



family to family

FOR FIRST-EPIISODE PSYCHOSIS FAMILIES

From Our Families

Personally, I feel very lucky because I regularly get to share my fears and frustrations with our local first-episode family support group. I find our discussions about managing day-to-day issues, broader family concerns and our own individual mental health needs to be very comforting and helpful.

Enjoying the holidays

At a recent meeting we discussed the upcoming holiday season and various families expressed their apprehensions. ***In response, we heard the following:***

“Try not to make the holiday ‘the best ever.’”

“I’ve had to let go of the past. The holidays are not like they used to be because life brings changes. You really set yourself up for disappointment if everything has to be just like the old days. It’s taken me awhile to reach this point. I’m asking my family what they would like to do this year.”

“We see him able to participate in the holidays more each year. In the early part of his illness, it was all he could do to make an appearance on Christmas morning. But, last year he enjoyed all the celebrations.”

“I make sure that I take some time for myself. I really try to not spend all of my time looking after everyone else.”

“Our son is very sensitive to bright or flashing lights and the din of places like shopping malls. So, his strategy is to visit the malls in the early morning, early in the week. He’s then able to shop, as he says, ‘in peace and quiet.’”

Coping

By Sharon Scott

I hate to say it, but the “holiday season” that is now upon us may bring little comfort and joy to families who face the unpredictability and challenge of an illness like psychosis. In fact, special occasions can heap additional stress onto already stressful situations.

As we know, living with psychosis in the family poses many types of challenges for each and every family member. Some days are easier than others, some weeks may go by virtually symptom-free. However, when symptoms are present, we need strategies – strategies that can help us cope – that can help us reduce the stress and move beyond the moment for the sake of ourselves and our loved ones.

This issue of *Family to Family* is devoted to coping strategies. It is intended to help us all “survive and thrive” – through the holiday season, through the winter ahead, through the challenges that may await us at any time of year.

We wish you a joyful and hopeful holiday season and a wonderful winter (despite those shortened winter days!). Remember to be kind to yourself and ask for help whenever you feel you need it.

Families can make a difference!
Sharon Scott, Editor

Taking care of yourself It's easier said than done!

- ▶ Go for a walk or run
- ▶ Practise meditation
- ▶ Keep in touch with friends
- ▶ Take a break
- ▶ Read a good book
- ▶ Enjoy a pet
- ▶ Go for a massage
- ▶ Accept help
- ▶ Let go of the need for everything to go right
- ▶ Delegate chores
- ▶ Stay with a routine
- ▶ Enjoy nature
- ▶ Take up a hobby
- ▶ Keep a good diet
- ▶ Set limits and keep time for yourself
- ▶ Celebrate the good times

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Coping STRATEGIES

Collected Wisdom

The information on the following pages draws heavily from a wonderful source that originated from the early intervention services in Northern Sydney, Australia. I've since seen many of the ideas show up in other resources for first episode families. I'm pleased to be able to share these with you and do hope they help. (Let us know!!)

Hallucinations

Hallucinations are when your relative sees or hears things that you do not see or hear. Remember the hallucinations may be distressing to the person experiencing them.

TRY TO:

- Stay calm by taking long, deep, slow breaths while you place your hand on your chest or stomach
- Distract the person if you can, by involving them in something else
- Ask the person to help you find something
- Engage the person in conversation

TRY TO AVOID:

- Figuring out what he or she is talking about or to whom he or she is talking
- Asking the person to try to force the voices to stop

"Food usually works for me! I once helped my son through this by calmly speaking to him and offering him his favourite breakfast."

Sleeping or withdrawing a lot of the time or sleeping at odd times

TRY TO:

- Remind yourself that your relative may need to sleep more during the recovery phase
- Leave your relative alone but make regular contact whenever he or she is up and about
- Let the person know that you are there if needed

TRY TO AVOID:

- Coaxing the person to come out of his or her room
- Fussing or worrying too much over your relative
- Inviting a lot of visitors home as it may be too overwhelming

"We're slowly encouraging our son to participate in family activities. Watching T.V. and rented videos has worked well for us."

"I try to keep leftovers in the fridge so at 3:00 a.m. my son only has to heat up a meal, rather than create a gourmet meal."

"I pack an 'evening' bag lunch for my daughter so when her stomach 'calls' she doesn't have to start cooking!"

Inactivity and not feeling like doing anything

TRY TO:

- Have a regular daily routine so that things are predictable
- Encourage your relative to join in or follow this routine
- Provide simple chores for the person to do. Break chores into small steps if they are difficult
- Offer simple activities such as listening to music, going for a walk if the person says she is bored
- Say thanks for the times when the person does the chores they should

TRY TO AVOID:

- Insisting your relative do much or go out
- Overwhelming the person with too many suggestions at once
- Nagging or criticizing

"My son told us that he found it very helpful when we made it very clear what we wanted him to do."

"We sat down and talked about the chores – and jotted down a list that we broke into smaller steps. Jeff crossed off each step as he went along."

"For a number of months Jeff was quite content to just stay home. He spent a lot of time in his room which was quite a worry for us. We finally stopped pushing for him to be more socially active. When he felt ready, he started venturing out."

"I didn't feel that I was coping well and finally decided to seek counseling for myself. What a difference that made."

“We now put a sticker on the calendar the week before the prescription needs to be refilled.”

Not taking prescribed medication

Family members are the “eyes and ears” for the clinician or doctor. Contact the clinician if you see marked changes in your relative’s behaviour. He/she could be missing doses of medication or may have stopped taking their medication.

TRY TO:

- Gently remind the person when it is time to take the medication if the problem is a result of forgetting
- Find a daily routine (eg. breakfast, teeth cleaning) when taking medication can become a habit
- Ask if he or she is having any side effects
- Urge the individual to keep their clinician or doctor informed if she or he stops taking their medication

“We found that a pill dispenser (dosette) works very well, but dosettes are not all the same. You may need to shop around for one which best suits your needs...convenient size, number of compartments needed, easy-to-read labels, etc. Together we fill the dosette for the coming week and make sure that it is safely stored in the same place on the kitchen shelf. The time spent together filling the dosette provides an excellent opportunity to reinforce the mantra: ‘I take my meds so I will feel better...I feel better when I take my meds’.”

“My daughter has difficulty remembering to take her medications during the day. She now sets the timer on her watch! It works for her.”

“When my son needs to take medications on an outing, but feels the need to be discreet, he takes a mini-size pill bottle with him.”

“Joel kept forgetting to get his prescriptions filled. We now put a sticker on the calendar the week before the prescription needs to be refilled.”

Street drugs and alcohol

The use of cannabis and other street drugs increases the risk of relapse and may also make the symptoms worse. Using street drugs can prolong the duration of symptoms and reduce the person’s chance of recovery.

TRY TO:

- Remind him or her that the drugs are particularly harmful to them because of their illness
- Assist your relative in developing ways on how to say “no” to offers of drugs or alcohol. (eg. I’m on medication right now and don’t want to mix my drugs. Drugs/alcohol don’t agree with me.)
- Look for possible stressors which may lead to drug or alcohol use, and discuss ways of minimizing these stressors
- Discuss alternative ways of being social or being with friends without using drugs or alcohol

TRY TO AVOID:

- Nagging or criticizing
- Letting family or friends encourage drinking or taking drugs by making these behaviours sound good
- Supplying the money needed for drugs or alcohol

“My daughter tried roller blading! It was something that she was able to do alone but she was also able to join her sister and her roller blading group. Great exercise!”

“Our family started watching how often we served alcohol with meals or on social occasions. The family tradition of let’s have a few beer while we barbecue changed to having non-alcoholic drinks.”

“Our family started watching how often we served alcohol with meals, or on social occasions.”

Aggressive Behaviour

People with psychosis are often withdrawn. However, aggression may sometimes occur and you should know what to do if your relative becomes aggressive.

TRY TO:

- Develop a plan as to what to do in the event your relative's behaviour becomes difficult. Discuss with your supportive relatives, friends or clinician (if you are fortunate enough to have one) what role each of them will play in helping with the situation
- Give a firm command such as "Stop please."
- Leave the person alone until they have calmed down.
- Discuss any threats and aggression openly in the family and with a clinician or doctor
- See what triggers the aggression, and avoid that behaviour/situation

TRY TO AVOID:

- Saying angry or critical things which may upset your relative
- Using the words "you" and "you should"
- Battling it out on your own – ask for help

"I left the house and stayed out in the yard until things had settled down a bit."

"My daughter and I have written out a contract about what is acceptable behaviour in our home. Since then everything has been great!"

"Arguing upsets both of us. It's ok to leave the situation and come back when we had both calmed down and the subject had changed."

Strange Talk or Beliefs

TRY TO:

- Gently and matter-of-factly withhold agreement with strange ideas
- Show understanding of the person's feelings and encourage the person to talk openly
- Change the subject to something routine, simple or pleasant in real life
- Say when you think something is not real, while acknowledging that it may seem real to your relative
- Help your relative tell the difference between reality and fantasy. Let them know "It's your brain chemistry that makes you think you're seeing something – it's not really there."

TRY TO AVOID:

- Allowing other family members to make jokes or criticize the person
- Arguing about the strange ideas – arguing never changes the ideas and only upsets both of you
- Pretending to agree with strange ideas or talk that you can't understand
- Keeping up a conversation that you feel is distressing, annoying, or too confusing for you. It's OK to say "I'll talk to you later."

"After a family meeting with her doctor, our daughter decided to use us to check her thinking and reality. It's worked really well."

"We once made the mistake of pretending to agree with our daughter's strange ideas. When she was well again, she was very, very distressed that we hadn't been truthful and provided her with a reality check."

Fears of Suicide

TRY TO:

- Listen to all your relative's feelings of depression but also point out that help is available
- Show appreciation of your relative's feelings and the fact that they confided in you
- Encourage your relative to be involved in pleasant, low key activities with someone they know well
- Help the person to be with someone with whom they feel accepted, so they don't feel isolated
- Let the person know you accept and care about them

TRY TO AVOID:

- Telling the person things like, "Pull yourself together"

Don't panic if your relative talks about suicide but do take his or her feelings seriously. Contact a clinician or doctor if suicidal ideas persist.

"When my son was in the throes of a depression we started attending football games together. This was something that we were both interested in and gave us something to look forward to that we could do together."

We would like to hear from you!

We are very interested in your ideas, comments, stories and suggestions regarding what you would like to see here. So if you'd like to share with us please contact:

Family to Family

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This newsletter was compiled by Sharon Scott and Brenda Wentzell with help from families across Canada. The information in this issue came from many sources including materials from "Information for Families" (North Sydney Health, Australia), "Coping when someone in your family has Psychosis" (EPI, British Columbia), "The Role of the Family in Psychiatric Rehabilitation" (Boston University) and numerous web-sites. A special thank you to Dr. Michael Eleff who has been our "behind the scenes" proof reader since our first issue!

This newsletter is intended as an additional source of information and support and does not replace the advice of your family's health care team. The views expressed in *Family to Family* are those of the contributors.

Our resources are limited and we are looking for sites in each province to assist with the distribution of this newsletter. If you are associated with an organization, agency or clinic that would find this newsletter useful for clients and could help by distributing a number of copies, please contact the Editor.

We also encourage everyone to photocopy and distribute this newsletter.

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