainly, medication usually brings some control of symptoms and may alleviate distress, but to date, there is no cure – just as there is no cure for the common cold.

The fact that no cure is presently available does **not** mean there is no hope for the future or that you cannot do anything to help. Success of treatment can be seen in terms of specific levels of wellbeing, rather than the illness getting better.

Recovery from mental illness is not prescriptive - it will mean different things to different people, therefore recovery and its outcomes will vary from person to person. There are however some central ideas underpinning recovery that families and carers should understand.

It is the individual person and their own lived experience - not other people or mental health support services that drive recovery.

While the individual determines the direction of their own recovery, people providing support also have a responsibility to:

- believe in a person's ability to recover
- work in partnership with the person as if recovery is a reality
- provide a platform so the person can manage their own recovery
- not get in the way of a person's recovery

There is good cause for hope that research may identify the specific causes of the illness in the future and that this may also point to a cure.

Many people who experience a mental health issue lead satisfying lives within their community of choice if treatment is effective and support services that meet their individual needs are available. Your local Community Mental Health Service or Arafmi can help with information on support options available in your area for you and your family member or friend.

Working for change

People who have a mental health issue (and their families) often experience stigma and discrimination because of widespread community misunderstanding. In some areas, they also have fewer options to access specialist housing, respite and disability support services that they need to assist them to live well in the community of their choice. This is the main reason why families and carers carry the responsibility of care and support of their family member. Without families, the strain on health and disability support services would be greatly increased.

Substantial improvements in treatment, housing and disability support services for people with a mental health issue are only likely to improve if the people most directly concerned – the people themselves and their families and friends – are prepared to work towards making them happen.

Along with many other community organisations, Arafmi is directly involved in this form of advocacy. You can help by joining in and working for a better understanding of the problems associated with mental illness and psychiatric disability and lobbying for improved services.

As well as having the satisfaction of helping to bring about change, many families and carers find that being involved in working for change can be an effective antidote for the many frustrations involved in the carer's role.

How to get help

Specific lists with telephone contacts rapidly become out of date, so we have resisted providing these here. Instead, a phone call to Arafmi Queensland, or Arafmi in your capital city for other states, will provide a current contact number for resources such as:

- **Information on specific mental illnesses**
- **Local Arafmi Carer Support Group meetings**
- **Respite and carer support**
- **Arafmi Groups around Australia**
- **Other support groups**
- **Community Mental Health Services**
- **Support services**
- **Advocacy and legal services**

Arafmi is a non-government, not-for-profit organisation for families and friends of people who have a mental health issue and offers support for carers of people with ***any*** mental health issue. A diagnosis is not necessary to access support through carer support groups, workshops for carers or the telephone support line.

Notes:

Notes: