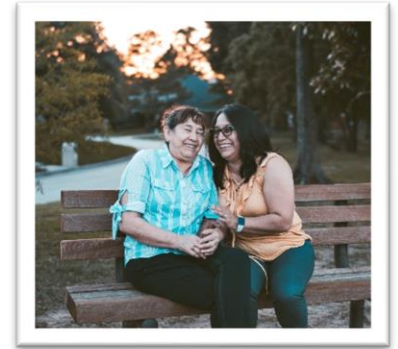


Family Workbook

CAREGIVING & MENTAL ILLNESS

This workbook has been adapted from [The Complete Caregiver Support Guide](#) authored by Ester R. A. Leutenberg, Carroll Morris, and Kathy A. Khalsa. The original Guide inspired us to develop a specific set of worksheets for caregiving families living with mental illness. We appreciate the generous support of the authors and for allowing us to adapt this important Guide to our project. We encourage you to review and use the Complete Caregiver Support Guide which has over 150 worksheets dedicated to supporting caregivers.



How to use this Workbook

Print off the entire workbook or just individual pages you want to complete. Use them individually, in support groups, and/or share them with your family members and compare responses. We hope this will provide insight into the experiences of each family member, and ways to build communication and mutual support. Please contact us at fmhproject@gmail.com with any questions, and ideas about adding to or improving it.

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HELPFUL IDEA EXCHANGE

What did you do recently that helped with managing care needs in your family?

Take time to write down as many examples as you can think of. Ask other family members to write down their own examples and compare to see the variety of ways that your family co-manages care needs.

Examples:

- I accompanied my brother to his psychiatrist appointment.
- I made leftovers so my mother wouldn't have to worry about making dinner.
- I helped my best friend get home safely after they told me they were feeling anxious.
- I mowed my neighbour's lawn since she is so busy with caring for her son.
- I put my appointments on the family calendar so everyone knows when they are.
- I meditated 10 minutes first thing in the morning so that I could feel ready for the tasks of the day.

- _____
- _____
- _____
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- _____

MAKING LIFE EASIER – SURVIVAL STRATEGIES FOR THE STRESSED

It may sound simplistic, but it's true: Taking time to plan your day and organize your environment can go a long way toward reducing stress and helping you feel you have some control over your situation. With your lists in hand, you will not have to wonder what it is that you need to do, whom you plan to call, where you want to go or what you intend to buy.

If you do not accomplish everything you hoped to in a given day, move undone items to the next day, putting those of highest priority first. If you repeatedly move the same item forward, ask yourself: Why do I resist doing it? Is it important or necessary? Can someone else do it for me?

Strategies for minimizing daily stress and irritations:

1. Organize your environment (cupboards, closets, a place for your keys, etc.)
2. Go through mail/email daily (sort, toss or keep)
3. Make lists in a portable notebook/device you can keep with you (to do, phone calls, groceries)
4. Schedule a realistic day (important things first, doesn't have to be perfect)
5. Prepare the night before (prepare meds, set table, review to-do lists)
6. Rise early to do something for yourself before other family members wake (read, shower, meditate, or enjoy a cup of tea or coffee)
7. Do one thing at a time (multi-tasking isn't always effective when you're stressed)
8. Know your limits and learn to say 'no' or 'not now' (protect your time, energy, health)
9. Be prepared (food and supplies in the house, full gas tank, extra house and car keys)
10. Keep up with maintenance (fix, replace, maintain – yourself or ask someone)
11. Take care of your own health (have a physical exam, eat healthy, sleep, exercise)
12. Maintain good relationships (apologize if needed, forgive others and yourself.)
13. Ask family members/close friends for help with any of the above.

What will I do to make life less stressful? (Compare your responses with others in the family)

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____

ADJUSTING TO A NEW NORMAL ... AGAIN!

Becoming a caregiver, especially to someone living with you, changes everything: your priorities, routine, demands on your time, and the way your household is set up, not to mention the support you may need from the family for your own health.

After what may be a difficult time of adjustment, life settles into a new routine. You've figured out what you need to do for yourself and your family member, and when. You've made changes so the living space is safe and comfortable. You're juggling – more or less successfully – your caregiving duties and other obligations. Life as it now is has become your new normal.

Then one day, you'll realize that your family member's condition has noticeably changed. A visit to the doctor may result in changes to treatment or medication. The once comfortable routine no longer works. Again, you have to figure out what needs to change, implement doctor's suggestions, and adjust to the new circumstances ... to another new normal.

You and your family may go through this recognition and adjustment pattern several times during a long-term illness. Whenever circumstances change in any way, complete the section below to help you gain insight and a new perspective.

Recently, what has changed in the management of the illness or condition? _____

What new help is needed now? _____

How has this affected the family routine? _____

What do you need to do differently? _____

How can you help your family adjust to these changes? _____

Not only does mental illness affect how and what needs to be done, it changes how family members relate to one another. The questions below may help you discover ways to remain close to your family member.

What activity did you do together that is now too difficult? _____

Can you continue to do it, but in a modified way? _____

If not, what activity can replace it? _____

Is there a way you connected emotionally that is no longer as effective? _____

In what new way might you sustain that connection? _____

DISCOVERING WHAT IS CAUSING YOUR ANGER AND FRUSTRATION

Anger and frustration are natural emotions that are experienced by family members caring for each other through mental illness. This worksheet is for any member of the family to explore these emotions further.

1. What has happened that adds to your stress? _____

2. Have the circumstances of a family member you care for changed? How? _____

3. Have your circumstances changed? How? _____

4. Do you feel overwhelmed? What do you wish your family members or close friends would do to help?

5. What care or caregiving issues do you and family members disagree about?

6. What are you fearful of in the near future? _____

7. Are you feeling under-appreciated or misunderstood? Explain why. _____

8. Are you running out of energy or are you not feeling well? Explain. _____

Look at your responses above. What is your most pressing need? What can you do about it?

THE GUILTS

In all families managing caregiving, there are times when those giving care and receiving care will question if they are doing the best they can for each other. You probably will too, and then you may feel as if you have fallen short of your own, and possibly others', expectations.

When that happens, be gentle with yourself. You are human, doing the best you can in a challenging situation.

Here are some typical reasons family members in a caregiving relationship may feel guilty. Check those that apply to you and add your own.

- You are impatient at times
- You speak abruptly or with a raised voice at times
- You've had thoughts such as, "I wish this wasn't happening to us"
- You feel guilty about taking time for yourself
- You've made decisions that have had consequences for others
- Your caregiving takes time away from normal life and time with other people
- You can't make your family member better, despite your best efforts
- You can't make yourself better, despite best efforts

- _____
- _____
- _____
- _____
- _____
- _____

Unresolved feelings of guilt can hamper your ability to participate fully in relationships with your family members. Once you have acknowledged the issues you feel guilty about, you can decide what you can do better or differently. Taking one or more of the steps below can help you maintain a more balanced, healthy perspective.

- Remind yourself that what you do makes a difference
- Set realistic goals
- Accept your shortcomings and take action in areas you can improve
- Arrange for time for yourself.
- Attend a support group regularly.
- Share your thoughts with a trusted friend or family member.
- Seek a therapist or counselor if you feel depressed or stressed over a prolonged period of time

FACING REALITY

Facing the truth about how you are being affected by mental illness and caregiving needs in your family is an important step toward taking action that will give you the power and strength to keep going.

1. What are you feeling right now? _____

2. On a scale of 1 (not very) to 10 (very), how stressed are you right now? Explain. _____

3. What are you doing to help yourself cope? _____

4. What more can do you do to help yourself cope? _____

5. What help do you need most? _____

6. How can you get more help? _____

7. Who can you talk to when you need to vent? _____

8. Who can you talk to, but haven't reached out to yet? _____

9. On a scale of 1 (not very) to 10 (very), how close are you to feeling like you could be facing caregiver burnout*? Explain.

**caregiver burnout: a state of being unable to sustain the caregiving role due to overwhelming and prolonged emotional, physical, and mental stress.*

10. If you rated yourself over 6 on either #2 or #9, perhaps it's time to see your physician, a social worker, or therapist. Who can you make an appointment with? (e.g., could your family doctor make a referral? Do you have access to counselling through your school or workplace?)

11. If you do not know of anyone, to where could you get information about supports and services?

Check out the [Family Guide to Mental Health website](#) for information and resources for caregiving families.

SIGNS OF CAREGIVER BURNOUT

When caregivers focus primarily on the needs of their family members, they may neglect their own health and wellbeing. This places them at risk for stress-related illnesses, anxiety and depression. Caregiver burnout is a state of being unable to sustain the caregiving role due to overwhelming and prolonged emotional, physical, and mental stress. If you recognize signs of burnout in yourself or others, reach out to a health professional or someone whose advice you trust to discuss making changes or seeking help to stay healthy.

Do you have signs of caregiver burnout?

Check those that apply to you and then add to the list and consider discussing them with someone.

- I wake up feeling exhausted, wondering how I'll get through another day
- I blow up at the slightest thing, cry for no reason, or laugh when it's inappropriate
- I use substances like caffeine, alcohol or cannabis to get through the day
- I don't spend much time with my friends anymore
- I'm not interested in activities the way I used to be
- I haven't had a decent night's sleep for some time
- I feel hopeless. I wonder when it will be over. Then I feel guilty.
- I've gained or lost weight. I reach for snacks instead of eating a meal.
- I don't care or bother with how I look or what I wear.
- I often have headaches, colds or aches and pain.
- I forget appointments and lose things. I can't concentrate.
- I'm reactive to comments people make about how I'm caring for my loved one.
- I don't remember what it's like to be happy.
- I sometimes ignore my family member or treat them unkindly.

- _____
- _____
- _____
- _____
- _____

Several checked boxes can be an indication that you need to arrange for regular breaks from caregiving. Finding a person or service that can spend time, do activities, or provide care for your family member will allow you to run errands, exercise, keep your own appointments, meet with friends, etc. Family members and/or trusted friends are often willing to spend time with a family member for a few hours at a time. Ask a healthcare professional about services that can take over some of the tasks you now perform. If possible, consider employing a professional care provider for short periods of time; if necessary, ask family members to contribute to the cost.

What steps are you willing to take? Check those that appeal to you and list other ideas below.

- Ask family members or good friends to take over specific tasks or to step in to provide regular breaks for you to do things for yourself. create a calendar showing who is going to help and when.

- Talk with a health professional about services that can help with specific tasks
- Talk with a service provider about services or groups that could increase family member's activities and social network.
- Attend caregiver support group meetings. (Great place to brainstorm and find people who understand)
- Take comfort in knowing that you are doing the best you can.
- Schedule yourself in activities important to your health and well-being: meditate, exercise, visit friends, resume a hobby.

- _____
- _____
- _____
- _____
- _____
- _____
- _____
- _____

FINDING MEANING IN CAREGIVING

Caregiving can be exhausting – physically and mentally. At some point or other, caregivers can feel unable to carry on. Exhaustion and frustration are exacerbated by thoughts such as: *This is too hard. I can't do it anymore. I don't want to do it anymore.*

What keeps caregivers going when they reach this moment? First, getting the help they need from family, friends, and professionals. Then, turning to their own inner sources of strength. Research shows that caregivers who have a strong faith or whose culture values caregiving are less at risk for depression. For these individuals, their caregiving has a meaning that helps them carry on in difficult times. The meaning caregivers can find in this challenging task is very personal.

As a caregiver, you can find comfort in knowing that what you are doing aligns with your personal, family, cultural and/or spiritual values.

For example:

- Love for, and deep commitment to, the family member.
- Determination to carry on a family or cultural tradition of caring for others.
- Desire to give back to someone who made a difference to you.
- Need to express your faith through compassionate caring.

You may also find satisfaction in your accomplishments.

For example:

- Performed many daily tasks on behalf of the family member.
- Learned life-skills in the process.
- Advocated in health care or other issues for the family member.
- Role-modeled ways to care for those we love for a younger generation.

The personal growth that can come through caregiving is also a source of strength and self-esteem.

For example:

- Ability to keep going in tough times.
- Inner strength you may not have known you had before.
- Greater insight and understanding of yourself and others.
- Deeper feelings of love and compassion.
- New sense of what is most important in life.

(Continued on the next page)

FINDING MEANING IN CAREGIVING (Continued)

How can I find meaning in my caregiving journey?

Use the following questions to help you discover, or rediscover, how your caregiving is an expression of who you are and the values you hold.

1. Have you seen others being cared for in your own family? In other families? _____

2. How important is it to you to continue this tradition? _____

3. How has your family member contributed to your life? _____

4. What difference did it make? _____

5. What do you hope to contribute to your family member's well-being? _____

6. What beliefs or values are most important to you? _____

7. How does caregiving reflect those values or beliefs? _____

8. How do you feel about yourself, knowing you contribute in this way? _____

9. Describe your relationship with your family member. _____

10. How do you feel about yourself, considering the care you are giving your family member? _____

11. In what ways are you the person who has always stepped up to the plate when action was needed? Explain.

12. What personal characteristics or commitments lead you to do that? _____

13. How is caregiving an expression of who you are? _____

CREATING A HEALTHY BALANCE

Sometimes caregivers don't have a clear picture of how well they are balancing caregiving and self-care. This worksheet can help you clarify your situation and develop action items for a healthier you.

What I do daily for my family member

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____

What I do daily for myself

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____

How many items are in your family member's "what I do" list? _____

How many things are on your list? _____

What does this tell you? _____

What choices can you make to help balance caring for another and caring for yourself?

1. _____
2. _____
3. _____
4. _____
5. _____

Think about how this might help both you and your care-receiver. _____

ENTERING YOUR CARE-RECEIVER'S WORLD

Emotions can run high in a family when caregiving is involved. Anger, frustration, blaming, etc., are all things that can come out when a family is under stress.

You may be able to avoid unpleasant scenes with a conscious commitment to enter the reality of your family member who needs caregiving. Doing so increases empathy and understanding, which are crucial to meaningful communication. Think of it as learning a skill that will improve your interactions with others now and in the future.

You can go through this worksheet as a reminder any time you need to shift or calm your reaction to the person you care for.

1. Walk around the block in your family member's shoes. What is it like to be that person today?

2. Listen to the feelings behind your family member's words. What do or could you say to acknowledge them? (*"You sound like you're feeling sad."* or, *"I can see this is frustrating for you."*)

3. Pay attention to your family member's body language. What does that language tell you? Is it different from their words?

4. Down-shift to a pace that matches your family member's. What can you do to remain calm and patient while waiting for them to do something you could do much more quickly?

5. Resist the urge to correct your family member or tell them not to feel that way. What can you do or say instead?

What technique can you use to stay centered and compassionate? (*For example: Count to 10, breathe deeply, etc.*)

HOW ARE WE DOING? A REALITY CHECK FOR CAREGIVING FAMILIES

For the family member in a caregiving role

Complete this page on your own and ask your family member to complete the corresponding page on their own.

If possible, come together afterwards and compare responses and perceptions. In what areas are your answers similar? In what areas are they different? What changes might you make based on your answers?

1. What are your major concerns at the moment? _____

2. Have you shared these concerns with your family member? Yes ___ No ___ Some ___

Explain your response. _____

3. Have you shared them with someone else? Yes ___ No ___ Some ___

Explain your response. _____

4. Do you have emotions or thoughts that you hold back from your family member?

Yes ___ No ___ Some ___

If yes, explain. _____

5. Do you share these emotions or thoughts with anyone else? Yes ___ No ___ Some ___

Explain your response. _____

6. How do you handle these thoughts and emotions? _____

11. Do you believe your family member knows how you are feeling right now?

Yes ___ No ___ Some ___

Explain your response. _____

12. Do you believe you understand your family member's wishes regarding medical emergencies and decision-making during crisis situations? Yes ___ No ___ Some___

13. Do you think other family members have a clear understanding of your current situation?

Yes ___ No ___ Some ___

Explain your response. _____

14. Is there something you would like to tell your family member, but haven't? What is it?

15. Can you find a way of saying what you would like to say that might work out well for both of you? How?

HOW ARE WE DOING? A REALITY CHECK FOR CAREGIVING FAMILIES

For the family member who is receiving care

Complete this page on your own and ask your family member to complete the corresponding page on their own.

If possible, come together afterwards and compare responses and perceptions. In what areas are your answers similar? In what areas are they different? What changes might you make based on your answers?

1. What are your major concerns at the moment? _____

2. Have you shared these concerns with your family member? Yes ___ No ___ Some ___

Explain your response. _____

3. Have you shared them with someone else? Yes ___ No ___ Some ___

Explain your response. _____

4. Do you have emotions or thoughts that you hold back from your family member?

Yes ___ No ___ Some ___

If yes, explain. _____

5. Do you share these emotions or thoughts with anyone else? Yes ___ No ___ Some ___

Explain your response. _____

6. How do you handle these thoughts and emotions? _____

11. Do you believe your family member knows how you are feeling right now?

Yes ___ No ___ Some ___

Explain your response. _____

12. Do you believe you understand your family member's wishes regarding the management of medical emergencies and decision-making for you during crisis situations? Yes ___ No ___ Some___

13. Do you think other family members have a clear understanding of your current situation?

Yes ___ No ___ Some ___

Explain your response. _____

14. Is there something you would like to tell your family member, but haven't? What is it?

15. Can you find a way of saying what you would like to say that might work out well for both of you? How?

IDENTIFYING THE LEVEL OF SUPPORT NEEDED

For the family member who is receiving care

The purpose of this worksheet is to offer you concrete examples to share at a family meeting focusing on identifying the level of support you believe you need. Compare and compile worksheets to develop a helpful family document to reference. **How able are you to perform the following functions?**

Housework: Needs No Help Minimal Help Lots of Help Complete Help

Details _____

How family and/or close friends can help _____

Other solutions _____

Action plan _____

Main contact? _____

Taking medications as prescribed: Needs No Help Minimal Help Lots of Help Complete Help

Details _____

How family and/or close friends can help _____

Other solutions _____

Action plan _____

Main contact? _____

Managing finances: Needs No Help Minimal Help Lots of Help Complete Help

Details _____

How family and/or close friends can help _____

Other solutions _____

Action plan _____

Main contact? _____

Shopping: Needs No Help Minimal Help Lots of Help Complete Help

Details _____

How family and/or close friends can help _____

Other solutions _____

Action plan _____

Main contact? _____

IDENTIFYING THE LEVEL OF SUPPORT NEEDED

For the family member in a caregiving role

The purpose of this worksheet is to offer you concrete examples to share at a family meeting focusing on identifying the level of support you believe someone else in the family needs. Compare and compile worksheets to develop a helpful family document to reference. **How able is your family member to perform the following functions?**

Housework: Needs No Help Minimal Help Lots of Help Complete Help

Details _____

How family and/or close friends can help _____

Other solutions _____

Action plan _____

Main contact? _____

Taking medications as prescribed: Needs No Help Minimal Help Lots of Help Complete Help

Details _____

How family and/or close friends can help _____

Other solutions _____

Action plan _____

Main contact? _____

Managing finances: Needs No Help Minimal Help Lots of Help Complete Help

Details _____

How family and/or close friends can help _____

Other solutions _____

Action plan _____

Main contact? _____

Shopping: Needs No Help Minimal Help Lots of Help Complete Help

Details _____

How family and/or close friends can help _____

Other solutions _____

Action plan _____

Main contact? _____

WHAT DO I WANT?

Any member of the family can complete this page to reflect about their circumstances, perhaps to do with family care or otherwise, that they can then share with their family if they choose.

I am thinking about _____

Here are three things (or more) that I know for sure that I DO want. _____

Here are three things (or more) that I know for sure that I DO NOT want. _____

Here are three things (or more) that I am not sure about and am still contemplating.

My biggest fear is _____

What single thing, if addressed by a family member, would offer you the most comfort?

AM I “HELPING” TOO MUCH?

With the desire to advocate for our family members, caregivers can, and sometimes do, step over the fine line between actions that are helpful and/or necessary to the family member, and actions that, though well-meaning, undermine the family member and/or deprive them of choice and their sense of control and personhood.

It is not always easy to sense the difference between taking a necessary action and carrying it to an extreme that is not healthy for you or your family member. Often family members do not realize they are encroaching on that line until their actions begin to cause problems. That can be avoided by periodically asking your family member if you are helping in ways that makes them feel cared for and acknowledged as a person.

Be prepared to accept their perception of your caring. If they object to some of your actions or attitudes, ask what you might change that would make a difference. Work together to find a satisfying solution. Even if your family member is not able to articulate clearly what actions are disturbing, paying attention to their body language and emotions can tell you a great deal.

As you go through the examples below, consider if your way of helping is closer to empowering or disempowering for your family member.

Being an advocate with health professionals but allowing your family member to speak for themself.

Answering questions that your family member could respond to if given a chance.

Making changes to home and routine for safety's sake.

Making changes without allowing your family member to have input.

Helping your family member with tasks that are difficult.

Doing things your family member is able to do, because they take too long.

Taking care of what needs to be done as efficiently as possible.

Being impatient when your family member is not doing things fast enough for you.

Making everyday household decisions together.

Making decision without asking for input from your family member.

MY CAREGIVING FAMILY

This worksheet can help you brainstorm and keep track of the people who you can depend on for support in times of need. These could be people who you consider part of your family and/or close friends. Fill in the name and contact information of the person who comes to mind for each type of support – if more than one person comes to mind, put them all down. Feel free to add more categories in the space provided.

Help During a Crisis

	Name	Contact Information
Can be called in an emergency		
Good at dealing with healthcare professionals		
Someone trusted by me and my family to act as a liaison when we feel unable to talk to each other		

Emotional & Wellness Needs

	Name	Contact Information
Good listener		
Good to grab a coffee/tea with		
Will go for a walk with me		
Will do something fun with me		

Practical Tasks

	Name	Contact Information
Will provide hands-on help with house chores		
Will provide care for children / pets / plants / others when I need help		
Will help make or get a meal		
Will help with organizing		
Will help with repairs at home		

Other Help

	Name	Contact Information

MENTAL HEALTH CARE PREFERENCES

From [SAMHSA's "A Practical Guide to Psychiatric Advance Directives"](#)

Name: _____

Address: _____

Phone: _____

Symptoms/problems I experience during a period of mental health crisis:

Medications that are helpful/not helpful. Try to give detail to assist medical professionals who may be helping you in crisis.

I agree to administration of the following medication(s):

I do not agree to administration of the following medication(s):

Other information about medications (allergies, side effects):

Preferences regarding treatment facilities. *Note: Admission to a specific facility may be limited because of lack of an available bed.*

Other information about hospitalization:

Emergency Contacts in case of mental health crisis:

Name: _____

Address: _____

Home Phone #: _____

Work Phone #: _____

Relationship to Me: _____

Name: _____

Address: _____

Home Phone #: _____

Work Phone #: _____

Relationship to Me: _____

Psychiatrist: _____

Work Phone #: _____

Case Manager/Therapist: _____

Work Phone #: _____

Crisis Precipitants. The following may cause me to experience a mental health crisis:

Protective Factors. The following may help me avoid a mental health crisis:

I usually respond to the hospital as follows:

Staff of the hospital or crisis unit can help me by doing the following:

I give permission for the following people to visit me in the hospital:

If I am hospitalized, I want the following to be taken care of at my home:

Other important information:
