

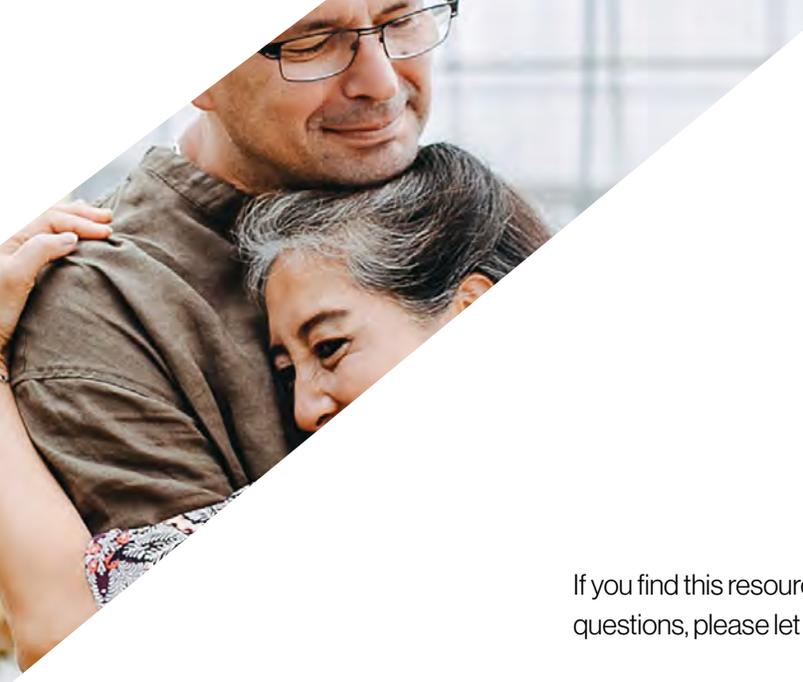
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SOCIÉTÉ CANADIENNE
DE LA SCHIZOPHRENIE

Facilitator's Manual | 2020

Family Recovery Journey





If you find this resource helpful, or if you have any suggestions or questions, please let us know.

Email messages can be sent to info@schizophrenia.ca, or phone **(204) 320-3188**.

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Family Recovery Journey was designed to meet the needs of a range of families, including those with a family member who has recently received a diagnosis of psychosis or schizophrenia. We thank the SSC Education Committee for recognizing the importance of educating families and other members of the natural support community about mental illness. The goal of developing Family Recovery Journey was to create a responsive, impartial, and flexible program for Canadians. It is written from a recovery focus as we believe that it is possible for an individual to live beyond the limitations of a mental illness with a sense of hope, purpose, meaning, and social inclusion. Recovery is a discovery that it is possible to live a full and meaningful life after a diagnosis of mental illness. Families are also in recovery from the traumatic effects of mental illness upon the family. As our CEO, Dr. Chris Summerville says, "Never close the door to hope. Hope changes everything!"

We appreciate the valuable input provided by the Executive Directors of the provincial schizophrenia societies, family members, and those living with early psychosis and schizophrenia.

We look forward to the continuing evolution of Family Recovery Journey as the needs of families and their loved ones change, and we remain dedicated to creating a responsive and timely education program.

Dr. Lori Triano-Antidormi, Ph.D., C.Psych
President, Schizophrenia Society of Canada



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Introduction to the Program

Background Information

The mission of the Schizophrenia Society of Canada is to, “build a Canada where people living with early psychosis and schizophrenia achieve their potential.” “People” includes the individual and their family members. This program grew out of the strong belief that Canadian families have a right to accurate and consistent information on early psychosis and schizophrenia from a recovery perspective.

Educating families of persons with schizophrenia has been found to have the following benefits¹:

- Reduces impact of illness on the family
- Provides tools for family management of illness impact
- Reduces individual relapse rates by up to 20%

Family Recovery Journey is a national program of the Schizophrenia Society of Canada (SSC). It is based on the Strengthening Families Together (SFT) program which was created in 2003 and was the first Canadian-based family psychoeducation program for schizophrenia. Since that time, changes in knowledge and in the mental health system necessitated an overhaul of the program, and so it has been rewritten and given a new name.

Significant changes from the previous program include:

- Less emphasis on pathology, and more on hope and recovery
- Focus is less on theoretical knowledge and more on “how-to” skills
- Changes in language (e.g. from “coping” to “management”)
- Family health and illness management strategies included in each session
- Reduction of number of sessions from 10 to 5
- Reduced number of slides per session to allow more space for discussion
- Slides contain less text and more images
- Addition of short videos
- Reduction in amount of printed material for participants
- Built-in flexibility for inclusion of locally relevant information, including cultural understandings of psychosis
- Emphasis on health literacy and e-literacy (how to discern reliable information on the Internet)
- Simplified registration and evaluation forms

¹Pitschel-Walsh, G., Leucht, S., Bauml, J., Kissling, W. & Engel R.R. (2001) The effect of family interventions on schizophrenia re-hospitalization: a meta-analysis. Schizophrenia Bulletin (2001) 27 (1): 73-92.

These changes were based on recognition of the need for hope and a recovery orientation, feedback from the provincial schizophrenia societies, and an understanding of adult educational theory.

Guiding Principles and Assumptions

1. The purpose of family psychoeducation is to provide families with education and practical skills for managing the impact of illness, and also with hope for the future.

2. A strengths-based, recovery-oriented approach is essential.

3. A national program needs to reflect Canadian values and therefore must include the voice of persons with lived experience, honour diversity, respect indigenous peoples, and be culturally safe.

4. People today not only need health literacy but e-literacy, due to the explosion of information online. The program should include teaching people how to find and use reliable health information, particularly as new research and knowledge is expected to continue to emerge.

5. Family psychoeducation is best provided in an interactive, face-to-face format. If at some point it is delivered online, it should be in a live “virtual classroom” where participants can interact with the facilitator and one another.

6. Technology today can assist the program to reach remote regions. For this, the material must be easily adapted to an online format.

7. The program must be adaptable to different regions (e.g. provincial Mental Health Acts differ) but also maintain consistency and integrity overall.

8. The program will need a way to incorporate new knowledge as it arises, while maintaining its overall consistency.

9. It is desirable to have one single program rather than multiple versions. There must then be some way for the program to be flexible for use in diverse regions and populations, while maintaining its integrity.

10. This material is best delivered by a Family Peer Support Worker working in collaboration with individuals living with early psychosis or schizophrenia, and recovery-focused mental health service providers.

Goals

To deliver a family psychoeducation program that reflects current knowledge, is recovery-oriented and culturally safe, and provides practical tools for family management of schizophrenia spectrum disorders and their impact on family relational health.

- **Support:** Families have an opportunity to discuss the daily challenges they face and to connect with others.

- **Awareness:** Families get accurate information about psychosis, treatment options, research, and available mental health services.

- **Tools:** Families are equipped with problem-solving, coping, advocacy and communication skills.

Participant Description

This course is designed for adult family members or friends of persons living with early psychosis. It is not intended to be taken by individuals who themselves live with psychosis, although individuals who are well along on their recovery journey may attend and find it useful, especially if they are also a parent or sibling of a person living with psychosis.

Learning Objectives

At the end of the program, participants will be able to:

1. Define psychosis and describe its symptoms, course, prognosis, possible causes, and bio-psycho-social-spiritual management.
2. Identify how culture and context influence the understanding and management of psychosis.
3. Define recovery and identify factors that promote recovery for individuals and families.
4. Identify practical strategies for managing common issues in living with schizophrenia.
5. Describe strategies for building and maintaining a strong family despite the impact of illness.
6. Understand the mental health system and mental health law in their region.
7. Use a strengths-based, recovery-oriented approach to managing the impact of illness on their family.
8. Develop a relapse prevention plan and crisis management plan for their family.
9. Support the recovery journey of their family member or friend.
10. Identify the characteristics of strong and resilient families and identify these in their own family.
11. Identify resources in their region as well as valid and reliable online resources.
12. Describe strategies for partnering with service providers and advocating for improvements in mental health services.
13. Feel a sense of empowerment leading to effective advocacy.

Format of Program

- Face-to-face small group sessions (adaptable for online delivery)
- Five 2-hour sessions with core content
- Alternative content (videos, examples) included for use with different populations
- Methods of delivery will include PowerPoint presentation, videos, small group activities, reflective activities, and discussion.
- Each session will incorporate practical tips for symptom management, family coping, local resources, etc.

Evaluation

- Optional brief evaluation each week – what was most helpful, what could be improved.
- Overall evaluation in last session – **required**; summary to be reported to SSC (see Appendix).



For Consideration

Feedback received during the first year of delivery of the Family Recovery Journey suggested that participants felt that at least 10 to 15 minutes of group discussion is very important each week and that more time should be allotted to hear from people with lived experience. It was also suggested that a check in meeting with participants be organized a month after the completion of the program. Facilitators are free to incorporate these types of suggestions into the delivery of the program, even if it means extending the program beyond a five-week period. Facilitators are free to determine what format (e.g.: five weeks or more; shorter sessions; etc.) works best for their audience.

As to the question of sublimating the material to FRJ, you may do so as long as it does not run contrary to the basic principles of FRJ. As to facilitating the whole material, we would expect you to exercise wisdom as to how much you draw attention to each module. You do not have to teach everything mentioned in the material, if the group is more knowledgeable on the issues.

The hardest thing is balancing personal self-support group questions with the objective EDUCATIONAL format we have used. It may be suggested to families who have recently received a diagnosis to take a “101 Introductory” session, then take the Family Recovery Journey program, and then enroll in a family peer support group.

Planning the Program

National Program With Local Connections

This program is owned and copyrighted by the Schizophrenia Society of Canada (SSC). As such, **changes must be approved by the SSC**. However, there is flexibility for tailoring the program to specific target audiences.

- Facilitators are encouraged to invite local guest speakers and provide information on local resources.
- Facilitators may adjust the order in which the sessions are delivered.
- Facilitators may deliver the program face-to-face or online.
- Slides include places where region-specific information may be inserted (e.g. provincial Mental Health Act).

It is not possible for a single national program to address all the unique cultural variations within Canada.

In order to maintain overall integrity of the program nationally, **facilitators are required to consult**

with SSC before making any changes to the number of sessions or core content of the program. This includes slides and handouts, except in identified parts where adaptation is expected.

Facilitators are encouraged to suggest new optional handouts or examples and may be invited to work with SSC to develop these.

Identifying Facilitators

Family Recovery Journey is designed to be facilitated by one or two facilitators for a maximum of 20 people in an interactive group setting.

Who can be a facilitator? Any person with lived experience as a family member and an understanding of recovery who has:

- A desire to facilitate the program and to help other families by sharing information along with personal knowledge and experience.

- An ability to share information from a personal perspective about the issues that friends and family members may face.

- Good communication skills, both as a speaker and a listener.

- An ability to co-lead and share the workload with another facilitator.

- A commitment to facilitating the full program.

- Experience and comfort leading adult groups.

Other individuals who have an interest in supporting families, such as family peer support workers, mental health professionals (nurses, social workers) or adult educators, can also facilitate this program.

Obtaining Funding

The amount of funding needed in order to offer Family Recovery Journey can vary. Generally, the program can be delivered with minimal funding. We encourage you to find volunteer facilitators and free session space. Remaining costs include printing and copying materials, refreshments, and guest speaker honorariums.

IMPORTANT: this program is to be offered free to participants. **No fees are to be charged.**

Getting Organized

Steps

1. Review the program materials and tips for facilitation in this manual. Follow guidelines for adapting slides as needed for your particular audience. Use templates to create handouts of locally relevant information and resources

2. Determine your method of delivery (face-to-face or online) and what equipment and other resources you will need.

3. Prepare yourself to be an effective facilitator.

4. Choose dates and arrange location. Invite guest speakers as desired.

5. Promote the program.

1. Review Program Materials

Manual

This manual accompanies a package containing the core materials to facilitate the program: facilitation outlines and notes, PowerPoint slides, participant handouts, and templates for inclusion of locally relevant resources. The material can also be accessed on the SSC website at www.schizophrenia.ca.

The manual is for the use of the facilitator(s) only. It includes a brief outline and notes for delivery of each session, as well as tips for facilitation.

Handouts

The handouts have been designed to match the facilitator's manual and slides. You may also add relevant brochures (e.g. in Manitoba, there is a brochure on the Mental Health Act available online). Feedback received in the first year of the program indicated that participants wanted to have more local links to resources, so be sure to pull what you can together as a handout.

Slides

Slides are editable to allow for adaptation to different regions; however, we ask that you do not fundamentally change the slides. Certain slides are marked as "placeholder" slides, and these are the ones that you can adapt for your particular audience. Slides may be handed out to participants. See the information below.

Images vs Text

Many of the slides are images rather than text. This is because educational best practices regarding use of PowerPoint recommend that there be few slides, and these should have images or a maximum of 6 points, 6 words per point. Details of the information should be in the handout(s). In this way, the presentation is more dynamic.

Educational research has shown that people remember the image more than the text and will therefore remember the content better. Also, people (including the presenter) tend to just read text slides rather than listening to the presentation, which makes for boredom and decreased learning. Please do not replace images with text.

Number of Slides per Session

We have kept the number of slides low per session. Please refrain from adding slides.

For a 2-hour presentation, allowing for discussion time and a break, there should be a maximum of 20 slides. Having too many slides creates pressure to “get through” them all and may lead to rushed delivery or too much lecture and not enough space for questions and discussion. If the details are in the handouts, you can focus on the key points and not worry about missing anything.

Optional and Placeholder Slides

Some slides are placeholders. Placeholder slides are ones that hold a place for a topic, but there are different options for that topic. An example would be a slide describing local supports, where each facilitator would insert their own information relevant to their region. Optional slides are typically at the end of the PowerPoint presentation and can be moved into the presentation as desired.

Optional slides contain information that is relevant to specific populations; for example, resources for rural Canadians.

Placeholder slides are marked as hidden and will not be seen in the slideshow unless the facilitator un-hides them. Optional slides are typically at the end of the PowerPoint presentation and can be moved into the presentation as desired.

Videos

Please refer to the instructional plan and introductory page for each session. These are videos whose content is appropriate for this program. A list of alternate videos can be found in Appendix B.

There are a lot of videos on YouTube that at first glance appear suitable but are in fact not accurate or appropriate. Please only use videos recommended by the Schizophrenia Society of Canada for this program. SSC has a YouTube Channel, and a playlist on that channel titled Family Recovery Journey, which contains videos deemed to be appropriate. The Schizophrenia Society of Canada’s YouTube channel can be found at <https://www.youtube.com/channel/UCwp8AFlo0N1psiyeHaH-LvQ/featured>

2. Determine Method of Delivery and Resources

FACE-TO-FACE

Equipment

- Laptop with PowerPoint

- Projector and screen

- Sound
 - Projectors that use HDMI cable connections may also transmit sound

 - A small Bluetooth speaker may be sufficient

Online

Online delivery is preferred when providing the program to rural and remote areas, or to immigrant and refugee families. Registration and signing of confidentiality and video-conferencing agreements can all be done online. Information for logging in to the program should only be sent once the agreements are signed. Participant notes should be emailed weekly after each session.

Please refer to Appendix C for information on how to deliver the program online.

3. Prepare Yourself to be an Effective Facilitator

One of the key skills that you'll need to lead the group successfully is the ability to facilitate effectively.

What is Facilitation?

- Understanding the goals of the meeting and the program, keeping the group on the agenda and moving forward
- Including everyone in the meeting, drawing out the quieter participants, and controlling the domineering ones
- Making sure that decisions are made democratically

Facilitation has three basic principles:

1. A facilitator is a guide who helps people move through a process together, not the seat of wisdom and knowledge. That means the facilitator isn't there to give opinions, but to draw out opinions and ideas from group members.
2. Facilitation focuses on how people participate in the process of learning or planning, not just what is achieved.
3. A facilitator is neutral and never takes sides.

A good facilitator is concerned with the outcome of the meeting or session, how the people in the meeting participate and interact, and the overall process. While achieving the goals and outcomes everyone wants is important, a facilitator also wants to make sure that the process is sound, that everyone is engaged, and that the experience is the best it can be for the participants.



See the “Before You Begin” tips for facilitation before Session 1.

Prepare for Working with Diverse Populations

INDIGENOUS FAMILIES

It is important to be aware of the history of oppression faced by Canada's indigenous peoples, and its impact on these families today. If you are a non-indigenous person, you need to recognize the impact of power and privilege on you and on your audience. **Be sure to open the program with an acknowledgement of First Nations territory.** Humility, respect, and a collaborative approach are essential.

Keep in mind that there is great diversity within and between indigenous groups. Adopt an attitude of being a learner about their culture. State your own cultural background and invite dialogue about different worldviews. (e.g. "My family crossed Europe from Holland to Russia before settling in Canada. I am a fourth-generation settler Canadian, and so I am influenced by that perspective. Please let me know if anything I say doesn't fit for you or is at odds with your understanding").

For guidance in acknowledging territory, see <https://native-land.ca/territory-acknowledgement/>

Also see these guidelines for working with indigenous peoples: <https://multiculturalmentalhealth.ca/clinical-tools/indigenous-peoples-guidelines/>

IMMIGRANT AND REFUGEE FAMILIES

We strongly recommend that you take the online Immigrant and Refugee Mental Health course from the Centre for Addiction and Mental Health (CAMH.ca), before delivering the program to this population. Immigrant and refugee families have particular needs, including language issues, and the need for an option to take the program at their own pace and in privacy. Many of these families are working two jobs and cannot go to a face-to-face group or are inhibited from attending by stigma in their community.

It may be beneficial to open the program with a statement of your own cultural background, similar to what is discussed above.

Register for the IRMH course here <https://irmhp-psmir.camhx.ca/courses>

Other Multicultural Groups

See the Multicultural Mental Health Resource Centre at <http://www.multiculturalmentalhealth.ca>

4. Choose Date and Location, and Invite Guest Speakers

DATES

There are three ideal starting times for this program: early fall (September), early winter (January or February), and early spring (March or April). Summer is generally not a good time to offer the program, as families often go away on holidays. Also, consider what other group programs are being offered in your community; finalize your date after consulting community calendars and social service organizations.

LOCATION

It is important to find a quiet, private room to hold the sessions. The group will be sharing very private information during the program, and every participant should feel safe in discussing personal matters. Some other things to consider:

- Is the location a familiar place, where people will feel comfortable? Is the meeting site accessible to everyone?

- Is the space the right size for the number of people you are expecting?

- Does the room have tables and chairs that can be arranged in a circle or U-shape?

- Is there access to Wi-Fi or wired internet connection (for YouTube videos)?

Hospitals and mental health centres often have rooms that are large enough to accommodate a group of 15 to 20 people. These rooms may also be free of charge to groups offering educational programs. Churches or schools may also be willing to provide a room free or at low cost.

ARRANGING FOR GUEST SPEAKERS

The session on Recovery (session 4) requires a guest speaker to tell their personal story. Speakers should be individuals who have experienced psychosis and are now well along their path to recovery. Arrange to meet your potential guest speaker for this session before the beginning of your program. It is all too easy to respond to the guest speaker using patronizing and token oriented words. Listen for the key messages and principles learned by the presenter. The point is not to sensationalize or just to listen to a story, but to understand and appreciate the value and power of lived experience and recovery.

Below are some questions that guest speakers may use to guide their presentations. Provide these questions to guest speakers as early as possible, to help them prepare their talk. We have allotted 30 minutes for the speaker, but the session schedule can be adapted if the speaker would like to speak for a longer or shorter period.

- What is your definition of recovery?

- What has been your process of recovery?

- Who and/or what has been important in your recovery?

- What was the most helpful thing that anyone did, to aid or support you in your recovery?

You may wish to invite other guest speakers to add variety and local information to the sessions. Remember to contact potential guest speakers while you are in the planning phase to ensure their availability. Be sure to ask persons whose information will be reliable and consistent with the values of the Schizophrenia Society of Canada.

When contacting someone about being a guest speaker, begin by explaining what the program is about and when you would like them to speak. Review the session topic with the speaker so that they know what information to cover. A speaker should discuss the topic set out in the session, and may enhance it with related information.

Who to invite? There are a variety of potential speakers for this program, depending on the session:

- A person with lived experience and/or family member (often called a peer support worker) to share how their family learned to cope with their illness or their loved one's illness, and to discuss their recovery

- Your local pharmacist to talk about medications and side effects, or ask a case manager or other health-care professional to explain the psychosocial resources available in your community

- A psychiatrist, psychiatric nurse, or social worker to bring a service provider's perspective to learning about mental illness

- A family member to discuss their self-care plan

- Someone who is living with a mental illness to give a first-person account of their experiences and recovery

- A representative from the local police branch or Crown counsel to help demystify the Mental Health Act or other related issues

- A representative from the local Schizophrenia Society chapter/branch to provide an update on advocacy activities and initiatives regarding mental illness and other resources available at the chapter/branch level

Guest speakers should be encouraged to write speaker notes prior to the session, and if it is possible, the group facilitators should review the speaker notes to ensure that a positive, hopeful message is interwoven throughout the guest speakers' presentation.

5. Promote the Program

In **Appendix A– Promotion Tools**, you will find some tools (including a sample flyer) you may choose to use. These tools are designed to help you inform potential participants and their referral sources about the program and your upcoming delivery. Keep in mind that word-of-mouth is often the most effective promotion tool.

Some ideas:

- Contact your local community newspaper for an estimate of the cost of placing an ad. Ask if they have a non-profit rate or if you can place an announcement free of charge. Many community newspapers have a section where a notice about the program can be placed without cost.

- Enquire about the possibility of a short Public Service Announcement (PSA) through your local radio stations.

- Get support for the program from medical and mental health professionals. Speak to local doctors. Ask if you can put literature about the program in their offices.

- Use the network established through your local and provincial schizophrenia society to advertise. Newsletters are a great way to promote the program.

- Provide your local schizophrenia society chapter/branch with information they can distribute at monthly support meetings.

Contact local mental health and service organizations such as:

- Mental health centres

- Early intervention programs

- Hospital psychiatric wards

- ACT/PACT teams

- Community centres

- Clubhouses

- Community non-profit organizations

- Libraries

- College and university information boards

- Local hospitals

ENLISTING THE SUPPORT OF LOCAL MENTAL HEALTH PROFESSIONALS

Developing a good relationship with your local mental health centre, early intervention clinics, psychiatrists, and other front-line staff will help you better promote the program, provide you with a list of potential guest speakers, and help you advertise the program to families. If possible, arrange to give a presentation about the program to local mental health teams.

RECRUITING PARTICIPANTS

It is often helpful to arrange a meeting with prospective participants before the program begins, to provide information and to make sure that they have a clear understanding of the content and approach of the program.

Provide information on:

- Who the facilitators will be, and their role

- When and where the program is being offered – dates, times, location

- Any further questions participants may have

You may want to ask potential participants some of the questions we have listed below to ensure that you get a sense of their expectations, their interest in participating, and whether the program will meet their needs.

- What interested you in taking this course?

- Costs for this course, including readings and all other materials, are covered by the organization presenting it. It is free to you and the only thing we ask of you is that you commit to attending all 5 weeks. How do you feel about this?

- How will it be for you to share your own story and to hear the stories of others?

- Outside of the sessions, who will you talk to during this course when you need some support?
- Is there anything else you want us to know?

If you and the potential participants decide that the program will be appropriate for them, wrap up by asking them to fill out a copy of the registration form included in Appendix B. Let potential participants know that you will be in touch again with a formal invitation and details about location and times.

Instructional Plan

Note: after Week 1 the order of sessions may be varied.

Week	Topics & Objectives	Activities/Content	Options/Variations	Handouts
1	<p>Introduction and Overview of Psychosis and Schizophrenia</p> <p>Objectives 1-3</p>	<ul style="list-style-type: none"> ○ Introductions ○ Discussion of ground rules ○ Lecture/discussion ○ Define psychosis & schizophrenia, causes & treatments ○ Define recovery (incl. statistics) ○ Treatment – brief review of treatments, mental health system ○ Video: Schizophrenia symptoms, causes & treatment https://youtu.be/PURvJV2SMso 	<p>May choose to show one of these videos:</p> <ul style="list-style-type: none"> ○ What is Psychosis? https://youtu.be/RRGGxK3OpNc ○ Avatar therapy https://youtu.be/4Gmp9llLUx4 ○ Personalized medicine (CAMH) http://www.canbind.ca https://www.facebook.com/watch/?v=695065870517107 	<ul style="list-style-type: none"> ○ Schedule & ground rules ○ Confidentiality agreements ○ Participant Notes (key points of presentation & relevant resources)
2	<p>Living with Psychosis and Schizophrenia (part 1)</p> <p>Objectives 4-7</p>	<ul style="list-style-type: none"> ○ How to communicate with someone in acute psychosis ○ How do I get my loved one to accept treatment? ○ The LEAP approach video: clips from Dr. Amador's TedX talk https://youtu.be/NXxytf6kfPM ○ Example of LEAP Approach https://youtu.be/bSSFhVGu3nl ○ What supports are there for me? <ul style="list-style-type: none"> › Local supports & resources › Online: how to identify valid sites ○ Self care 	<p>Schizophrenia with substance use (4:37) https://youtu.be/bSSFhVGu3nl</p> <p>Living Well with Schizophrenia for a young woman's personal story and insights: https://www.youtube.com/channel/UCENqBBxNax3mLX_WGLf2Lg</p> <p>Optional videos:</p> <ul style="list-style-type: none"> ○ How do I get my loved one to go to therapy? https://youtu.be/uyCf6p4FChk ○ How to Help a Spouse with Schizophrenia https://youtu.be/XKdsQAGTzwY ○ It's Not About the Nail https://youtu.be/4EDhdAHrOg 	<ul style="list-style-type: none"> ○ Participant Notes ○ Local supports and resources ○ Questions to ask the psychiatrist (handout available under session 2 materials)

Week	Topics & Objectives	Activities/Content	Options/Variations	Handouts
3	<p>Managing Crises</p> <p>Objectives 5,7,8</p>	<ul style="list-style-type: none"> ◦ Substance use ◦ Suicide ◦ Disturbed behaviours, especially aggression ◦ Dealing with police ◦ Involuntary assessment/admission ◦ Crisis resources ◦ Understanding the link between violence and mental health (2:57) https://youtu.be/FA2KJoZhSJw ◦ Emerging from Fear video to Activities: https://youtu.be/kn2wH5_5xH4 	<p>Videos:</p> <ul style="list-style-type: none"> ◦ Drug Use Problems and Mental Illness: Co-Morbidity Explained https://youtu.be/5RbEotf0jql ◦ How to Support during Crisis Moments https://youtu.be/JYCruJsVzyk ◦ Understanding agitation: de-escalation https://youtu.be/i1D0tdiilskA 	<ul style="list-style-type: none"> ◦ Participant Notes ◦ Region-specific information (e.g. Manitoba Mental Health Act)
4	<p>Lived Experience & Recovery</p> <p>Objectives 9, 10, 11</p>	<ul style="list-style-type: none"> ◦ Lecture/discussion <ul style="list-style-type: none"> › What does recovery really mean? › What helps recovery? › What can families do to support the recovery journey? ◦ Relapse prevention plan ◦ Personal story 	<p>Optional videos if no person with lived experience available:</p> <ul style="list-style-type: none"> ◦ Recovery: Hope changes everything https://youtu.be/5Q2zkeirxK4 ◦ What does a person need in their environment in order to recover? (5:53) https://youtu.be/jalEW3yceOO ◦ When The Voices Fell Silent trailer (3:19) https://youtu.be/MxRqFl6MsYs ◦ Sean and Doris Miller: A Story of Hope (13:35) https://youtu.be/EDblspgSoc0 ◦ What is the evidence that people with schizophrenia can in fact recover? (4:25) https://youtu.be/cY9DNCnRzcU 	Participant Notes
5	<p>Building Strengths and Going Forward</p>	<ul style="list-style-type: none"> ◦ Self-care revisited ◦ What makes a family strong? ◦ Future planning: housing, finances ◦ Advocacy 		Participant Notes Relevant local resources



Delivery Readiness Checklist

3 Months Before the Program Begins:

- | | |
|--|--|
| <input type="checkbox"/> Determine start date and confirm with local organizations to avoid conflict with other programs | <input type="checkbox"/> Begin developing promotional material (ads, flyers, announcements, press releases) |
| <input type="checkbox"/> Confirm group facilitators | <input type="checkbox"/> Review each session and prepare or gather handouts with local information e.g. Manitoba Mental Health Act brochure. (See templates) |
| <input type="checkbox"/> Establish registration procedure (if online, ensure forms are on website and functional. | <input type="checkbox"/> Print and assemble the material for each facilitator |
| <input type="checkbox"/> Book facility/room | <input type="checkbox"/> Review the material |
| <input type="checkbox"/> Establish funding needs and pursue funding source(s) | <input type="checkbox"/> Contact potential guest speakers |

5 Weeks Before:

-
- Finalize promotional flyers and distribute to relevant sources
-
-
- Place information ads in community newspapers and with other local media (radio, television) Send out press releases to local media; follow up contacts to explore their interest in an article
-

2 Weeks Before:

-
- Check registration list for number of registrants
-
-
- Contact potential participants to review suitability of program (sample email in Appendix A) and complete registration form (Appendix B)
-
-
- Online delivery: see Appendix C for sample email.
-
-
- Confirm date based on registration; assess need for additional promotion
-
-
- Confirm guest speakers and meet with them to review what they will be presenting in their session. Review the content of the sessions with co-facilitator; confirm who will do what and decide on the flow of the program
-

1 Week Before:

-
- Contact group participants to remind them of the start date, time, and location and to confirm their attendance.
-
-
- Online delivery: send log-in instructions to registrants who have completed video conferencing and confidentiality agreements.
-
-
- Purchase supplementary materials, such as name tags and activity supplies
-
-
- Plan for refreshments
-
-
- Photocopy participant handouts
-

Delivering the Program: Before you Begin

Setting Up the Room

Arrive early to set up the room. Some things to consider:

- **Seating Arrangements:** Arranging chairs in a circle or around a table encourages discussion, equality, and familiarity.
 - › Are there enough chairs for each participant, facilitator, and guest speaker, if one has been invited?
 - › Can group leaders see one another so verbal and non-verbal communication cues can be assessed?
 - › Can all group members see one another when they're sitting down?
- **Refreshments:** Plan to have water, coffee and tea available, and make the necessary arrangements well before the meeting begins. Consider whether or not you will provide any snacks.
- **Equipment and supplies:**
 - › Are supplies readily at hand? Check for markers, whiteboards, flip-chart paper, etc.
 - › Will you need any equipment? Arrange for it and make sure that it works before the meeting.
- **Special Needs:** Do any group members have any special needs, such as mobility, hearing, or visual difficulties?
- **Climate:** Is the room too warm or too cool? Facilitators may want to ask group members at the beginning of the session.

Creating a Positive Group Environment

It is essential for group facilitators to set up a safe, positive, and predictable group environment from the very first group meeting. This will involve establishing guidelines, starting and finishing the group on time, and ensuring that time limits during the session are adhered to.

Initial Greetings

Greet each person by introducing yourself and welcoming them to the group. Provide them with the handouts for the session.

Establishing Guidelines

Guidelines help group members feel more comfortable with each other and become more connected and committed to the outcomes of the group. They help reduce the anxiety and insecurity group participants may feel upon coming into a new environment where sensitive issues or experiences may arise. See the Notes for Delivery for this session, for how to establish group guidelines and obtain confidentiality agreements.

Ensuring Confidentiality

Because of the stigma and discrimination attached to mental illness, some family members may come to the group concerned that what they say to group members could be communicated to people outside the group. It is important for the facilitators to communicate the seriousness of the confidentiality agreement and also to suggest ways of preventing a violation of the agreement. Before the program begins, facilitators should discuss what should happen if a group member does violate the agreement.

Group members should read, discuss, and then sign a written confidentiality agreement. This will eliminate conflict and increase the safe participation of all group members.

When facilitators meet with potential participants before the program begins, the importance of confidentiality should be addressed. In the first session of the program, each participant will sign a confidentiality agreement.

Tips for Facilitation

Coordinating the Presentation

You may have noticed that the notes for delivery (NFD) for each session follow the information in the participant notes and slides, with less detail in some areas.

- When a video is used to present content, that information does not need to be repeated by the facilitator. You may need to clarify some points or answer questions, but otherwise let the video speak for itself. Important information that we want participants to retain from videos is in their notes.
- Try to avoid just reading the slides and NFD in a boring lecture. Add your own examples and stories to liven up the material.
- Where it says "Discuss", open the floor for questions and comments.

Beginning and Ending Each Session

Check-in

Each group will begin with a check-in. The most common question used in the check-in is, "What is one thing you did to take care of yourself this week?" A question like this conveys the message that self-care is important. A check-in time can also provide group members an opportunity to raise questions that have come up during the week.

Check-out

Each PowerPoint presentation ends with a summary slide. Close the session with a brief summary of key points, a statement about the following week, and the mini-evaluation (optional). Allow 10 minutes for this closing sequence if doing the evaluations.

Always thank the participants and acknowledge their contribution to the discussions. Use the participants' feedback to make any necessary adjustments for the following week, and to improve the program the next time it is delivered in your community. If a group member feels that something is not working for them personally or that the group is not meeting their needs or expectations along the way, facilitators should encourage the group member to speak to them outside of group time.

Facilitating the Session

- Greet participants warmly at each session, making an effort to greet them by name

- Ensure your voice is clear and understandable

- Encourage participants to ask questions, and listen to their questions

- Invite the equitable participation of all present

- Treat all participants with respect and patience

- Manage group time effectively, being mindful of start, break, and finish times

- Slow down when discussing complex and difficult topics; use questions to verify comprehension

- Be well-prepared and organized for each session, and familiar with the activities, handouts and discussion topics

- Be aware of what material has been covered in previous sessions

- Take time to clarify difficult topics

- Help families learn from one another by encouraging them to come up with solutions to shared problems

- Clearly stress the main points at the end of each session

- Share your stories and experiences wisely, always maintaining the focus on your role as a facilitator and not a participant

- Create a safe environment by ensuring that everyone has an understanding and agreement on the importance of confidentiality

- In face-to-face sessions be sure to provide refreshments – coffee/tea, juices, water and a healthy snack.

Managing Challenges in the Group

No One Talks

People may be shy about speaking up. Some tips for generating discussion are:

- Pair-share: ask participants to discuss the topic or question with their neighbour for 1-2 minutes, then invite sharing with the larger group. This enables people to open up more and not feel like they are being put on the spot.

- In online sessions, use the breakout room feature to create small groups or pairs.

- Use a talking stick or object that is passed around the room. Whoever has the talking stick discusses the question or can pass if they so wish. In this way everyone has an opportunity but are not being pressured to speak.

- Provide scraps of paper or index cards for people to write their questions or ideas on. Collect these at a break and respond to them after the break. In this way participants can speak up anonymously. If any comment or question seems to require more of a response than you have time for, read it out and invite the person who wrote it to speak with you after the group.

- If you notice someone never speaks, ask them directly if they want to add anything to the discussion. If they say no, respect that, but continue to offer them opportunities.

Angry Person

You may have people in the group who are frustrated and angry with their experiences in the mental health system, or with their family member. If you aren't careful, the group can get swept up in this and the session deteriorates into complaining and anger. Your goal is to maintain a safe environment for people to express their feelings and be supported in constructive ways. Some things you can do:

- Include this in your group guidelines – what can the group expect you to do if there is a lot of anger or frustration being expressed?

- Listen and allow venting, up to a point.

- Acknowledge how frustrating the system can be.

- Briefly speak to their concerns by offering some resources or options.

- State that these are valid issues, and you do plan to address them; however at present you'd like to keep on track with the presentation.

- Offer to talk more with them during the break

Dominant Person

Sometimes one person will talk a lot, and there is little opportunity for others – including the facilitators! Strategies for this are:

- State in your introduction that you may ask someone to hold back so that others will have a chance.

- Agree on a "time-out" signal.

- Listen to their story up to a point, then give the signal, acknowledge what they have said, and move on.

- You can say "hold that thought" or "what you are saying is important, and I hate to cut you off but we do have a lot to cover".

Other Challenging Behaviours

Behaviour	Motivation	What to Do
Overly talkative/ interrupting	May be a show-off or “eager beaver.” May be well-informed	Interrupt by acknowledging their point, then turn it over to the group
Argumentative or hostile	May have a gruff personality. May be naturally good-natured but upset by a particular problem	Keep your cool. Find merit in one of their points and move on. Talk to the person privately during a break to find out what is really bothering them. Turn discussion back to group, Does anyone else have some thoughts on this?
Overly helpful	Really trying to help. Keeps others out of the conversation	Thank the person. Use their points to summarize discussions Need a line
Rambling	Talks about everything except topic at hand. Uses unusual analogies and gets lost	When the person stops, refocus on the relevant points and move forward. Indicate that while their point is interesting, it is a bit off track
Personality clashes within the group	Two or more participants clash. Can divide the group into factions	Emphasize points of agreement and minimize points of disagreement. Ask that people set aside personal differences
Won't participate	Bored, indifferent, timid, shy, or feels superior	Arouse interest by asking for the person's opinion. Ask all participants one-by-one to comment
Negativity/complainer	Everything is wrong or bad	Ask if person can find anything positive in the situation and how to cope with issue



Session 1: Introduction and Overview of Psychosis and Schizophrenia



Objectives:

At the end of the session, participants will be able to:

1. Be more comfortable with one another and establish group norms
2. Define psychosis and describe its symptoms, course, prognosis, possible causes, and biopsychosocial-spiritual management
3. Identify how culture and context influence the understanding and management of psychosis
4. Describe ways to communicate with a person experiencing acute psychosis
5. Identify the role of the Mental Health Act in regulating mental health admission and treatment

Local Materials:

- o Information on local resources and mental health act

Remember to open your browser to YouTube, and have the video playlist loaded before you start.

Outline:

Note: Times are approximate to allow flexibility for questions and discussion.

Topic/Activity	Time	Materials
Welcome & Introduction to Program	20-30 min	Program schedule & guidelines Confidentiality agreements
Psychosis & schizophrenia <ul style="list-style-type: none">o Definitions, prognosis (hope for recovery)o Symptoms & causeso Stress-vulnerability model	30 min	Index cards Participant Notes Videos: <ul style="list-style-type: none">o What is Psychosis?o Schizophrenia symptoms, causes & treatments
Break	10 min	
<ul style="list-style-type: none">o Treatment overviewo Mental health system introductiono Communication tips	50 min	Participant Notes Video: one of the optional videos if time permits

Online Delivery:

- Registration, confidentiality & agreement for video conferencing must be done prior to sending log in information to participants, so these only need brief review in this session.

- Advise participants that room will be locked after everyone is there, or 15 minutes into session, to preserve privacy.

- Use online whiteboard instead of index cards

- See Appendix C for more details.

NOTES FOR DELIVERY**Slide 1: Title Slide****Introduction to the Program**

- Welcome participants

- Acknowledgement of traditional First Nations/Inuit/Metis territory

- Introduce yourself – why you became involved in the program

- Invite group to introduce themselves to each other – write names on a paper for yourself or provide table name cards or nametags

- Housekeeping – when will break be, refreshments, washrooms

This is a national program of the Schizophrenia Society of Canada. Its overall goal is to improve the quality of life for families as well as for the family members who experiences psychosis.

Note: *This is a general educational program. We may not be able to advise you on specific situations.*

Hand Out and Review Schedule and Guidelines and Confidentiality Forms

- Why do we need “ground rules” and confidentiality agreements?

- Sensitivity of topics

- Personal information

- Need for all to feel comfortable and safe in discussions





Discuss:

1. **Facilitator's Role:** To offer information and invite group's input. Also keep things on track and maintain safety of group, so may cut off lengthy stories or discussions, or ask someone to tone it down. Facilitator is here as an educator, not as a therapist. If consultation is needed on specific concerns, may refer to Schizophrenia Society or other local resources.
 - a. Co-facilitator or co-host (online) – introduce and discuss their role.

2. **Drop-ins:** This is a closed group – only people who have registered should attend. However, if someone wants to bring another family member to a later session, is that okay with the group?

3. **Confidentiality:** Review confidentiality agreement and get signatures (note: drop-ins should also sign)

4. **Discussions:** Share air time. Okay to express feelings but maintain control.

5. **Respect:** Be supportive of each other, respect differing opinions (note: facilitator must model this!)

Ask:

What other guidelines should be in place for you to feel safe and comfortable in this group?

Slide 2: What is Psychosis?

Do activity first, then show video

Activity: Provide each person with an index card. Instructions to participants:

- Write a word or draw an image that comes to mind when you hear the word "psychosis".

- Discuss this with your neighbour (2 min).

After 2 minutes, ask for volunteers to share their ideas. Write these on the flipchart or whiteboard.

Slide 3: What is Psychosis?

Discuss Key Points:

- Themes that emerge (e.g. Are all the words scary and negative?)

- Psychosis occurs when a person finds it difficult to tell what is real from what is not real.

- It is a set of symptoms that can occur in a variety of situations, not only schizophrenia
 - > Symptoms are delusions, hallucinations, and problems in thinking and behaviour

 - > May be short term, or may last for years, depending on its cause

 - > We have a North American/European understanding of psychosis. What are other ways that different cultures might explain psychosis?



Facilitator Resource:

- The following points come from a review by Laroi et al (2014) Culture and hallucinations: overview and future directions. Schizophrenia Bulletin, 40(Suppl_4), S213-S220. https://academic.oup.com/schizophreniabulletin/article/40/Suppl_4/S213/1874317
 - > Culture can affect what is identified as a hallucination (what is “reality”, what is unusual or bizarre).
 - > Hallucinations occur at different rates in different cultural settings.
 - > Culture affects the meaning and characteristics of hallucinations (e.g. what voices say, how threatening they are, whether they are voices of people they know, etc.)
 - > Hallucinations are often culturally meaningful (e.g. contact with gods, spirits or the dead). They must be understood in the context of local beliefs and practices.

Facilitators are encouraged to read the Laroi article for more examples of cultural variations in psychosis.

Slide 4: What is Recovery?

Activity Instructions:

- Turn your index card over
- Now write a word or draw an image that you associate with recovery
- Discuss with your neighbour

After 2 minutes, ask for volunteers to share their ideas. Write these on the flipchart or whiteboard.

Ask:

- Is it difficult for people to associate recovery with psychosis or schizophrenia? Why is that? (media messages, don't know anyone who has recovered, etc.)
- Did you know?
 - > 50-60% recover to a significant degree.
 - > Many studies have found that with appropriate treatment and support, up to 2/3 can be free of psychosis!

Slide 5: The New Mantra – Psychosis is Treatable, Recovery is Expected

Key Points:

- Recovery is more possible today than ever before!
- Even people with severe lifelong disability can have significant improvement in functioning and quality of life with modern treatment and rehabilitation.
- Cognitive impairment predicts functional outcomes better than symptoms.

- Personal and social functioning determine the degree of disability.
- Culture can also influence recovery – how much a behaviour or symptom is tolerated, for example.
- Recovery means different things for different people.

Slide 6: The Schizophrenia Spectrum

Explain Slide:

- SZ is a syndrome, in which different people have different experiences. We also now see it as part of The Schizophrenia Spectrum – mental disorders in which psychosis is a primary feature.
- We will talk about what is currently known about schizophrenia, but you should be aware that research is ongoing and new discoveries are being made all the time.
- The video you are about to see will explain schizophrenia in some detail. We will pause at intervals to discuss what it is saying. You can follow along in your notes if you wish.



Facilitator Resource:

For up-to-date summaries of new research, go to:

- DSM-5 updates <https://www.psychiatry.org/patients-families/schizophrenia>
- Science Daily https://www.sciencedaily.com/news/mind_brain/schizophrenia/

Slide 7: Schizophrenia Symptoms, Causes and Treatments

Video Part One:

Schizophrenia Symptoms, Causes and Treatments (to 4:08) <https://youtu.be/PURvJV2SMso>

Pause Video: at 4:08 to discuss symptoms.

Explain:

- Temperature regulation is impaired, so wearing multiple jackets on a hot day is not really bizarre or purposeless, but because of this impaired “thermostat”.
- Note that delusions may be an attempt to explain hallucinations or inner experiences.
- Correction: “flat” affect is lack of response. “Inappropriate” affect is an odd response, such as laughing at sad news.
- Note that video states people “cycle through” 3 phases, but in fact the “prodromal” phase is only before the first acute episode.
- Prodrome is easy to miss, often looks like normal teenage behaviour.
- We prefer to call the residual phase the recovery phase. What this video omits is that many people do in fact recover.

Video Part 2 from 4:08 to End:

- Clarify what the DSM-5 is (if you want to learn more about the DSM-5 for yourself, go to <https://www.psychiatry.org/patients-families/understanding-mental-disorders>)

**Facilitator Resource:**

- Cultural differences might influence the diagnosis of psychosis, even when using the same diagnostic criteria.
 - > A comparison of psychiatrists in India and the USA found differences in which symptoms were given the most weight when diagnosing depression and mania. There was agreement on the top four symptoms of psychosis. https://www.researchgate.net/publication/304713952_Cross_Cultural_Variations_in_Psychiatrists%27_Perception_of_Mental_Illness_A_Tool_for_Teaching_Culture_in_Psychiatry
- Vulnerabilities to schizophrenia are likely to be diverse, involving genetic factors interacting with environmental risk factors at crucial phases of development.
- Some researchers suspect neurotransmitters or nerve cells within the brain may be involved for certain subtypes of schizophrenia. Other researchers suggest certain proteins may increase the risk of certain types of schizophrenia.
- Prenatal infection or genetic mutation may create biological vulnerability to psychosis.

Slide 8: Causes – Biological Vulnerability**Discuss:**

Schizophrenia spectrum disorders have underlying biological abnormalities. Refer to Participant Notes for details.

Key Points:

- Both brain structure and function show impairment.
- The precise causes of schizophrenia are still unknown, but are likely to be diverse.
- Brain dysfunction leads to increased vulnerability to stress.

Emphasize: Both vulnerability and stress must be addressed!

Slide 9: The Stress-Vulnerability Model



Discuss:

- Vulnerability is due to genetics, prenatal infection, etc. (note: impaired function of HPA axis means increased vulnerability to stress).

- Stress related to expectations, environment, etc.

- These work together to increase or decrease the likelihood of illness as follows:

- High vulnerability + high stress = ill

- High vulnerability + low stress = may be well or only mildly disabled.

- High stress + low vulnerability = ill (perhaps brief psychotic episode).

- Low stress + low vulnerability = well.

- Treat vulnerability with medications and other physical therapies (nutrition, etc.).

- Treat stress with psychosocial and spiritual strategies (cognitive-behavioural therapy, etc.).

Slide 10: Tips for Communicating with Persons Experiencing Acute Psychosis

- **Briefly Review:** These are listed on the slide and detailed in participant notes.

- **Key Points:** remaining calm, neutral and supportive.

- Next week will have a heavy focus on communication.

Slide 11: Co-Occurring Disorders

Briefly Review: Note that issues such as suicide will be addressed in Session 3 so avoid spending too much time on them now.

Key Points:

- Physical health is affected by social and environmental factors, medication side effects, or the illness itself.

- Important to have a family doctor, dentist, etc.

- Vulnerability is a significant concern (will discuss violence risk in a later session, for now emphasize that most persons with psychosis are not violent; more likely to be assaulted by someone who is under the influence of alcohol).

Optional Video: (2:12) Schizophrenia, comorbidities and suicide <https://youtu.be/eNNtOb7neM4>

Slide 12: Treatment Approaches

These are detailed in the Participant Notes.

Key Points:

- Treatments include biological (e.g. meds), psychological (e.g. CBT) and social (e.g. psychiatric rehabilitation). Persons who live with psychosis are also at high risk of other psychiatric and medical conditions and may also include spiritual activities.

- Important to have a wholistic approach

- New treatments are being researched

Slide 13: The Future of Treatment for Psychosis

New Research Directions: (details are in Participant Notes)

- Virtual reality or avatar therapy: the person learns to control hallucinations by controlling an online “avatar”

- Personalized medicine: medications are tailored for the individual based on their DNA. <https://www.facebook.com/watch/?v=695065870517107>

- “Nutraceuticals”: Nutrition is being hailed as the “future of psychiatry”. Research shows a number of mental health benefits from nutrition. More information on nutrition can be obtained at <https://ca.ctrinstitute.com/blog/food-for-thought-nutrition-impacts-on-mental-health/>.

Slide 14: Avatar Therapy video (optional)

Show video if time permits. Preface it with a warning – the avatar is kind of creepy at the beginning!

- Video is 3 minutes 45 seconds (3:45); <https://youtu.be/4Gmp9llUx4>

- Alternate shorter video (1:51); <https://youtu.be/ualyndhm5eo>

Slide 15: Personalized Medicine (optional)

- Genetic clinic at CAMH <https://youtu.be/hDJnql074Ew>

32

60

Slide 16: Understanding the Mental Health System

Note: Inform participants that this will be covered in more depth in a later session.

**Image on slide is from Manitoba Mental Health government website – replace it with one relevant to your region if you so can.*

Provide local handout on Mental Health Act in your region.

Key Points:

- Every province/territory has its own version of a Mental Health Act. These are similar but may have some important differences.

- The information we are providing does not constitute legal advice.

- Mental Health law attempts to strike a balance between individual autonomy and the good of the person or community. In the past there have been abuses of power where people were “committed” to hospital for things like being an unwed mother. That is why the criteria are so strict.

- Psychiatrists can only admit a person to hospital if strict criteria are met. This is where your information can be very useful. If you can provide what is called “collateral” information about what you have been seeing, that will help the psychiatrist make their decision.

Briefly Discuss: The Mental Health Act in your region – it may work best to do this as a question and answer session.



Facilitator Resources: For specific information about the law in your region, see:

- This list of legislation relevant to mental health and disability in Canada, from the Canadian Civil Liberties Association <https://ccla.org/an-overview-of-relevant-legislation-related-to-mental-health-and-disability/>

- Involuntary hospital admission of mentally ill people and length of stay: <https://www.legalline.ca/legal-answers/involuntary-hospital-admission-of-mentally-ill-people-and-length-of-stay/>

- <https://www.priv.gc.ca/en/about-the-opc/what-we-do/provincial-and-territorial-collaboration/provincial-and-territorial-privacy-laws-and-oversight/>

- Patient rights
 - > Ontario: <https://www.camh.ca/en/your-care/your-rights/bill-of-client-rights>

 - > Manitoba: <https://web2.gov.mb.ca/bills/39-3/b230e.php>

 - > Saskatchewan: <http://publications.gov.sk.ca/documents/13/99258-Your%20Rights%20Fact%20Sheet.pdf>

 - > BC: https://www.interiorhealth.ca/YourCare/MentalHealthSubstanceUse/MentalHealth/Documents/Survival%20Kit_YourRightsasaPersonwithMentalIllness.pdf

- Family involvement policies - Vancouver Mental Health has a Family Bill of Rights <http://www.spotlightonmentalhealth.com/family-bill-of-rights-4/>

Slide 17: Families in the Mental Health System

Key Points: The goal of our mental health system is to support, educate and partner with families.

- Changing a big system takes time, but the expectation is that the family needs are addressed.

- We will look at this in detail in Session 5.

Slide 18: Navigating the System

Refer to participant notes and emphasize key points:

- Knowledge is power – learn as much as you can

- If you are providing care, you may have a legal right to whatever information you need in order to do that.

- Hospitals and doctors may be bound by privacy laws about what they can tell you, but there is nothing to stop them from receiving information from you!

- Power of attorney or “psychiatric living will” can reduce crises – we will talk about this more in Session 3

- Bottom line: Medical personnel should be working WITH you AND your family member; it’s supposed to be a partnership. These tips may help you to achieve that.

Slide 19: Check-out

Thank you for coming! Next week’s topic is...

Evaluation

Provide **10 minutes** at the end of the session for participants to complete an evaluation form, with instructions to send it in to their facilitator.



Session 2: Living with Psychosis and Schizophrenia



Objectives:

At the end of the session, participants will be able to:

1. Problem-solve some of the common issues in family life
2. Describe ways to communicate with a person experiencing psychosis
3. Identify the steps of the LEAP approach
4. Use a strength-based, recovery-oriented approach to managing the impact of illness
5. Develop a self-care plan

Materials:

- o Participant Notes
- o Brochure: Questions to Ask the Psychiatrist
- o PowerPoint with video

Local Materials (in box)

- o List of resources and supports in your area.

Outline:

Topic/Activity	Time	Materials
Introduction/Check-in	15 min	
Common issues in family life	40 min	Participant Notes Videos: the LEAP approach, and Schizophrenia and Substance Use
Break	10 min	
Finding and accessing supports	20 min	Participant Notes List of local supports Questions to ask the psychiatrist
Looking after yourself	20 min	Participant Notes
Check-out	10 min	



Notes for Delivery

Slide 1: Title slide

- Greet participants. Check-in – How was your week?
- Provide handouts

Slide 2: The Impact of Psychosis on the Family

Today we will look at some of the most common issues facing families. All of these are common experiences. We will look particularly at Communication & Conflict, and Isolation

Slide 3: Everyone is Impacted Differently

Key Point: Each person in the family will be affected differently. We can't assume everyone sees things the same way.

Resource for detailed info on this: <https://www.heretohelp.bc.ca/sites/default/files/family-toolkit-module-4.pdf>

Slide 4: Fractured Relationships: The Treatment Battle

This section addresses the Communication and Conflict impact that commonly occurs.

Explain: Cartoon shows two people looking at the same thing and seeing it differently. This is often the core problem when we disagree with our loved one about treatment. They have a different perspective on it than we do – for example, they may find medication side effects distressing, or feel like we are trying to control them.

Slide 5: Arguing About Treatment: How We Go in Circles

Slide shows circular interaction pattern. EXPLAIN in a **non-blaming** way how this pattern develops. A **well-meaning** attempt to get a person to accept treatment contributes to resistance. Emphasize:

- It is very common for families to get stuck in a pattern of trying to persuade someone to accept treatment. We end up going in circles with everyone getting more and more frustrated.
- Do not beat yourselves up for this! You have been doing the best you can with what you knew at the time.



Discuss: What other thoughts might people be having when they are stuck in this pattern?

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.

Slide 6: A Better Way: The LEAP Approach

Dr. Xavier Amador has developed an approach which changes these conversations to be more supportive and more productive. He explains this approach in this video. <https://youtu.be/NXxytf6kfPM>

Video Part 1: Dr. Amador (start at 1:20, stop at 8:28 for discussion of anosognosia; ASK:

- Have they heard of anosognosia before?
- How does knowing this change how you might view your loved one's behaviour?

Video Part 2: Restart and play to end of video

- Follow with discussion –
- ASK: How would adopting this approach change your relationship with your loved one?

Strategies for Encouraging Collaboration with Treatment (in Participant Notes)

- Have the group read these and then ask which ones seem most do-able for them.
- Emphasize that we are not talking about "compliance" but collaboration – engaging the person as an active participant in their own recovery.
- Participant Notes also include other tips for managing problem behaviours. Reminder that patience is key and we cannot ultimately control what other people do.

Optional Video: How do I get my loved one to go to therapy? (3:56) <https://youtu.be/uyCf6p4FChk>

Slide 7: Strategies



Discuss strategies regarding:

- | | |
|--|---|
| ○ Encouraging Collaboration with Treatment | ○ Social Withdrawal and Isolation and Isolation |
| ○ Bizarre or Unusual Behavior | ○ Hygiene and Appearance |

Refer to Participant Notes for details of strategies for these four common concerns. Invite participants to offer other ideas they may have found helpful.

Slide 8: Example of LEAP Approach

Video: Schizophrenia and Substance Use (Distance Learning Australia). Introduce by stating that there are two scenarios – first is someone not using the LEAP approach and in the second scenario she does use it. Observe how the different approaches elicit different responses.

<https://youtu.be/bSSFhVGu3nl>

Slide 9: Overcoming Isolation

Discuss: Isolation and lack of support are big barriers for families. Some of this is due to stigma, but also to the individual-focus of our legal and health care systems.

We will talk about family-centred mental health services in session 5, so don't spend too much time on it here.

Slide 10: Identifying Your Supports

Discuss: Local supports – if desired, go online and show them. For example:

- o Manitoba <https://mbwpg.cmha.ca/links/>

Hand Out: A local resource guide (prepare a local resource guide if one is not readily available for handout).

Exercise: Instruct group to use the back of the participant notes:

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

Ask and Discuss:

- o Which of these are most helpful to you?
- o Which way does energy flow? i.e. are you putting more into any of these than you are getting back?
- o What supports have you used in the past that you could access now?
- o What stops you from using supports?



Slide 11: Online Supports

Discuss:

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?

Refer people to the list of recommended websites at the end of their Participant Notes.

Slide 12: HON Foundation

- Show participants how to 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>
(Under Patient/Individual, choose HONcode, and then on the left side menu choose HONcode principles.)

Slide 13: Caring for Yourself

Discuss:

- It is common for families to let their whole lives revolve around the illness.
- We need to ensure that we remain healthy and get our own needs met.
- Take time to consider what kinds of things you can do to look after yourself.
- Some families resist the concept of self-care as they feel that the system dismisses their needs, does not provide enough support, and just says “do self-care”. Discuss this if it seems appropriate.

Slide 14: A Self-Care Action Plan

- <https://www.youtube.com/watch?v=w0iVTQS8ftg>

- Use the following questions for optional small group discussion (suggest group discuss ONE question if doing online since they can't see the slide once they go to breakout rooms):

- > What do you do to take care of yourself?

- > What did you used to do, and could do again?

- > What is something new you could do?

Slide 15: Creating a Self-Care Plan

Review: The self-care plan which is in their notes

Self-Care Plan: Assign as “homework” – there likely will not be time to work on it in the session.

Slide 16: Conclusion

Next session.

Evaluation

Provide **10 minutes** at the end of the session for participants to complete an evaluation form, with instructions to send it in to their facilitator.



Session 3: Managing Crises



Objectives:

At the end of the session, participants will be able to:

1. Identify risk factors, warning signs, and strategies for managing crises related to substance use, suicide or aggression
2. Identify local resources to access in case of crises
3. Develop a crisis plan for their family

Materials:

- o Participant Notes
- o PowerPoint with video(s)
- o Optional: WRAP personal crisis form from mentalhealthrecovery.com

Topic	Activity	Time	Materials
Check-In	Round table	15 min	
Substance Use	Present slides 1-10 first	30 min	Participant Notes
Break		15 min	
Suicide	Present slides 13-15 briefly Video (7:11) Discussion	20 min	Participant Notes List of local supports Questions to ask the psychiatrist
Aggression	Videos (2:57) and (7 min) Discussion	20 min	Participant Notes
Family Crisis Plan	Individual reflection – take this home as homework	10 min	
Check-out		10 min	

Important: The videos and discussions of what to do will be the most important – avoid spending too much time presenting statistics or facts that are in their handouts, which they can read later.

Provide a trigger warning before discussion of suicide in particular. You may choose to talk about suicide and aggression first, so people can decompress during the break. In online delivery, advise people that they can take their own break during the suicide presentation if needed. Allow time for debriefing and discussion after this section.

Notes For Delivery

Important: there is a lot of detail on this session in the Participant Notes. Refer to them as needed.

Slide 1: Title Slide

- Check-in: How did you do with your self-care plan?
- Introduce the session – topics will include substance use, suicide, aggression, and how to create a family crisis plan.

Slide 2: Emerging from Fear

Instructions: Before showing this video, briefly discuss how fear and anxiety can be part of the family's experience. This video shows one woman talking about how her family were able to get past the fear. She notes that it took them several years, but please be aware that times vary widely, and it may not be that long for your family.

Slide 4: Substance Use

Define: Concurrent disorders – person lives with both a mental illness and a substance use disorder

- OPTIONAL VIDEO: Drug Use Problems and Mental Illness: Co-Morbidity Explained
<https://youtu.be/5RbEotf0jqI>

Key Points from Participant Notes:

- High risk for persons with psychosis to also have substance use problems
- Alcohol is the most commonly abused substance, followed by whatever is most available

Slide 5: Which Came First, the Substance Use or the Psychosis?



Discuss:

- It is most useful to think of these as independent problems that interact with each other.
- Substance use increases risk of psychosis.
- On the other hand, problem substance use may follow the onset of a psychotic illness and can be an attempt to deal with certain psychotic symptoms.



Slide 6: Why do People with Psychosis use Substances?

Key Points:

- The same reasons as everyone else

- “Primary addiction theory” suggests there may be a common cause of both psychosis and substance-use disorders.

- People with psychotic illness may use substances to “self-medicate” as a coping mechanism

- Risk factors can be identified

If time permits, discuss the Common Misconceptions and “True Picture” listed in Participant Notes.

Slide 7: The Impact of Substance Use

Key Points:

- Psychosis and substance use interact with one another to make each diagnosis worse.

- Chart in Participant Notes lists how both family and the individual can be affected.

Slide 8: Signs That Your Relative May Have Problem Substance Use

Key Points:

- Any change in a person’s behaviour can be an indicator (see list in Participant Notes).

- Because it is difficult to distinguish between a toxic psychotic state (brought on by drug use) and a first episode of psychosis, it is always a good idea to seek help from a professional.

Slide 9: Specific Substances

Key Points:

- Participant Notes have brief summary: Note that more detailed information can be obtained from the CAMH website

- Alcohol and Marijuana are most commonly used

- There have been a number of studies on cannabis and psychosis. This website has excellent information and resources for families and young people <https://cannabisandpsychosis.ca>

- Cocaine, methamphetamine and hallucinogens are also dangerous

- <https://www.camh.ca/en/health-info/mental-illness-and-addiction-index/cocaine>

- <https://www.camh.ca/en/health-info/guides-and-publications/straight-talk-methamphetamines>

Slide 10: How are Concurrent Disorders Treated?

Key Points:

- Early intervention programs have been shown to be effective in reducing both problem substance use and psychotic symptoms.
- The best approach for individuals with concurrent disorders is to combine treatment of both conditions together. This is called integrated treatment.

Slide 11: Integrated Treatment in Your Region [placeholder slide]

Insert information about programs in your community. The Manitoba CODI program is shown here as an example.

Slide 12: Helping your Family Member Get Help

The decision to seek help for a relative or friend can be a difficult one for many reasons.

Review strategies in the Participant Notes.

Slide 13: For More Information

Point Out: schizophreniaandsubstanceuse.ca (an SSC site) and the other sites listed in their handout.

If you have an Internet connection, and time permits, you may choose to actually go to one or more sites and surf them a bit, to demonstrate what is there.

Slide 15: Suicide

Trigger Warning: participants may go for a break if they anticipate this will be too difficult for them.

Key Points:

- A leading cause of death in schizophrenia
- May be deliberate and planned, or impulsive, accidental, or a response to command hallucinations
- Always has a devastating impact on family and friends

Slide 16: Risk Factors

Review: (on slide and in Participant Notes)

- Young, male, newly diagnosed and/or newly discharged from hospital most at risk
- Remission or newly discharged – may have realized they have illness, but do not yet have hope
- Social isolation significant
- Importance of providing hope, teaching about recovery, finding supports

Slide 17: Warning Signs of Suicide



Discuss:

- Sometimes you can detect these signs
- Sometimes there is no warning, such as with command hallucinations or impulsive acts
- The video we will see next will talk about some of the things you can do

Slide 18: VIDEO: Caring for Someone Who is Suicidal

Show Video and Discuss: Several of the points in the next two slides will be addressed in the video https://youtu.be/JXo7k0hDF_I

Slide 19: What to Ask



Discuss:

- Don't be afraid to ask!
- Ask about ideation, plan, access to means, intent, gestures, attempts
- Ask about command hallucinations (questions in handout) even though this is a less common cause.
- If you have any concern at all, seek help. Don't try to handle it alone.

Note: some families may feel this is not something they can do. You may choose to discuss this as what health professionals will ask – families may only ask if the person feels suicidal and then contact a crisis line or health professional for assistance.

Slide 20: VIDEO: Suicide: How to Support During Crisis Moments

Instructions: Acknowledge to participants that this is a scary subject. This video will describe practical things you can do if someone is suicidal. It offers encouragement and hope.

<https://youtu.be/JYCruJsVzyk>

Slide 21: What to Do if Someone is Suicidal

Review Information in Participant Notes:

- Talk about it.
- Get help immediately – mobile crisis team, suicide hotline or 911 depending on situation.
- Be supportive.
- An important note: Occasionally, a suicide occurs without warning and nothing can prevent it from happening. Also consider seeking help for yourself, as you may have experienced intense anxiety and worry from this incredibly stressful situation.

Slide 22: What to Do if Someone is Missing

Explain Slide: Sometimes people go missing and it turns out that they have died by suicide. This guide was created by the family of Arun Sud in Manitoba, after his death, to help other families in similar situations.

Slide 24: Aggressive Behaviour



Discuss:

- Although most people with psychosis are not aggressive, for some this can be a significant concern.
- Aggression may be a response to fear or feeling threatened. The person feels they must protect themselves. Or they may be acting on delusional beliefs or command hallucinations. Agitation is NOT aggression but can escalate to it if not able to calm self.
- It is important that families know they can and must make their own safety a priority. The tips in the handout are from <https://www.earlypsychosis.ca/aggression/>

Optional Video: Understanding the link between violence and mental health (2:57) <https://youtu.be/FA2KJoZhSJw>

Slide 25: What to Do

Video: Understanding agitation: de-escalation – stop at last minute when he starts talking about staff. https://www.youtube.com/watch?v=6B9Kqg6jFel&feature=emb_title



Discuss Key Points: (details are in their notes):

- Safety is first priority
- Activate your crisis plan
- Calm the person by giving them space, ensure exits aren't blocked, be as calm and non-threatening as you can be (lower your voice, etc.)
- After everyone is calm, discuss what happened, plan for future

Slide 26: When the Police Get Involved



Discuss:

- It's normal to be reluctant to involve police, however sometimes it is the only choice
- See the tips for phoning the police in Participant Notes; following these can help things go more smoothly

Slide 27: Local Resources [placeholder slide]

Insert information about local resources. The Vulnerable Persons Unit of the Winnipeg Police Service is used as an example.

Slide 29: Creating a Family Crisis Plan

Key Points:

- Having a plan will help everyone to manage the crisis
- The person who experiences psychosis should be involved in planning; this will increase its effectiveness.
- The plan can include things to do early on, to prevent a situation from escalating into crisis

Review the Planning Process in Participant Notes: Assign it as homework

Slide 30: WRAP Wellness Recovery Action Plan

Describe: This form is downloadable from [mentalhealthrecovery.com](https://www.mentalhealthrecovery.com). It is longer and more detailed than the form in the Participant Notes. <https://www.wellnessrecoveryactionplan.com/what-is-wrap/>

- There is also a **Family WRAP** - for more information see this link: <https://www.wellnessrecoveryactionplan.com/living-a-family-wrap/>
- The Mental Health Commission of Canada has a link to **FRAP- Family Recovery Action Plan** (FRAP): <https://www.wellnessrecoveryactionplan.com/bookstore/>

Slide 31: Conclusion

Next session.

Evaluation

Provide **10 minutes** at the end of the session for participants to complete an evaluation form, with instructions to send it in to their facilitator.

Session 4: Lived Experience and Recovery



Objectives:

At the end of the session, participants will be able to:

1. Use a strength-based, recovery-oriented approach to managing the impact of illness on their family.
2. Develop a relapse prevention plan for their family.

Materials:

- o Participant Notes
- o PowerPoint with video(s)

Note: guest speaker – reorganize your slides as desired. Your guest may want to speak before you do.

Option: Invite two guests – one person with lived experience and one family. If you do this, you don't need to present any of the slides, just invite the speakers to tell their stories, and facilitate discussion with the group.

Topic /Activity	Time	Materials
Recovery story Guest speaker & discussion	50 min	If no guest, show video Hope for Recovery and discuss.
Break		
Recovery: Destination or Journey?	5 min	Participant Notes
What is the Evidence?	10 min	Optional Video: What is the Evidence that People with Schizophrenia do Recover?
Dimensions, phases, who & how of recovery	15 min	Participant Notes
How families can support recovery	15 min	Participant Notes
Relapse prevention planning	5 min	Participant Notes
Conclusion	5 min	



Notes For Delivery

Slide 1: Title Slide

Check-In

Slide 2: Recovery Journey

Guest Speaker: Make every effort to find a person with lived experience to tell their story! This is the most meaningful and powerful part of the entire program.

The story can be up to 30 minutes in length and should address:

- What was the experience of psychosis like for them?

- What has helped them on their recovery journey?

- What was the most helpful thing that family (or anyone else) did?



Discussion: Prepare your guest ahead of time to take questions.

- Guide the discussion to ensure it remains respectful.

If no guest is available show **video:**

- Recovery – Hope Changes Everything (16:19) <https://youtu.be/5Q2zkeirxK4>

Optional Videos:

- What does a person need in their environment in order to recover? (5:53) <https://youtu.be/jalEW3yceO0>

- When the Voices Fell Silent trailer (3:19) <https://youtu.be/MxRqFl6MsYs>

- Sean and Doris Miller: A Story of Hope (13:35) <https://youtu.be/EDblspgSoc0>

- What is the evidence that people with schizophrenia can in fact recover? (4:25) <https://youtu.be/cY9DNCnRzcU>

Slide 3: Destination or Journey?

Key Points:

- Recovery from mental illness is not new – has been recognized since the 1980's

- It is both a process (journey) and a goal (destination)

- Unique for each person

Slide 4: What is the Evidence?



Discuss:

- Media and society lead us to believe schizophrenia is catastrophic and incurable
- This is not the case! Refer to statistics in Participant Notes – significant number do recover
- Several factors influence this, which we will look at in the next slides

Optional Video: Dr. Liberman – What is the evidence that people with schizophrenia can recover? (4:25) https://www.youtube.com/watch?v=cY9DNCnRzcU&list=PLkZB0pYfxQ5bOACKFchxalp5X03ICf_kq&index=7

- Note that Dr. Liberman's video is from 2011 – language has changed since then e.g. “persons with lived experience”. Also he refers to criteria for recovery – discuss with people, what do they think the criteria should be? Who decides?

Optional Video: Interview with Dr. Fred Frese <https://youtu.be/90T3kQFhTxo>

Slide 5: Dimensions of Recovery

Key Points:

- Recovery has both internal and external dimensions
- What we see from the outside may differ quite a bit from what the person experiences internally
- We tend to define quality of life and recovery by our own standards, but these may mean very different things to the person who is in recovery

Slide 6: Phases of Recovery

Key Points:

- Important to recognize the phase and adjust your expectations accordingly
- Similar to stages of change: several steps to go through before a person is ready to change <https://www.prochange.com/trans-theoretical-model-of-behavior-change>
- Patience is required as person goes through the process
- The LEAP approach is similar to Motivational Interviewing, which is the method counselors use to encourage change and growth.

Slide 7: Who Will Recover?

Key Points:

- Hard to predict i.e. we can never write someone off, they could surprise us

- Less cognitive symptoms is associated with better recovery, but there are many factors

- Need to identify which factors we can control or influence and which we can't

- Focus our energy on those things we can influence

Slide 8: How Do People Recover?

Key Points:

- Not a straight road – like a slide, has twists and turns, sometimes loops back for awhile

- We can't make anyone recover, it comes from within and requires their active involvement

- We can offer support, create supportive low-stress environments, and encourage confidence and hope

- Discuss importance of self-efficacy – the more a person comes to have confidence in their ability to recover, the more they will engage in recovery-oriented behaviours

Slide 9: How Families Can Support Recovery

Discussion Points in Participation Notes

Key Points: (note words on slide)

- Expect ups and downs, don't give up too soon

- Emphasize strengths perspective – avoid focusing only on problems

- Convey hope

- Recovery does not require acceptance of the diagnosis! Can still use LEAP approach to identify and work towards goals

- Be supportive – assist in practical ways and also emotional support

- Provide structured, predictable and calm environment

Slide 10: Setting Goals and Expectations

Key Points:

- Clarify expectations and negotiate consequences – don't just dictate

- CAUTION re: ultimatums – must be prepared to follow through

- Avoid unrealistic expectations

- Set realistic short-term and long-term goals. May need to be VERY small goals in the short term in order for success to be possible.
-

Slide 11: Managing Relapse

Key Points:

- Note that relapse may have many causes, it is not always due to stopping medications.
 - Relapse is not the end of the road – a person who relapses can still recover.
 - Each person has their own unique cues or warning signs, which tend to be consistent so that relapse can be detected early, and the prevention plan put into action.
 - Personal relapse plan is in participant notes – point it out and assign it as homework.
-

Slide 12: The Goal: A Recovery-Oriented Mental Health System

Note: This slide shows Manitoba Health web page – change it to your region if you can find a similar page.

Briefly Comment: Recovery is not just an idea, but is something that our health care systems are working towards. We'll look more at this in Session 5, but for now be aware that it is increasingly recognized and supported as a goal of mental health treatment and care.

Slide 13: Check-Out

Assign relapse prevention plan as homework (to be done together with their loved one).

Remind the participants that the next session will be the last, and ask how they'd like to celebrate. If you choose to host a celebration, you can invite the participants to each bring an item for the refreshment table. Participants often want to demonstrate their appreciation for the support they have received in a group, and this is an easy way for many people to contribute.

Evaluation

Provide **10 minutes** at the end of the session for participants to complete an evaluation form, with instructions to send it in to their facilitator.

Session 5: Building Strengths and Going Forward



Objectives:

At the end of the session, participants will be able to:

1. Identify the characteristics of strong and resilient families and identify these in their own family.
2. Describe strategies for partnering with service providers and advocating for improvements in mental health services.

Materials:

- o Participant Notes
- o PowerPoint with video(s)

Topic /Activity	Time	Materials
Check-in	5 min	Participant Notes
What are factors in family recovery? Internal & external strengths	20 min	
Other considerations: Housing, employment & finances	20 min	
Break	15 min	
Advocacy & the Mental Health System	30 min	
Wrap-up	20 min	
Check out	10 min	Feedback forms

Notes for Delivery

Slide 1: Title slide

Check-In

Slide 2: What are Factors in Family Recovery?

Summarize: Families have both internal and external strengths which can be tapped into and built upon, to overcome the impact of mental illness.

Slide 3: Internal Strengths

Discuss:

Six characteristics are found in strong families. <http://family.jrank.org/pages/593/Family-Strengths-Family-Strengths-Perspective.html>

- Some of these are easy to develop e.g. can choose to express more appreciation or have regular family time.
- Some are more difficult and may require assistance.
- Our 8 Stages of Healing program is one way families can develop their strengths.

Slide 4: External Strengths

Discuss: The biggest factor in families' ability to cope with mental illness is Social Support.

- Supports can be informal (friends, family) or formal (support groups, spiritual leader, therapist, etc.)
- When choosing a formal support, investigate their credentials. e.g. not everyone who calls themselves a therapist actually has the training and experience required.

Slide 5: Going Forward: Other Things to Consider

Discuss: There may come a day when you are not able to provide the kind of support you are doing now. Fostering your family member's independence can also assist in recovery of the family as a whole. Some things to consider include housing, employment and financial support.

Slide 6: Housing

(Adapted from: Housing for People with Mental Disorder and Addictions <http://www.heretohelp.bc.ca/publications/factsheets/housing> and Centre for Addiction and Mental Health. Housing Discussion paper. https://www.camh.ca/-/media/files/pdfs---public-policy-submissions/housingpolicyframework_final2014-pdf.pdf)

Key Points:

- Housing is fundamental to mental health. There is a strong link between having access to safe, secure, and affordable housing and better health.
- Choice, safety, support, and housing security are essential.
- A number of barriers exist that may make it difficult to get appropriate housing.
- There are different types of supported housing - GIVE EXAMPLES FROM YOUR REGION.

Slide 7: Employment Options

Key Points: Employment is a key factor in recovery, and the benefits far outweigh the costs – yet 70-90% of persons living with a mental illness are unemployed.

- The Mental Health Commission of Canada is working to promote employment options by providing a number of initiatives including a practical toolkit for employers.
- The Canadian Association for Supported Employment, and Mental Health Works, are other resources that assist both employers and employees.
- An example of supported employment is Clubhouse, which offers transitional employment, supported employment and absentee coverage. (definitions of these are in the participant notes)

Give examples of supported employment in your region.

Slide 8: Finances: What is Tax Deductible?

Tax credits for your family member if they meet these criteria.

If desired, click on the link in slide to show website:

<https://www.canada.ca/en/revenue-agency/services/tax/individuals/segments/tax-credits-deductions-persons-disabilities/information-medical-practitioners/mental-functions-necessary-everyday-life.html>



Discuss: This information, and the next slide, are federal programs. Your region may have its own deductions and tax credits. Find out what these are and provide information about them.

Slide 9: Caregiver Tax Credit



Discuss:

- Tax credits for you (the family)
- An individual is considered to be dependent on you for support if they rely on you to regularly and consistently provide them with the basic necessities of life, such as food, shelter and clothing.
<https://www.canada.ca/en/revenue-agency/services/tax/individuals/topics/about-your-tax-return/tax-return/completing-a-tax-return/deductions-credits-expenses/canada-caregiver-amount.html>

Slide 10: Estate Planning

Key Points:

- Having a valid will and doing estate planning is essential. It is particularly important if you have assets and/or children, and even more important if you have a child with a disability.

- Not having a will can result in considerable delays in disbursing your assets, as your estate will be distributed by a court administrator. Money may go to people you do not wish to leave anything to.
- You may also be leaving your estate in legal limbo, which will delay the distribution of funds and result in extra costs and taxes for your heirs.
- Although you can buy legal will kits, it is important to consult a lawyer and/or an independent estate planner, especially if you have an heir with a disability and you have reasonable assets.

Slide 11: Advocacy

Define: Advocacy

- The process of working to improve a situation, for yourself or on behalf of someone else



Discuss:

- There are many ways that families can advocate.
- The family and individual voices are essential to getting our systems to change for the better.
- To be effective, learn what changes are needed and how to take an active role in implementing system changes.

Slide 12: The Broader Context of Mental Health and Illness in Canada

Note: We have had a national mental health strategy since 2012. The overall goal is to have a recovery-oriented, family-centred mental health system. We still have a long way to go to achieve this!

Point out goals 4 and 5 – these are the ones that families most often advocate for:

- The role of families in promoting well-being and providing care is recognized, and their needs are supported.
- People have equitable and timely access to appropriate and effective programs, treatments, services, and supports that are seamlessly integrated around their needs.



Slide 13: Families in the Mental Health System

Discuss:

- Families have a major role in the system, which relies heavily on them. So what should the system be providing to help families?
- The Mental Health Commission of Canada (MHCC) has developed guidelines for health professionals to work with families. <https://mentalhealthcommission.ca/resource/national-guidelines-for-a-comprehensive-service-system-to-support-family-caregivers-of-adults-with-mental-health-problems-and-illnesses/> and has also published this Promising Practices Guide <https://www.>

[mentalhealthcommission.ca/sites/default/files/2020-04/Promising_Practices_Guide_eng.pdf](https://www.mentalhealthcommission.ca/sites/default/files/2020-04/Promising_Practices_Guide_eng.pdf)

- o Family-Centred Mental Health Care - Approach that sees families as partners in care and encourages family involvement. <https://www.porticonetwork.ca/treatments/approaches-to-care/family-centred-care>

Slide 14: Pyramid of Family Care



Discuss: These are the services that should be provided to families, according to the MHCC.

- o Minimum (bottom of pyramid) every family should get assessment of needs and connection to supports
- o Everyone should get general education
- o Next level is psychoeducation – that's what this program is
- o Family consultation (previously discussed)
- o Family therapy (previously discussed)

Slide 15: Progress on the Goals: How Are We Doing?

Briefly Comment:

The Mental Health Commission of Canada is tracking a number of indicators to see what is being done. There is progress in a number of areas, though not as fast as many would like. To see what is currently happening across Canada, go to <https://www.mentalhealthcommission.ca/English/media-centre/news/releases> (if you have Internet access, you might want to show them this website and explore it)

Caution:

Don't let this deteriorate into a complaint session! Acknowledge we aren't there yet, but offer hope that progress is happening. It's hard to turn a system around!

Slide 15: Barriers to Change

Slide 16: Barriers to Change



Discuss:

Barriers to progress include complexity of the system, stigma, laws and funding. Laws and funding sources are provincial responsibilities therefore they vary. Also, there is a general lack of funding for mental health services, which may be at least partially related to stigma. Acknowledge how frustrating this is for everyone affected and use this to lead into discussion of advocacy.

However a great deal of change has happened, and we mustn't give up hope!

Slide 17: Advocacy Issues

Comment: Slide shows Vancouver Health's Family Bill of Rights. Advocate for your loved one, but also for your family as a whole.

- There are a number of things that can be advocated for. It's easy to be overwhelmed.
- If you choose to get involved in advocacy, don't try to do it all, or to do it alone.

Go through the following slides fairly quickly: ensure there will be time at the end of the session for evaluation forms and farewells.

Slide 18: Individual Advocacy

Comment:

- There are a number of tips in the Participant Notes, many of which we have discussed already
- Canadian Patient Safety Institute Shift to Safety tips and tools <http://www.patientsafetyinstitute.ca/en/About/Programs/shift-to-safety/Pages/public.aspx>

Slide 19: National/Provincial Advocacy

Comment: Some people choose to work at a bigger system level. For example, many family members are on the board of SSC or similar organizations.

- Slide shows the advocacy page on the SSC website. CONNECT to the site on the Internet.
- POINT OUT the links to the Advocacy Toolkit, and sample letters.
- SSC Advocacy Resources <https://schizophrenia.ca/>

Comment: Be aware of this toolkit as well.

<https://mentalhealthcommission.ca/resource/caregiver-mobilization-toolkit/>

- Patient Safety in Mental Health
- <http://www.patientsafetyinstitute.ca/en/Topic/Pages/Mental-Health.aspx>

Slide 20: Family Advisory Councils [adapt this slide: insert image of local FAC]



Discuss: Not everyone wants to be politically active, but there are other things you can do, listed in the Participant Notes. One of these is joining a Family Advisory Council or participating in a focus group.



Slide 21: #1door4care (optional)

Comment: this is one example of an advocacy campaign using social media - #1door4care.on.ca (families who have children with special needs)

Slide 22: To Recap...

Comment: This program has been an overview of the main topics and issues for families living with psychosis. We have hit the highlights on the following:

- What psychosis and schizophrenia are, and the broad categories of treatment approaches
 - How to understand and navigate the mental health system
 - How to manage daily life, relapse prevention, and crisis management
 - The bigger picture and the need for advocacy
 - MOST OF ALL – HOPE FOR RECOVERY!!
- There is a lot of information that could not be covered in these 5 weeks, but we hope that you have some tools now to manage better, and to find the specific information you need.
- Please remember that the Schizophrenia Society is always here as a resource for you, and we encourage you to maintain connections with the people you have met in this group.

Slide 23: Continuing the Journey

Wrap-up and Check-Out:

- Thanks for your participation!
- Review accomplishments
- Program evaluations (If doing online delivery, send link to evaluation on Google Docs after session).
- Remind everyone of where to go from here:
- Eight Stages of Healing
- Family Support Group

Evaluation

Provide **10 minutes** at the end of the session for participants to complete an evaluation form, with instructions to send it in to their facilitator.





Wrapping Up the Program

Record Keeping

Registrations:

- Keep all registrations in a secure location.
 - You are not required to send SSC any information on registrants other than the number of participants for each five week program. There is a space for this number on the Program Evaluation for Group Members form in Appendix B.
-

Evaluations:

- After summarizing the participants' Program Evaluation for Group Members data into the Program Evaluation Summary form, please scan or photocopy the latter and send to SSC (fran@schizophrenia.ca).
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Submission of Information to the Schizophrenia Society of Canada

Because this is a national program of SSC, quality monitoring and support will be done by the National office. The following information will need to be submitted at the end of the program:

1. Registration statistics as described
 2. Evaluation feedback
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