

# Family Recovery Journey

Living with Psychosis and Schizophrenia

## The Impact of Psychosis on the Family

### Common Issues

- Grief and loss
- Communication breakdown and conflict
- Isolation and stigma
- Caregiving
- Role changes

### Everyone is Impacted Differently

#### Parents

- May feel guilt or self-blame
- Often continue or return to parenting role for adult children; life revolves around this
- Worry about other children

#### Children

- Scared, confused
- Worry that they will inherit mental illness
- Over-responsible; caregiver for parent

#### Siblings

- Scared, confused
- May feel neglected and resent their ill sibling
- May be protective of sibling; become over-responsible, grow up too fast

#### Spouse

- Take on added family responsibilities
- Changes in couple relationship
- Financial stress

For detailed information, see

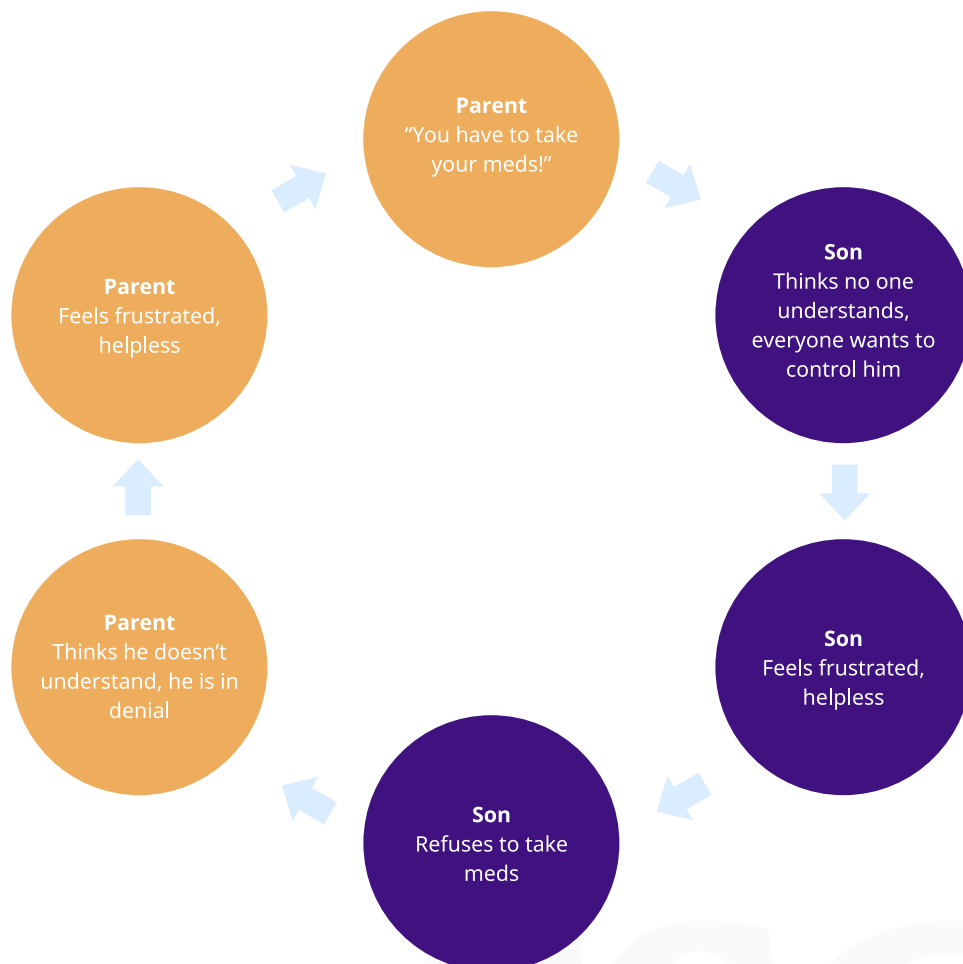
<https://www.heretohelp.bc.ca/sites/default/files/family-toolkit-module-4.pdf>

# Fractured Relationships: The Treatment Battle & How We Go in Circles

This issue of treatment often turns into a negative interaction pattern in families. See the diagram below, as an example of how such a pattern might look.

The solution to changing this is to make the relationship your priority. Instead of persuading and pushing, take a step back to try to understand:

- Refusal to accept treatment may be a symptom, known as anosognosia. Like someone who has had a stroke, and forgets that their arm or leg doesn't work, many people with psychosis are not able to recognize that they are ill. This is not the same thing as denial.
- For others, there may be very good reasons for resisting treatment. These could include unpleasant side effects, not wanting reminders that they are ill, or feeling coerced.



## A Better Way: The Leap Approach

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Dr. Xavier Amador: <https://youtu.be/NXxytf6kfPM>

- Listen (reflexively and without judgment)
- Empathize (strategically with emotions stemming from delusions and anosognosia)
- Agree (find areas of agreement – abandon your goal of agreeing the person is sick)
- Partner (on those things you can agree on – not being ill)
- Delay (giving opinions like “You’re ill. You need medication.”)
- Opinion (3 A’s – Apologize for such opinions. Acknowledge your fallibility. Agree to disagree.)
- Apologize (for not agreeing, too much reflective listening, involuntary hospitalization, etc.)

## Strategies for Encouraging Collaboration with Treatment

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1. Understand your relative's treatment, including medication side effects.
2. Use the LEAP approach to discuss the benefits and risks of treatment.
3. Remind your relative to take their medication when appropriate.
4. Encourage use of daily pill boxes or other systems to help them keep track of their meds.
5. Discuss medication management with the healthcare team, including options such as quick-dissolving oral meds, or long-acting injectable meds.
6. Encourage your relative to assume their own responsibility for managing their health.

## Other Strategies for Families

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### For Bizarre or Unusual Behavior

1. Sit down and talk calmly with your family member about your concerns.
2. Be firm, without threats, about behaviour that you do not like.
3. Be clear about behaviour that you do like.
4. Remind your family member clearly and firmly about what is okay and what is not okay.
5. Avoid discussions about whether or not what they experience is real.
6. Give personal space.
7. Tolerate behaviours that may appear a little different but that are not dangerous or harmful.
8. Offer household activities such as helping with chores.
9. Offer reassurance to allay family member's fears.
10. Solicit information and support from the healthcare team.
11. Encourage learning about symptom management strategies.

### For Social Withdrawal & Isolation

1. Involve relative in family social activities with no pressure i.e. allow them to just be present without insisting that they actively participate.
2. Acknowledge that your relative needs to be alone at times
3. Encourage your relative to become involved in a peer support group and/or social rehabilitation program. Discuss with the healthcare team what options are available.
4. Encourage your relative's friends to do things with them.
5. Suggest activities for your relative and their friends to do.
6. Do not push too hard on withdrawal. Your relative needs "down time" for sorting out their experiences, and to decrease stimulation.

## For Hygiene & Appearance

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|---|---|
| <ol style="list-style-type: none"> <li>1. Acknowledge what your relative is already doing well.</li> </ol>                                | <ol style="list-style-type: none"> <li>3. Share your feelings with your family member about their appearance and hygiene in a non-judgemental way.</li> </ol> |
| <ol style="list-style-type: none"> <li>2. Recognize that poor hygiene may be due to anosognosia – the person truly is unaware.</li> </ol> | <ol style="list-style-type: none"> <li>4. Acknowledge the range of styles that are appropriate among their peers.</li> </ol>                                  |

## What Supports Are There for Us?

Support is the number one need identified by families living with mental illness. Unfortunately, stigma and shame often prevent families from being able to access support.

**Local Supports** – see Resource Guide

### Natural Supports

Each member of the family will need a support system and healthy coping skills. The following list outlines what a support system can include. Take a moment to think about how many of these support systems are in place for you and your family. If you feel you don't have a strong support system, make it a priority to create one. Remember there are others who will be searching for a support system as well.

- A self-help/support group that focuses on coping with problems and learning to problem-solve rather than just telling or retelling traumatic events
- Friends who can empathize. Friends who do not need to drink or use mood-altering substances for entertainment
- A professional counsellor (this relationship can be temporary, but you should feel that you can rely on it during difficult transition periods)
- Recreation time with others at least once a week
- Involvement in a group or activity that caters to your personal interests, such as volunteering or adult education classes

With support, you can ensure that you do not deplete your “emotional bank account.” It is essential to your health that you nurture your needs.

## Exercise: Identifying Your Supports – Use the Back of this Handout

- Draw a large circle surrounded by smaller circles
- In the central circle, write the names of your family members, or draw your family.
- In the surrounding circles, write the names of your support persons and groups. Connect these to your family circle with lines.
- Are there supports you could use, but don't? Add more circles for these.

## Online Supports

The Internet is full of information, and not all of it is reliable. How can you be sure that you are getting the best information?

**First:** go to the recommended websites listed on the last page of this handout.

**Second:** use the Health On the Net foundation tools to assess the validity of websites: What to look for: the HON code principles:

- Authority – gives qualifications of authors
- Complementarity – information to support, not replace
- Confidentiality – respects the privacy of site users
- Attribution – cites the sources and dates of medical information
- Justifiability – justification of claims/balanced and objective claims
- Transparency – accessibility, provides contact details
- Financial disclosure – provides details of funding
- Advertising – clearly distinguishes advertising from editorial content

HON code website and toolbar <https://www.hon.ch/HONtools/Patients/index.html>

# Looking After Yourself

As carers for a person experiencing a psychotic illness, it is vital to also care for yourselves.<sup>1</sup> The BC Schizophrenia Society has published an excellent overview of the needs of families, including how different members of the family are impacted differently by mental illness: <https://www.heretohelp.bc.ca/sites/default/files/family-toolkit-module-4.pdf>

## Self Care Planning

### Step 1: Begin With a “Taking Stock” Exercise

List your current caring activities and your other responsibilities, and then list your current self-care activities.

Caring Activities and Responsibilities	Self-Care Activities

The key is to try to achieve a balance between your responsibilities and stresses, on the one hand, and those things that help you to “recharge” and maintain your health and quality of life on the other hand. Both sides of this scale will look different for each of us. They will also likely change over time as your caregiving situation and/or other parts of your life change.

How are you doing? If your current responsibilities significantly outweigh your self-care activities, think about ways that you could achieve a better balance and go to Step 2.

<sup>1</sup> The term “carer” is replacing “caregiver” in healthcare worldwide. This reflects that fact that families are not always “caregiving” in the traditional sense, but are caring and involved in a variety of ways to support their loved ones health.

## Step 2: Drafting a Self-Care Plan

Your self care plan can be developed by:

- Continuing to do... those things that you are already doing that rejuvenate you and positively contribute to your health and quality of life.
- Start doing... new activities or accessing services that will enable you to recharge and achieve better balance in your life.
- Stop doing... those things which are optional and add to your current responsibilities and stresses, and/or those things for which you can enlist the help of others to lighten your load.

Take a few minutes and identify activities and lifestyle choices that can help you improve your emotional, spiritual, physical, social, and intellectual aspects of life. Also note those responsibilities and stresses which you can stop doing on your own or altogether.

Here are some suggestions that other carers have included in their self-care plans:

### Emotional

- Participate in a self-help group or one-on-one peer support with another carer for practical information-sharing and emotional support
- Seek emotional support for yourself from family and friends and/or from professional counsellors

### Spiritual

- Take time for regular spiritual rituals that are important to you (e.g., meditation, attending organized religious services)
- Take time to enjoy nature

### Physical

- Maintain good nutrition
- Exercise regularly
- Seek services to relieve you of some physical caregiving tasks (e.g., home and yard maintenance and cleaning services)

### Social

- Take time to maintain regular contact with other family members and friends to maintain these important relationships
- Take time for regular participation in your favourite recreational activities

### Intellectual

- "Knowledge is power" – Seek out information about mental illness and available resources so that you are well-equipped to deal with the challenges of supporting someone living with a mental illness.

Obviously, this is not an exhaustive list, so think creatively about your own situation and what would make a difference for you.



Continue to Do	Start Doing	Stop Doing
Emotional		
Spiritual		
Physical		
Social		
Intellectual		

(Source: MS Society of Canada Taking Care: A Travel Guide for Your MS Caregiver Journey SAFE Program, Oklahoma City Veterans Affairs Medical Center)



# Recommended Online Resources

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## Canadian

Cannabis and Psychosis <http://cannabisandpsychosis.ca>

## Centre for Addiction and Mental Health (CAMH)

- Supporting a Family Member with Schizophrenia - Downloadable manual and other resources <https://www.porticonetwork.ca/web/schizophrenia-family-strategies/home>
- Public education online tutorials [http://www.camh.ca/en/education/Patients-Families-Public/public/mental\\_health\\_and\\_addiction\\_101\\_series/Pages/mental\\_health\\_and\\_addiction\\_101\\_series.aspx](http://www.camh.ca/en/education/Patients-Families-Public/public/mental_health_and_addiction_101_series/Pages/mental_health_and_addiction_101_series.aspx)
- Mental health information A-Z [http://www.camh.ca/en/hospital/health\\_information/a\\_z\\_mental\\_health\\_and\\_addiction\\_information/Pages/default.aspx](http://www.camh.ca/en/hospital/health_information/a_z_mental_health_and_addiction_information/Pages/default.aspx)

## Early Psychosis Intervention

<https://www.earlypsychosisintervention.ca>

## FAME for Families

- Website <http://www.fameforfamilies.com>
- YouTube channel <https://www.youtube.com/user/fameforfamilies/videos>

## Family Guide to Mental Health Recovery

- YouTube channel <https://www.youtube.com/user/FamilyGuideProject/videos>
- Website <http://www.familyguidetomentalhealth.com>

## Schizophrenia Society of Canada

Video resources at <https://schizophrenia.ca/video/>

## Mind Your Mind (for youth)

<https://mindyourmind.ca>

## Family Smart

<https://familysmart.ca>

## Family Guide to Mental Health Recovery

<http://www.familyguidetomentalhealth.com>

## Other

Children of parents with a mental illness (COPMI) – has videos for children as well as for parents

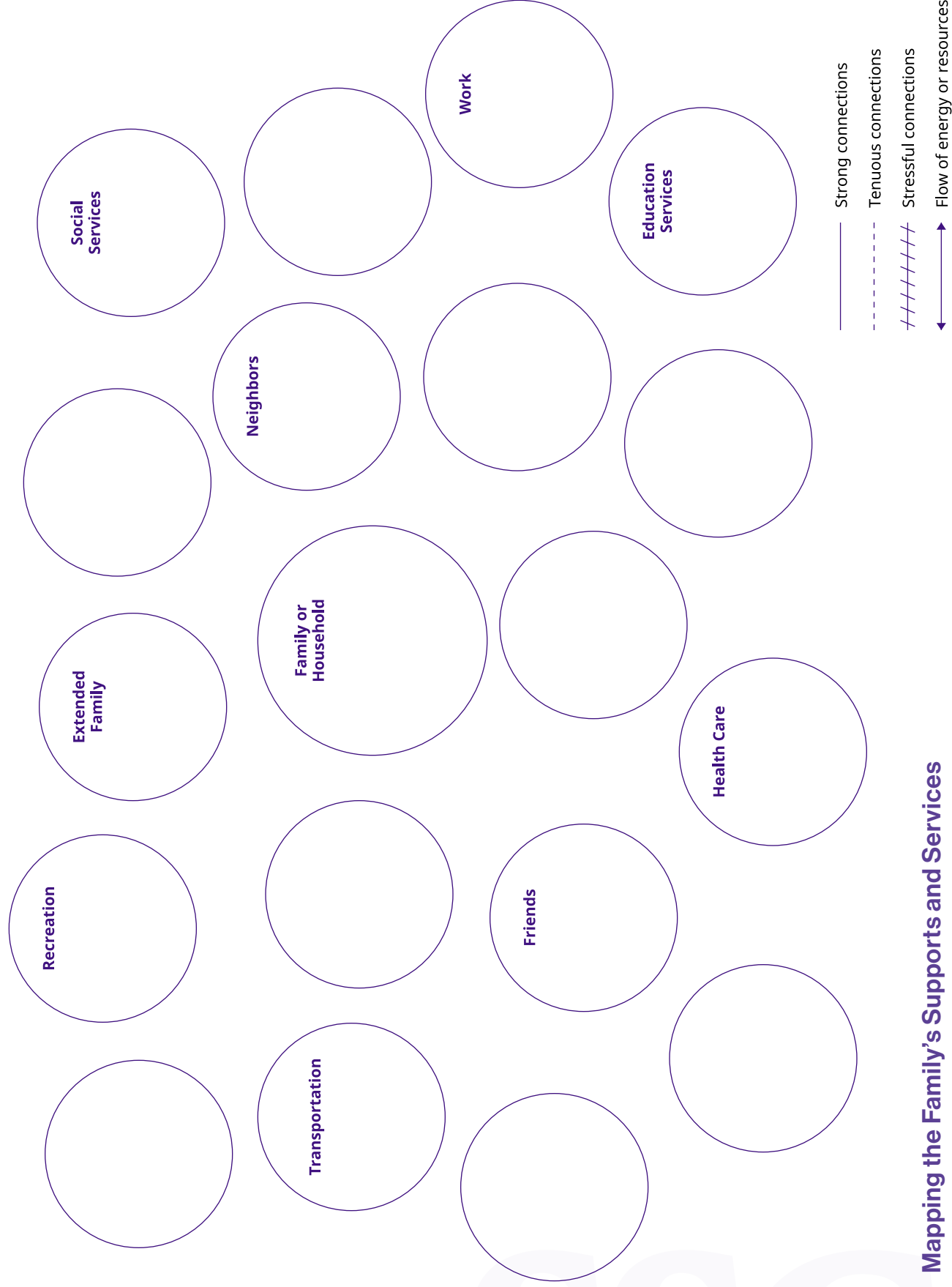
- <http://www.copmi.net.au>
- <http://www.copmi.net.au/kids-young-people/about-mental-illness>

## Common Ground (Dr. Pat Deegan)

<https://www.patdeegan.com>

## How to support your spouse with schizophrenia

<https://www.youtube.com/watch?v=XKdsQAGTzwY>



Mapping the Family's Supports and Services