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#### Disclaime

The information provided in the 'Caregivers' Guide' is intended for educational purposes, to provide information useful for increasing readers' understanding and does not claim to guarantee absolute 'results', nor is it intended to serve as a stand-alone guide to successful caregiving of persons with mental illness.

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# Caregivers' Guide



# DEAR CAREGIVER,

We understand that caring for your loved one with mental illness is not easy. As a caregiver, you may lack the necessary support or knowledge on how to manage your loved one's symptoms or challenges as a result of the illness. Over time, you are at risk of feeling distressed and burnt out.

This Caregivers' Guide is produced with the aim of giving you basic but useful information on how to care for yourself and your loved one.

It is our sincere wish that the information in this Guide will help you better manage your stress levels and in turn, enable you to support your loved one's journey with the illness.



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# **CAREGIVER STRESS**

# **Common Challenges**

#### Difficulties in caring for a loved one with mental illness

The duties involved in caring for your loved one can interfere with your daily life even as you continue to manage your personal, family and work commitments. You may end up having less time and energy for your own activities nor even have enough time to rest. As a result, your social, family and work relationships may be affected. This emotional and physical strain of caregiving is what you will experience as caregiver stress.

#### Some common challenges you may face include:

- The need to take time off from work for multiple medical appointments or to manage crisis situations.
- Not having family members who may be able to or want to help with the many daily tasks and there is not enough time or energy to do them.
- Having to deal with interpersonal conflicts arising from misunderstandings between you and your loved one or other family members.
- Having to provide financially on short or long term basis due to your loved one's inability to work or need for long-term care.
- Having your own illnesses to manage while managing your loved one's mental illness.
- Constant need to adjust to changes in everyday events or routines as a consequence of assuming new caregiving responsibilities.

#### Over time, you may find yourself experiencing caregiver stress which can result in these changes within yourself:

- Mood and Feelings
- Increased irritability, moodiness, anxiety, anger
- Feelings of helplessness, hopelessness, loss of interest in daily activities or hobbies
- Thinking
- Poor attention span, concentration and memory
- Difficulty expressing your thoughts clearly
- Behaviours
- Less interest in general activities
- Changes in appetite or sleep patterns (e.g. difficulty sleeping or sleeping all the time)
- Less time or interest to socialise, have a higher tendency to feel irritated or angry easily
- Health
- Feeling more tired often, having frequent headaches or stomach discomfort
- Falling ill more frequently

# **Commonly Experienced Emotions**

It is normal for you to experience strong feelings when someone you love is diagnosed with mental illness. These emotions can be overwhelming for you. Caring for him or her may thus challenge you emotionally in ways that are completely new. It is therefore important for you to acknowledge and understand these emotional reactions as part of your caregiving journey and learn how to cope with them.

#### The range of emotions you may experience include:

- Shock
- Fear

- Sadness
- Anger

- Shame
- Resentment
- Isolation
- Anxiety

- Guilt
- Denial
- Frustration

# **How to Cope with these Emotions**

- Keep track of your stress levels.
- Find out why you are upset. Focus on your thinking and perception of the situation rather than on other people's behaviours.
- Make time to de-stress, for example, participate in new activities.
- Share your concerns and feelings with supportive family members or friends.
- Find new effective ways of coping with your negative feelings.

# See Caregivers' Self-Care and Stress Management section at Pages 8 - 11

#### What You Can Do For Yourself...

Do more of these:

- Be frank/open about your feelings and encourage other family members to do the same.
- Avoid making your loved one the centre of your life or your family.
- Maintain focus on living and enjoying your own life.

#### Do less of these:

- Thinking that you are totally responsible for your loved one's welfare.
- Pretending that the illness has not affected you or your family.
- Controlling your loved one's behaviour.
- Trying to solve all of your loved one's problems.

# **CAREGIVER STRESS**

#### Where to seek help:

Most of the time, you are usually capable of managing your stress and emotional frustrations on your own, with the support from family members and close friends. However, situations can get stressful at times. During these down times, you can consider seeking confidential, professional advice from trained professionals.

You may wish to contact your medical social worker or local Family Service Centre (FSC), or reach out to your family doctor for a referral to a social service agency that may be able to help you. Alternatively, you can also call one of the several free telephone helpline services listed in this guide.

# **Caregiver Stress Checklist**

Use this checklist to check your stress levels. Tick the response that is most true for you and add up the points.

In the last 2 weeks, have you been	Yes (1)	No (0)
1. Feeling more irritable than usual?		
2. Feeling more unhappy or resentful about looking after your loved one?		
3. Having less energy to complete usual tasks?		
4. Having less interest in attending or participating in social events?		
5. Experiencing less enjoyment from your favourite activities?		
6. Getting angry very quickly?		
7. Feeling tired most of the time?		
8. Spending less time on yourself as compared to before?		
9. Feeling less motivated to get up in the mornings?		
TOTAL SCORE		

<sup>\*</sup> If you score more than 5 points, you are likely to be feeling more stressed than usual. Should this persist, do seek advice from your family doctor or the mental health professionals involved in your loved one's care.



# **SELF CARE**

Do recognise that the demands of caregiving can be stressful for you. To sustain care for your loved one, it is very important for you to maintain your own emotional health so as to prevent burnout. To be an effective caregiver, you need to look after yourself first before you can care for others.

Below are some ways that can help you stay healthy while providing support to your loved one.

# **Tips on How to Take Care of Yourself**

#### Care for yourself first

- Meet your own needs physically, emotionally, spiritually and psychologically.
- Ensure that you eat well and rest sufficiently.
- Go to places that allows you to gain strength spiritually and gives you fresh perspectives.
- Make time for yourself on a weekly basis to rest, be alone or to be with friends just to relax.
- Set aside time to participate in activities that you enjoy.

#### Set realistic expectations of yourself

- Be reasonable and honest about how much you can do.
- Recognise that you cannot always prevent something "bad" or unexpected from happening.
- Acknowledge that when you cannot do anything to change a situation, it is because it is beyond your control.
- Give yourself credit for all the work and effort you have put in.

#### Balance the needs of all parties

- Take into account the needs of your loved one, as well as of your family's and your own.
- Develop a sense of balance between the needs of all these people around you, including yourself.

#### Prioritise your responsibilities and commitments

- Assess the level of urgency and importance of each task.
- Decide on an action plan according to the urgency and importance of each task.

#### Share your caregiving responsibilities with others (e.g. family members or close friends)

- Limit the number of things you are in charge of.
- You do not have to be the only person responsible, even though you are the main caregiver.
- Have family discussions on a regular basis to update each other on your loved one's progress and needs.



#### Keep a 'Care Organiser' - for easy access of important information

It is useful to have health care information of your loved one readily available. It should contain information like:

- Medication information e.g. drug allergies, current and past medications taken
- Appointment dates
- Contact details of health care services and professionals

#### Acknowledge your feelings

- Be honest with how you have been feeling. It gives you a better idea on how you have been coping.
- Share your feelings with a trusted friend or loved one.
- Speak to a counsellor if you prefer to receive confidential professional advice.

#### Attend psychoeducational and support group sessions for caregivers

Participating in educational and support groups for caregivers is a good way to manage your stress levels. You are likely to meet others who are in a similar situation as you, and you can share and find ways to overcome your problems together.

#### Keep up-to-date with knowledge about mental illnesses

Keeping yourself updated with the latest information about mental illnesses can enable you to be an active participant in your loved one's treatment and recovery. Do speak with your loved one's doctor or medical social worker for more information.

# **Caregiving Guidelines**

Caring for your loved one can be very challenging as you adjust to understanding his current ways of expressing his thoughts, feelings and behaviours. You may need to find new ways to help him and yourself maintain mental and physical wellness.

Here are some simple and practical tips on how you can successfully care for your loved one.

- Keep a positive or neutral attitude
   Caring to support recovery requires a positive attitude. Do maintain a positive attitude even during setbacks.
- Communicate simply and positively
  Speak simply, calmly, and positively. Maintain good eye contact and a pleasant facial expression.
  Remember, nagging is unhelpful.
- Have realistic expectations of your loved one
   Evaluate your expectations of your loved one.
   Accept him as he is now while observing him for progress. This will help you set realistic expectations.
- Help your loved one carry on with life as usual
   Establish a new daily living schedule and
   re-establish family routines as quickly as possible.
   Encourage him to plan an enjoyable 'out-of-home'
   activity at least 1-2 times weekly.
- Focus on the positives
   Encourage your loved one by focusing on his strengths. This will improve his self-confidence and it will motivate him to work on his 'not-so-strong' points.
- Be sensitive, avoid comparisons
   Focus on your loved one's progress, instead of making comparisons against other people or criticising him.

- Avoid making all the decisions for your loved one
   Offer to help your loved one choose whenever he
   needs to make a decision. Avoid making decisions
   for him as he may perceive you as being controlling.
- Encourage independence
   As your loved one's symptoms improve, provide more opportunities for him to care for himself.
- Respect his personal space
   Give him space and time to do his own things and
   make his own decisions.
- Discuss limits/rules for living at home
   Agree on what behaviours are considered acceptable
   and unacceptable. Set clear limits. Take it easy with
   the 'not-so-important' things such as a slightly
   untidy room or waking up late. You can work on
   such behaviours once his mental state and
   motivation improves.
- Do not tolerate physical and/or verbal violence
  Tell your loved one calmly that such behaviour is not
  acceptable. Report any acts of violence to your loved
  ones' professional caregiver, or to the police.
  Tolerating violence will only encourage it to occur
  more often.
- Participate in fun activities with your loved one regularly
   Having an enjoyable time together not relating to responsibilities is a good way to build positive

relationships.

# **Tips on How to Effectively Manage the Illness**

- Help your loved one set personal activity plans (daily, weekly, monthly)

  Develop predictable routines for your loved one to follow, such as sleep-wake times, meal and physical exercise times etc. Break tasks into small steps. Help him along the task by giving him prompts and simple instructions. These techniques can help your loved one overcome his lack of motivation.
- Have plans to manage disturbed behaviour, crisis and relapses
   Discuss strategies with your loved one's mental health team on how to manage disturbed behaviour, such as aggressive and/or suicidal behaviours.
- Help your loved one identify their relapse warning signs/symptoms
   Observe and discuss with your loved one and his doctor if his usual warning or relapse behaviour changes. Find out what both of you can do to prevent his symptoms from worsening into a relapse. Agree on a plan of action.
- Work with your loved one's mental health professionals

  Mental health professionals (psychiatrists/nurses/case managers/medical social workers/psychologists) are
  the most important resource people to help your loved one maintain mental wellness. Establishing good
  communication and working relationship with them will lighten your caregiving responsibility.
- Report aggressive behaviours
   Always report actual or threat of violence immediately to the police or the professionals looking after your loved one. You can contact the Mental Health Helpline for advice.

# **EFFECTIVE AND CONSTRUCTIVE COMMUNICATION TIPS**

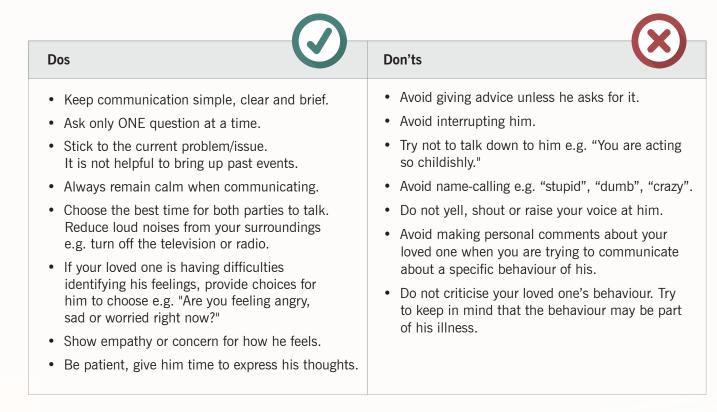
Mental illness changes the way a person communicates. Persons with mental illness often speak, hear and understand information differently from others. They are likely to misinterpret events and what people say. It is also common for them to struggle with expressing their thoughts and feelings, as they may not feel comfortable or safe to do so.

# **Managing Non-Communicative Behaviours**

Below are some helpful tips on how you can manage your loved one's non-communicative behaviours.

Behaviour/Symptom	What can you do in response
<ul> <li>Difficulty in concentrating</li> <li>Agitation and/or restlessness</li> <li>Mood swings</li> <li>Preoccupation with his own thoughts</li> <li>Delusional thoughts (talking about or wanting to act on them)</li> <li>Social withdrawal</li> <li>Habouring of fears</li> <li>Feelings of insecurity</li> <li>Low self-esteem</li> </ul>	<ul> <li>Speak simply; repeat if you have to.</li> <li>Acknowledge his discomfort, ask if there is anything you can do.</li> <li>Give him personal space to relax.</li> <li>Give him some space to calm down.</li> <li>Should he say hurtful things, try not to take them personally.</li> <li>Approach him gently and slowly to get his attention.</li> <li>Don't argue with him. Listen and let him express his thoughts. Encourage him to talk to his psychiatrist, case manager, medical social worker or psychologist.</li> <li>Try to initiate conversations. Do not pressure him if he does not wish to talk.</li> <li>Stay calm and talk to him gently.</li> <li>Show concern, love and acceptance.</li> <li>Stay positive and supportive.</li> </ul>

## Dos & Don'ts in Communication



# MANAGING RELAPSES AND CRISES

A relapse is the worsening of symptoms after an apparent recovery. Experiencing a relapse can be distressing for your loved one and your family. Below are a number of steps that you can take to minimise relapses of your loved one.

# **Minimising Relapses**

- Help your loved one plan and keep to a regular routine.
- Take note of any unusual changes in his or her behaviour or daily living patterns, such as difficulties communicating or carrying out of daily tasks.
- Be aware or involved in his medication-taking schedule. Be certain he takes his medication as prescribed by his doctor.
- Establish open and positive communication. This will foster trust in your relationship with your loved one and he is more likely to tell you when he is feeling unwell.
- If you are concerned about your loved one having a relapse, do notify mental health professionals who are caring for your loved one and request for an evaluation. Keep the mental health professionals' contact details in an accessible place.
- Prepare a 'Crisis Plan' such as a list of contact details of family, friends and professionals who can help when a relapse has occurred. Discuss with family and friends beforehand if they are willing to help in such situations.

# When Your Loved One is Having a Relapse

- Remain calm. Use a calm tone when talking to him. Find out what your loved one is troubled by (e.g. voices, strange beliefs etc.).
- Give him some space and time to calm down.
- Encourage your loved one to let you accompany him for treatment at IMH.

# When the Relapse Turns into a Crisis

- · Remain calm, do not panic.
- Talk to your loved one in a calm and soothing voice.
- Ask him how he would like to be helped.
- Keep a distance if your loved one is behaving in an aggressive or violent manner.
- Call the Mental Health Helpline (24-hour) on 6389 2222 for assistance, or for a non-medical emergency ambulance at 1777 if transportation is needed.
- Seek police assistance when actual or threat of self-harm or harm to others has occurred.

# Stay positive. Stay supportive.



### **Your Mental Health Team**

Your loved one will usually have a Mental Health Team looking after him or her. You, as a caregiver, can and should work with the team closely. To help you understand how you can work better with them, below is a description of what they do. You can and should get their names and contact details early on, if possible.

Mental Health Professionals	Name	Contact Number
Psychiatrist The psychiatrist diagnoses mental illness, manages other medical conditions and the treatment plan. He may also refer you and your loved one to other mental health professionals for further assistance where necessary.		
Nurse The nurse assesses the physical care plan, administers care and medications to your loved one, and also keeps records regarding the treatment and recovery progress.		
Pharmacist The pharmacist screens the medication history, possible drug allergies and potentially dangerous drug interactions. He also provides psychoeducation on safe and appropriate use of medications, side effects and management.		
Case Manager The case manager provides psychoeducation on mental illnesses, symptoms management and medication compliance. He also assists in monitoring the mental health condition in the community and reminds your loved one of his follow-up appointments at IMH.		
Medical Social Worker  The medical social worker provides social and financial interventions to enable a smooth journey in care and recovery. These are done through care planning, family sessions, counselling, linkages to resources and practical assistances.		
Occupational Therapist The occupational therapist carries out functional assessments and conducts individual as well as group activities to help your loved one develop community living and social skills.		
Psychologist The psychologist carries out psychological assessments (e.g. IQ assessments, personality assessments, neuropsychological assessments) and conducts different therapies (e.g. Cognitive Behavioural Therapy, Eye Movement Desensitisation Reprocessing, Psychodynamic Psychotherapy) to improve understanding of the illness and responses to the illness.		
Physiotherapist The physiotherapist treats your loved one's physical illness, injury or deformity by methods such as massage, heat treatment and exercise.		

# **IMH Services**

For more information on services and programmes at IMH, you may refer to the list of contact numbers and/or emails below:

For general enquiries	Tel: 6389 2000 (Contact Centre) 24-hour hotline Email: enquiry@imh.com.sg	
For enquiries regarding outpatient appointments	Tel: 6389 2200 (Ambulatory Services) Email: imh_appt@imh.com.sg	
For enquiries regarding patient admissions	Tel: 6389 2003 / 6389 2004 (Emergency Services) 24-hour hotline	
For enquiries regarding billing and payment of treatment fees	Tel: 6511 4338 (Business Office) Email: enquiry@imh.com.sg	
For enquiries regarding social, care and financial assistance schemes	Tel: 6389 2059 (Medical Social Work Department) Email: admin_msw@imh.com.sg	
For enquires regarding medications	Tel: 6389 2077 (Pharmacy Department)	
For enquiries regarding medical reports	Tel: 6389 2031 (Medical Records Office) Email: mro_imh@imh.com.sg	
For feedback on services at IMH	Tel: 1800 386 4541 (Patient Relations Office) Email: QSM@imh.com.sg	
For help with Addictions-related issues	Addictions Helpline Tel: 6-RECOVER (6-732 6837)	
For help with Problem Gambling	National Problem Gambling Helpline Tel: 1800-6-668-668	
For mental health crisis	Mental Health Helpline Tel: 6389 2222 24-hour hotline	
For a free and confidential mental health check for those between 16 and 30 years old	CHAT Helpline Tel: 6493 6500 / 6493 6501 Email: chat@mentalhealth.sg	

# **Community Mental Health Services & Helplines**

For Caregivers	Caregivers Alliance Limited Tel: 6460 4400 Email: general@cal.org.sg	Provides information, accepts referrals, offers befriending services, emotional support and training for caregivers.	For Counselling	SAGE Helpline for Seniors Tel: 1800 555 5555	Provides counselling to enhance the total well-being of the older persons and their caregivers with a special focus on the psychological and social aspects of their health
	<b>Dementia Helpline</b> (Alzheimer's Disease Association) Tel: 6377 0700	Provides a listening ear for caregivers and assist them in managing any crisis situation at home.		Samaritans of Singapore (SOS) Hotline Tel: 1800 221 4444	Provides counselling for anyone in crisis and persons with suicidal tendencies, thinking of suicide or affected by suicide.
	TOUCH Care Line Tel: 6804 6555	Provides information and referral services for caregivers.	For locating other Community Mental Health	Agency for Integrated Care (AIC) E-care Locator	Helps you identify and locate relevant services for your senior loved ones.
Te Fa	Comcare Helpline Tel: 1800 222 0000	Provides assistance to the public by directing to the appropriate agency and links all FSCs for the public to access. Operates in English, Mandarin, Malay and Tamil.	Services & Helplines	Website:	
	Family Justice Courts Tel: 6435 5471	Provides information and hears the full suite of family-related cases including all divorce and related matters, family violence cases, adoption and guardianship cases, Youth Court cases, applications for deputyship under the Mental Capacity Act, and probate and succession matters.		Family Service Centre Locator Website:	Helps you locate the nearest family service centre to your place of residence.
	Legal Aid Bureau Tel: 1800 225 5529	Provides legal representation and advice in civil matters to persons of limited means.		Social Service Office Locator Website:	Helps you locate the social service office nearest to your place of residence.
				National Council of Social Services Navigator	Helps you identify and locate relevant social services for you and your loved ones in the

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Website:

community.