

Session 5

Family Recovery Journey

Building Strengths & Going Forward

What Are Factors in Family Recovery?

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

- Internal strengths include flexibility, unity, and positive communication.
 - External strengths are the supports you are able to access.
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Internal Strengths

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

1. **Appreciation and Affection** - demonstrate your caring, liking and respect for one another. Small acts of appreciation or affection can go a long way. A hug, smile, shared joke or simple thank you are easy to offer to each other.
 2. **Positive Communication** - It can be easy for conversations to start to focus on problems or stressors. Be sure to also talk about the positives in your family and offer each other support. Acknowledge that each person in the family may experience the impact of the illness differently. Validate efforts being made to manage this impact. Avoid playing the blame game!
 3. **Adaptability (Flexibility)** - Grow your family's ability to adapt by being flexible and open to change. Often one person becomes the primary caregiver or support person for the ill family member. Share this role as much as possible. Seek outside help if needed, to find new ways of responding to the impact of the illness.
 4. **Unity** - Having family rituals and routines will help build unity. This could be regular family dinners, family fun night, or retelling favourite family stories. What is important is that you are doing something together. If possible, these family events should include the family member who lives with the illness.
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5. **Spiritual Well-Being** - Even if you do not have a religious faith or spirituality, your family can seek and find meaning in shared values such as compassion, or altruism. You may feel a sense of oneness with other families who have similar experiences, or hope for the future. Many families I know have become advocates within the mental health system, or volunteer at mental health support organizations.

6. **Commitment** - This one can be difficult if your family does not have trust in each other. However, it can be developed by being dependable and reliable, and practicing honesty (with kindness!).

External Strengths

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

- Reach out to family and friends - let them know that you are dealing with an illness in the family, and what kind of support you need from them. Tell them what would be most helpful for them to do for you right now.

- Determine who needs to know what:
 - > It's not always necessary to say what the illness is exactly, only how it is affecting you.

 - > Share to the extent that you feel comfortable and also respectful of your ill family member, who may have concerns about their personal privacy.

 - > If you share your own emotions and needs, rather than talking about the ill person, you can often elicit support without needing to go into details.

- Find a formal support group
 - > **Family consultation** = getting advice and help with problem-solving around a particular issue. Usually requires only one or two meetings.

 - > This does not mean your family is "dysfunctional"! It is, in fact, part of adaptability to be willing to seek help when your own efforts are not working.

 - > **Family therapy** = working to change your family dynamics and relationships: how you interact with each other.

- Look for a therapist or consultant who has professional credentials. A list of family therapists can be found at the Canadian Association for Marriage and Family Therapy: <http://camft.ca>

- Other qualified family consultants may be advanced practice registered nurses, social workers, psychologists or other professionals with training and experience in family dynamics and mental health.

- Take part in advocacy

Going Forward: Other Things to Consider

Social support includes finding supports for your family member, to promote their independence and reduce some of the responsibilities of caregiving for the family. Housing and employment are both key to individual and family recovery. The following is general information about the types of supports that may be available. For specific housing and employment resources in your region, refer to the list of resources you received in Session 1.

Housing

Housing is fundamental to mental health. There is a strong link between having access to safe, secure, and affordable housing and better health.

What does adequate housing for people with mental illness look like?

- Choice of housing arrangements according to an individual's wants and needs - having a choice is associated with housing satisfaction, residential stability and emotional well-being, and recovery.
- Units that are clean, quiet, safe, and close to amenities and support services
- Access to housing located in a variety of neighbourhoods
- Affordable housing units and furnishings to accommodate the needs of people on fixed or low incomes
- Access to flexible, 24-hour supports as needed
- Options for maintaining the same housing arrangement regardless of changes in a person's mental health needs

Barriers

- Availability of safe and affordable housing
- Lack of support to live successfully in these settings
- Loss of income during long periods of illness and repeat visits to the hospital
- Some people in this situation may decide they are better off on the street, but without a fixed address, they may be cut off from a range of social services – including health care.
- A small number of people may go without treatment for the disorder until they are arrested, and depending on the circumstances, end up in the criminal justice system.
- Emergency rooms also repeatedly see and discharge frequent users, many of whom are mental health clients, with most recovery gains lost when the person is back on the street. Known as the “revolving door syndrome,” this cycle is perpetuated by the lack of affordable housing and emergency supports available for people with mental illness.

The majority will not want or need specialized housing. They use their own resources to live in the community like any other citizen. In some cases, however, especially where the illness is more serious, the need for a specialized resource comes into play. Current research suggests that many individuals, even with serious mental illness, can live in independent living arrangements with appropriate supports.

Supported housing is a place that is affordable, even for individuals on income assistance. Staff are there to help the person keep appointments and take medication. Supported living staff also help clients learn basic skills to manage a household, look for a job, or go back to school.

1. Supported Independent Living

- Supported apartment buildings are built especially for people with mental illness; subsidized rent and daytime support are provided
 - Satellite apartments are leased in private market buildings; tenants have access to subsidized rent and outreach services
 - Supportive hotels: single rooms are leased and managed by non-profit societies; on-site staff support provides services to adults with mental illness
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2. Residential (Group Homes)

- Group homes provide subsidized rent; tenants share a home and the services of a community living support worker
 - Licensed community residences provide 24-hour supervision with professional staffing available on a daily basis; staff supervise use of medications unless a resident applies for permission to take their own medications
 - Supported living homes offer support staff during daytime hours; residents take their own medications
 - Family care homes are privately owned and provide care and supervision to one or two individuals who wish to live in a family setting
 - Residents may be required to be out of the home during the day, which can be a barrier
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3. Emergency Accommodation

- Emergency facilities offer short-term accommodation for people with no other immediate housing options available to them. Length of stay is usually less than 90 days.
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Housing for People with Mental Disorder and Addictions

<http://www.heretohelp.bc.ca/publications/factsheets/housing>

Centre for Addiction and Mental Health

http://www.camh.net/Public_policy/Public_policy_papers/housingpaper.html

Employment Options

The Mental Health Commission of Canada (MHCC) states that:

“ Employment plays a key role in the recovery of persons living with a mental illness. ”

“ Research shows that individuals living with a disability (including those living with a mental illness) are as, if not more, qualified, reliable, loyal, and productive than their colleagues who do not have a disability. ”

The MHCC is working to identify barriers as well as innovative practices to assist people living with mental illness to secure and sustain meaningful employment. This initiative, called The Aspiring Workplace – Employment and Income for People with Serious Mental Illness can be found on the MHCC website. It includes a business case for employing workers who live with mental illness, and a practical toolkit for employers, among other things.

<https://mentalhealthcommission.ca/aspiring-workforce/>

There are many models of supported employment. One of the earliest was the Clubhouse Model, originating at Fountain House in New York City. Clubhouses around the world provide transitional and supported employment:

What is Transitional Employment and Supported Employment

Transitional Employment (TE) is our part-time work program that sets members up to work in companies around New York City. This, combined with work that members do within Fountain House, gives them the skills and experience they need to find permanent employment.

Supported Employment (SE) is a competitive process in which members contend for jobs at New York City organizations against others that do not face the same challenges. Fountain House helps members navigate this process by building relationships with employers and providing member training and support.

Absentee Coverage Policy

A unique attribute of the Fountain House employment program is its absentee coverage policy. If a member is unable to work on a given day, a Fountain House staff worker fills in, providing vital stability and support.

Source: <https://www.fountainhouse.org/employment>

Resources in Canada

- Mental Health Works <http://www.mentalhealthworks.ca>
- Canadian Association for Supported Employment <https://www.supportedemployment.ca>
- Employment For All <https://www.employmentforall.ca/content/resources/001.html>

Finances and Future Planning

1. What is Tax Deductible?

A. Therapy prescribed and supervised by an MD, nurse practitioner, or psychologist

- Person must be eligible for disability tax credit
- “Marked restriction in performing mental functions necessary for everyday life”.
- <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>

B. Therapy prescribed and supervised by an MD, nurse practitioner, or psychologist

- 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>

2. Estate Planning

(Adapted from an article by Marvin Ross in The Advocate, Winter 2001-2002, Schizophrenia Society of Ontario)

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. The distribution of assets could be delayed for up to one year from the date of death and assets may have to be sold at unfavourable rates. Your heirs might also wind up paying hefty estate taxes.

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. Even something as simple as owning your house would constitute reasonable assets.

After planning for the needs of your family, you can help others through a planned giving provision in your will. This can benefit you, your heirs and a charity of your choice. Not only can you help others but you can provide tax relief for you now and your estate later on. There are many ways to make a planned gift, and it's best to consult with an expert to find out what is best for you.

This is not intended as a full explanation of the options that you have for estate planning. That would be based on your particular case and needs, which should be evaluated with either your own accountant, an independent specialist in estate planning and/or your family and local advisor. Personal and family considerations should always be taken into account.

Don't wait to prepare a will. If you die before you complete one, government bureaucrats will decide what to do with your assets, possibly tying up your assets for a considerable period of time.

Prepare an inventory of all your assets and liabilities, such as RRSPs, personal property such as cars and jewellery, real estate, and investments such as mutual funds and stocks.

Identify your estate planning objectives.

Seek specialized legal counsel to make arrangements for a trust in your will that will meet the ongoing needs of your child. Don't assume that every lawyer or financial advisor has expertise in creating trusts for people with disabilities that do not jeopardize government benefits.

Consider asking your lawyer or financial advisor for references.

Ensure that your trust is carefully worded so that your child is deemed not to legally own the asset, so government benefits will not be jeopardized. Instead, assets should be in the care and control of a trustee, to be administered for the benefit of the beneficiary.

Have your will professionally reviewed regularly, to ensure that it has not been impacted by changes in government legislation or your personal family situation.

Make sure there are family discussions of financial plans to ensure there is understanding and cooperation of everyone involved.

Know your rights: there are legitimate ways to leave a financial legacy for your child without affecting their government assistance.

(Source: Ottawa, Ontario-based lawyer Ken Pope and Wealthcare, an Ontario-based medical-financial)

Advocacy

What is Advocacy?

- The process of working to improve a situation, for yourself or on the behalf of someone else
- Advocacy can take many different forms

What can Families Do?

- Families can be effective agents of change
- Advocate for recovery-oriented mental health systems and services
- Contribute knowledge, energy, determination and commitment
- To be effective, learn what changes are needed and how to take an active role in implementing system changes

The Context of Mental Health and Illness

In 2009, the federal government put forward a framework for a national strategy for mental health. Three years later, the Mental Health Commission of Canada released Canada's first National Strategy for Mental Health. The overall goal is to have a recovery-oriented, family-centred mental health system.

The framework set out 7 goals for a transformed mental health system, which the National Strategy aims to address:

1. People of all ages living with mental health problems and illnesses are actively engaged and supported in their journey of recovery and well-being.
2. Mental health is promoted, and mental health problems and illnesses are prevented wherever possible.
3. The mental health system responds to the diverse needs of all people living in Canada.
4. The role of families in promoting well-being and providing care is recognized, and their needs are supported.
5. People have equitable and timely access to appropriate and effective programs, treatments, services, and supports that are seamlessly integrated around their needs.
6. Actions are performed on the best evidence based on multiple sources of knowledge, outcomes are measured, and research is advanced.
7. People living with mental health problems and illnesses are fully included as valued members of society.

- Toward Recovery and Well-being: a Framework for a Mental Health Strategy for Canada (2009)
https://www.mentalhealthcommission.ca/sites/default/files/FNIM_Toward_Recovery_and_Well_Being_ENG_0_1.pdf
- Changing Directions, Changing Lives: Canada's first national mental health strategy
https://www.mentalhealthcommission.ca/wp-content/uploads/drupal/MHStrategy_Strategy_ENG.pdf

Families in the Mental Health System

The Mental Health Commission of Canada (MHCC) has developed guidelines for health professionals to work with families. <https://projects.invhttps://mentalhealthcommission.ca/resource/national-guidelines-for-a-comprehensive-service-system-to-support-family-caregivers-of-adults-with-mental-health-problems-and-illnesses/>.

Its goals are:

- Implement a mental health system that supports family caregivers and requires that health care professionals proactively engage family caregivers
- Recovery-oriented services that: acknowledge the importance of family caregivers, support them, and respond to their needs

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>

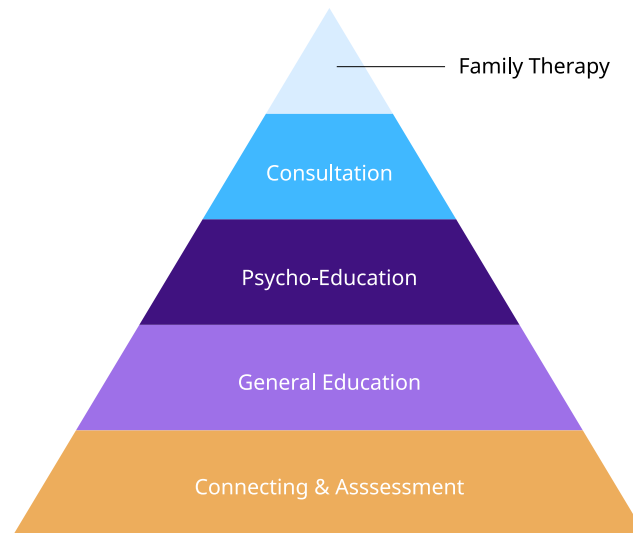
Role of Family in the System

- Provide transportation and housing
- Educating others about the illness
- Providing guidance around community resources
- Money management
- Personal safety and hygiene
- Encouraging and motivating ill relative
- May be caring for grandchildren
- Advocating and navigating health care system
- Coordinate care, "case management"



Pyramid of Family Care

The services that should be provided to families, according to the MHCC.



Progress on the Goals: How Are We Doing?

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 happening across Canada, go to: <https://www.mentalhealthcommission.ca/English/media-centre/news/releases>

Barriers to Change

- It's a large and complex system.
- Stigma in society and within the health system creates barriers.
- In Canada, responsibility for mental health services lies with the provinces. This means that there is variation between the provinces.
- Laws governing mental health services can be restrictive.
- Funding of programs and services can be difficult to obtain.

Individual Advocacy

- Get a comprehensive evaluation
- Insist on the best
- Ask lots of questions about any diagnosis or proposed treatment

- Encourage your loved one to ask questions and self-advocate

- Make sure you and your loved one understand the full range of treatment options available

- Insist on care that is “patient-and-family-centred” and which builds on strengths

- Ask about specific goals and objectives

- Ask about comprehensive “wrap around” or individualized services

- Be prepared – keep track of all information, including past consultation and treatment reports

- Seek a second opinion

- Help and support your loved one in their efforts to learn about their illness

- Insist on access to appropriate mental health consultation services

- Canadian Patient Safety Institute Shift to Safety tips and tools
<http://www.patientsafetyinstitute.ca/en/About/Programs/shift-to-safety/Pages/public.aspx>

National and Provincial Advocacy

- Become politically active

- Gather evidence

- Talk to other families, build coalitions

- Fight stigma

- Work with local professional organizations

- Join a Family Advisory Council

- Attend regional and national conferences

- Don't give up!

- Advocacy Toolkit
<https://schizophrenia.ca/>

- Caregiver Mobilization Toolkit
<https://www.mentalhealthcommission.ca/English/initiatives/11847/caregiver-mobilization-toolkit>

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

- The Schizophrenia Society of Canada also has sample letters to the editor and to government representatives, as well as other useful tools on their website.



In Conclusion

- This program has been a fairly quick overview of the main topics and issues for families living with psychosis. We have discussed:
 - 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.

