Remember the 2009 science fiction movie Avatar? The hero recovers the use of his crippled legs through interaction with an avatar. Now thanks to Dr. Julian Leff in England, science fiction isn’t fiction any more. He has developed a computer-generated avatar that allows people tormented by auditory hallucinations to speed their recovery and reclaim their lives.

The hostile, frightening voices that often take command of people suffering from schizophrenia evoke feelings of frustration and helplessness. They erode the ability to concentrate, study, work and sustain social relationships. Worse, they can lead to tragedy.

Standard treatment for hallucinations consists of antipsychotic medication and/or cognitive behavioral therapy. Patients are often advised to ignore the voices or use distraction as a coping skill. An estimated one in four don’t succeed. Studies have shown that patients who have a dialogue with their hallucinated voices feel a greater sense of control, but it’s difficult to talk to an invisible entity, especially one that’s persistently abusive.

Leff, a psychiatrist known for his work in research and schizophrenia, is professor emeritus of the mental health sciences unit at University College London. He wanted to learn if using a visible avatar would furnish people with new-found strength and level the playing field when they communicated with it. He turned to computer technology to achieve his goal.

Researchers enlisted 26 people who had suffered from abusive voices continually for at least six months even after being on antipsychotic medication. The participants were divided into two groups, both of which would receive treatment for seven weeks. One group received the standard therapy, the second began working with avatar therapy.

Each participant in the avatar group was instructed to design a computer-generated face. Custom-made software was then used to produce a voice that matched the one they had been hearing in their minds. Lastly the program synchronized the avatar’s lips with its speech.

This meant that a therapist seated in another room could talk normally with a patient or speak through the avatar using real-time voice software. Patients heard a voice echoing that of their hallucinations, saw the avatar’s face and were encouraged to have a conversation.

After a diagnosis, many people have difficulty making a decision as to whether or not to keep the information to themselves. They worry that they’ll be unfairly judged, misunderstood, stigmatized and rejected. Then again, disclosure of a diagnosis can lighten the burden of coping with a mental illness single-handedly.

So what to do? It all depends.

**Family and friends**

If your illness has caused you to misbehave socially, duck your obligations or otherwise act in a way people don’t expect of you, disclosure will allow them to make sense of your recent behavior. Their understanding will encourage acceptance and strengthen ties between you. Those feelings of closeness and safety are most welcome, as they’re important factors in helping you develop positive feelings towards yourself.
in direct-talk mode, the therapist helped patients to confront their demons. Using training techniques, the therapist gradually allowed the avatar to come under the patient’s control and shifted the avatar’s character from abusive to helpful and encouraging.

“Patients interact with the avatar as if it were a real person, but it’s their creation, so they know it can’t harm them,” says Leff. “Compare that to the voices inside their heads, which often threaten to kill or harm them and their family.”

For continuity, each session was recorded and given to the patients on MP3 players. “Like having a therapist in their pocket,” says Leff. “They could listen whenever the voices harassed them.”

And those voices can be overpowering. Because of the fear experienced, only 16 of the 26 participants completed their therapy. Some were threatened or bullied to withdraw.

**A go-ahead to continue**

Nevertheless the results of the pilot study were encouraging. Compared to the group receiving standard therapy, the avatar group showed greater improvements in the frequency and intensity of their hallucinations. They gained the confidence and courage to oppose both the avatar and their persecutor and reported a positive change in their beliefs about the authority and malicious intent of the voices. After six sessions most said their voices had improved; three said they had stopped completely. Levels of depression and suicidal thoughts also decreased.

As a result of its early success, England’s Wellcome Trust, a medical charity, has given Leff’s team two million dollars to test the therapy on larger groups.

The beauty of avatar therapy, says a psychiatrist who will lead that study, is that it’s simple and brief. Many other therapies seeking to treat auditory hallucinations are costly and can take months to deliver. Results of the second study are expected towards the end of 2015.

If the larger trial proves successful, avatar therapy could be widely available in Britain within a few years. It’s believed that many mental health professionals already have the necessary skills to use it. From science fiction to scientific study. Amazing.

To learn more about the new trial, email AVATAR@kcl.ac.uk.


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**Book review**

**Far From The Tree**

*Parents, Children, and the Search for Identity*

by Andrew Solomon

For families struggling with the difficulties of doing what’s right and best for their child living with a mental illness, this remarkable book will be an eye-opener, a comfort and even a life-changer.

In the very first paragraph of his work, Solomon rejects common understanding. There’s no such thing as reproduction, he writes, only acts of production. Genetics notwithstanding, parents of exceptional children, meaning those very unlike themselves, can find they sooner or later face the same crucial question: to what extent should they accept their children for who they are and how far should they go to help them become their best selves possible?

*Far From The Tree* (Scribner, 2012) is a book of stories about parents and their progeny, children who are either born or grow to become different in profound and challenging ways. In 10 chapters, Solomon tells of families coping with deafness, autism, dwarfism, Down syndrome, schizophrenia, multiple severe disabilities, with children who are prodigies or transgender, those who are conceived through rape and those who become criminals. While each of these situations sets a family apart, Solomon sees the differences within families as a universal link. We are all united in our diversity, he believes.

In preparation for this *tour de force* of a work, Solomon interviewed some 300 families, accumulating over 40,000 pages of transcription. From his 700 pages of reportage, a reader soon encounters a startling fact: how eloquent ordinary people can be when facing extreme challenges.

Their narratives are full of heartbreak and joy. Together they celebrate the full range of human experience and what it’s like to be a parent. Some family experiences end on a happy note, others not so much, but each lays bare humanity’s pain, inspiration and hope, the unconditional love of parents for their children and the desire in all of us to be valued as human beings.

Learning that other families are dealing with problems of difference will give heart to parents who often feel overwhelmed and isolated. And there is hard evidence that many families grow closer through the challenges of raising an exceptional child. Many find support from broader, similarly affected communities. Some are sustained by the very conditions they once feared through advocacy and activism.

A lecturer in psychiatry at Cornell University, Solomon was a National Book Award winner for *The Noonday Demon: An Atlas of Depression* (a personal experience). The first and last chapters of *Far From The Tree* reveal the troubles in his own life: the mental illness, how his family helped him overcome dyslexia, how he steered both his parents and himself to coming to terms with his conflicted identity, specifically the fact that he was gay. This last evolved happily with his eventual decision to become a father.

Learned and super-sized though it may be, this is far from an academic book. Themes of generosity, acceptance and tolerance abound, as does the evidence that prejudice is no match for love. It’s a gripping voyage into the world of families and identity, easy to read and hard to put down.

*Far From The Tree* is available in our library.
WHEN PSYCHOSIS THREATENS

As a family caregiver, you’re the ideal person to help your loved one navigate a schizophrenia crisis. But your approach can make all the difference in how well you succeed.

W hen people with schizophrenia are threatened by a psychosis, they’re often unaware that anything is wrong. So as a caregiver you need to recognize the early warning signs that trouble is coming and know what to do if professional help is needed. Just as important is how the two of you interact. Your attitude can be a game-changer.

Some early warning signs
- Anxiety, depression or irritability
- Suspicion, hostility or fear
- Difficulty sleeping
- Unusual waking hours
- Appetite changes
- Loss of energy, interest or motivation
- Hyperactivity
- Concentration or memory problems
- Preoccupation with certain ideas (e.g., religion)
- Social withdrawal from family and friends
- Racing or slowed-down thoughts
- Difficulty meeting responsibilities
- Worsening self-care and personal hygiene
- Appearing perplexed
- Change in personality

Knowing how to react when faced with the symptoms of psychosis can be difficult. There really isn’t one “right” thing to say or do. And unless several signs persist or grow more pronounced over time, one sign by itself doesn’t necessarily indicate a looming crisis. Still, you’re ahead if you keep these general rules in mind:

Try to understand what your loved one may be experiencing and don’t take any hurtful comments personally.

Avoid long debates where you insist that the hallucinations or delusions aren’t real. This will only reinforce your relative’s feeling that there’s no point talking to you about the subject. Try to find neutral things to discuss that won’t upset either of you. Tempting though it may be, don’t go along with any delusions or hallucinations; just listen and sympathize instead.

Do your best to minimize any stress and stimulation around the house during these times. A person experiencing or recovering from a psychosis can seem almost child-like and may need your help in making decisions. Show your care and concern by avoiding confrontations, criticism and blame.

During or after a psychosis there’s an increased potential for suicide. Take very seriously any threats or gestures of self-harm. Don’t be afraid to ask about your loved one’s mood. Do they feel safe or are they thinking of hurting themselves? Talking about suicide doesn’t make it happen, but it can enable you to take preventive action.

Confidentiality is another aspect of this risk factor. If you’re privy to “secret” thoughts or information, especially regarding suicide or possible harm towards others, do you keep the confidence or act to prevent a tragedy from happening?

Don’t make promises you can’t keep, but remain supportive, compassionate and firm as to where the confidentiality must end. When you hear of any such plans, you might say, “I can’t imagine what you’re going through, but I want to help you. Tell me how best to go about it.” Or “I can’t keep your suicide plan to myself. I’d like to arrange for us to see a doctor together.” Don’t say, “You need to pull yourself together and snap out of it.” Or “Let me tell you about my problems, which I’m sure will help you forget about yours.” These remarks aren’t supportive, helpful or compassionate — and may even be dangerous.

Despite risking feelings of anger or betrayal, you need to pass on any information suggesting someone is at risk of being harmed. Get your loved one to a mental health professional pronto.

After the psychosis

Once the psychotic episode subsides, your relative may be able to handle more responsibility. A good place to begin is with self-care tasks like personal hygiene, getting dressed and eating scheduled meals. Another option is assigning simple household chores.

Try to gently encourage socializing. Invite one or two guests for dinner perhaps. Suggest a drive or a walk in the country, somewhere peaceful and quiet. Steer clear of noisy, hectic places such as malls or downtown streets. If you go out for a meal, choose a small restaurant and go during the least busy time of the day.

Avoid questions that sound like pry- ing: “What are you thinking about?” Or “Why are you doing that?” Focus on neutral, unemotional events, perhaps a movie or TV program instead of world affairs and politics. Your relative may find it difficult to talk about anything, in which case you can watch TV together, play cards or a game, listen to music or read.

Without forcing the issue, mention you’d like company when you set out to do errands. Any time you’ll be late getting home, encourage responsibility by suggesting your relative starts preparing dinner.

Family caregivers are often the only friends their ill relative has, so be a friend, a respectful friend. If you’re asked not to reveal the nature of your loved one’s illness to others, then don’t, even if you feel your experience may help other caregivers coping with the same problems.

Your respect, patience, compassion and gentleness will go a long way towards helping both of you begin to live fulfilling lives again.

Edited from Caregiver and Schizophrenia: How to Handle the Psychosis, SZ Magazine, fall 2013.

STAY INFORMED

Our website is updated regularly with the latest news about our programs, services and upcoming events. Get the good habit of checking our homepage often. There’s always something happening. www.amiquebec.org.
ON THE JOB

Carol Plathan, an AMI board member, has held various administrative positions at Concordia University over 22 years. Nowadays she works with data base management, which involves figures galore, dealing with faculty, academic scheduling and urgent situations that arise at any time. It’s a key position and in her absence someone always needs to replace her.

Daniel, age 25, has been a troubled son since his teens. By grade nine he had already attended five different high schools. There was drug addiction, problems with the law, a year at Shawbridge and another year at Portage West Island, a drug rehab clinic for youth. Homeless for six months, he had his first psychosis at age 20.

“I have a degree in psychology and worked in a homeless shelter for many years, but schizophrenia never even occurred to me,” says Plathan. “Then Daniel became very paranoid and locked himself in the bathroom with a baseball bat for 24 hours. I called the police to break the door down.” He spent the next six months in the high-care unit at the Jewish General and Plathan told her boss what was happening.

The woman was understanding and said they could arrange something in case of an emergency. How reassuring compared to Plathan’s previous superior, who once told her, “If you have a medical problem with your son, please hire a nurse because you’re not allowed to take time off.”

Daniel’s first psychosis became a routine. He normally spends six months in hospital, six problem-filled months at home, then back again. And every time, the hospital requires a court order for admission. Plathan is angry that the routine can’t be simplified, especially for chronic patients. So many steps taking so much of her time: see the lawyer, fill out the form, meet with the court administrator, go to the courthouse to file the order, back for the court hearing, spend a morning waiting for the court order, go to Emergency to tell them her son is coming in, make arrangements at the police station, notify her mother (with whom Daniel shares an apartment) to let the police in. Total, five days. “The last time it happened, I had to wait for weeks until the Christmas break, because even with my understanding boss, I couldn’t spare the time,” she says.

Time is money

Plathan has worked out a time-off system that’s acceptable to them both. She accumulates hours by putting in a good deal of overtime, work for which she’s compensated in hours, not money. She supplements that with vacation days when necessary. Her union contract stipulates she’s legally entitled to 35 hours emergency leave in any one year to look after an immediate family member or a person in permanent residence. It’s not much and it’s not a perk; she needs to make up the hours she uses at some future date. So far she hasn’t touched any. She’s mentally putting the time aside for the day when she may have to move her elderly mother into a nursing home.

When the workday is over and most of us can relax, Plathan is just getting her second wind. Daniel and his grandmother, who rarely goes out because she suffers from hip pain, live close by and she visits every day. She also does all their grocery shopping, cooks for her son, takes the garbage down and does laundry for the three of them. She pays half the rent on her mother’s apartment and half the services, too, including phone, TV, internet and electricity. Needless to say, there’s no money to burn. She also works a part-time job to make ends meet.

Astonishingly, Plathan still finds time to look after herself. She’s given to ruminating, which she describes as a type of anxiety that results from high-level caregiving. To forestall it, she’s into cardio at the gym three or four times a week. There are visits to the Queen Elizabeth cognitive behavioral therapy clinic, where they focus on anxiety-reduction techniques. At 9:00pm it’s finally lights out.

Asked what changes would improve working life for caregivers, Plathan answers, “Flexibility and time. Sure, it can impact the job when people take time off. But a happy employee is more productive. Without the flexibility to deal with family emergencies, a company will have a disgruntled, depressed and seriously stressed-out worker.”

Another thing that rankles: anyone who tells her to have hope. “Please don’t ever tell someone to have hope when they’re in a hopeless situation. I want people to accept the fact that my situation is difficult. I don’t deal with hope at all, only acceptance.”

And yet Plathan can summon up the self-assurance to describe herself as “a very happy and relaxed person, more or less.” That sounds a lot like courage. Or is it hope?

The Standard
to ensure a safe and healthy working environment for all

Last year the Mental Health Commission of Canada championed a document to draw attention to the importance of mental health among employees. Titled the National Standard for Psychological Health and Safety in the Workplace, it is a systematic approach designed to help employers avoid or correct factors that might contribute to psychological distress and substitute effective practices in their place. To learn more, visit the Commission’s website: mentalhealthcommission.ca/English/node/5346.
From the beginning the Benitahs understood that life for their son would never be the same and neither would theirs as a family.

It was 1992. Alain was 18 and in his second year at Vanier when, seemingly out of the blue, he suffered a psychosis. In retrospect there had been subtle warnings, but now came the worst news: schizophrenia.

“We were devastated,” says Jean Claude. “There was no mental illness in the family and we didn’t know that much about it.” They went on a reading binge, looking for information wherever they could find it. They discovered AMI. (Jean Claude is currently president.) And they made a decision that went against conventional wisdom. When Alain was discharged from the hospital, he would continue living at home.

It didn’t take long for the reality of life with mental illness to set in. “When the psychosis hit, Stella and I were also at Vanier as members of the teaching staff,” says Jean Claude. “Alain’s doctor had recommended that he go back to school and I was upset when Vanier turned a deaf ear to my explanations and request for insight. They told me their policy was to treat all their students the same and I shouldn’t expect leniency just because.”

Jean Claude read about Jewish Vocational Services Workshop, an organization that helps people with a physical or mental handicap to gain experience in the field of packaging. It was a lucky break.

A cousin owned a lamp factory and, over objections and lack of understanding of more than a few employees, Alain joined the company. Cooperation was minimal and Alain learned soon enough that working there was no bed of roses. He stuck it out nevertheless, trusting in his parents’ advice when they told him that work would be good therapy. It was only some 10 years later, when the lamp production was outsourced to China, that Alain found himself unemployed.

And then, another lucky break: Agence Ometz found Alain a job at Richards Packaging in the warehouse. July will mark six years that he’s been there.

For Stella and Jean Claude, life goes on, only differently. They’re a threesome now because Alain goes wherever they go — restaurants, concerts, holidays, everywhere.

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There’s one major loss, they concede. They’ve always loved to travel. When Alain’s siblings were living at home and could stay with him, they’d plan for two major trips yearly. Now it’s three weeks once a year, because that’s all the time their working son is allowed.

No couch potato

Alain has a busy life. He’s up at 5:45am, showers, makes his breakfast and most times takes the bus to work, where his day begins at 7:30. He swims three times a week and attends synagogue on Saturdays. He used to play piano and still connects with music. His tastes are eclectic, from fifteenth century French to the Beatles.

He’s never had a relapse. Exactly how large a part work has played is hard to pin down, but there’s been a major boost in his self-confidence. He’s calmer and his mood swings are milder. “I’m more mature,” is how he sees himself. And something else: “Ten years ago, Alain would never laugh,” Jean Claude reveals. “If anyone else did, he couldn’t understand why. Today he finds things very funny and laughs a lot. It also used to annoy him when he heard some...

continued on page 6
Young Adult Group off to a flying start

O ur Young Adult Group, an offshoot of the fundraising committee, was created expressly for creative, energetic 18-35-year-olds with new ideas on how to break down the stigma surrounding mental illness.

Plans for their first event are already underway. The Full Moon Party will take place June 14 at Espace Reunion. There’s a different sort of theme — inVISIBLE (because mental illness is invisible but those who live with it are not). There’s also a contest: dream up a hashtag for the party. The winning slogan will be printed on t-shirts. Buy one and that’s your ticket to an evening of fun. The hashtag winner takes home an iPad; runners-up win tickets to Just for Laughs. All will be awarded during the evening.

There’ll be music, dancing and an open bar. Sounds like a ball. Be there Saturday, June 14, 9:00pm-2:00am, Espace Reunion, 6600-6610 Hutchison.T-shirts, $65. For information on joining YAG, call Pam Litman at 514-486-1448 or email pam@amiquebec.org. Visit our website for further details: www.amiquebec.org.

Art for Charity Fundraiser

J oin us on April 24, 5:00-9:00pm, for a vernissage (free admission) at the Liane and Danny Taran Gallery, 8170 Montview, TMR, and take home one of the beautiful works of art on display. All are affordably priced from $100-$500. 85% of the event proceeds will benefit AMI’s programs. Watch our website for further details.

Harris ... continued from page 5

would reassure him.

About 25 people work at Richards. They consider themselves a family and not everyone was pleased with the company’s hiring decision. They wondered why Benitah was there. The answer was simple: “We’re helping someone out. He’s okay.” Still, there was even some bullying, which Harris abhorred and made his feelings known. “It’s always the weakest person who’s the victim. Alain told me he used to be bullied in high school, pushed against the locker. I can’t protect him from everybody and all of life, but bullying isn’t tolerated here. We may have our arguments, but there’s no violence.”

Trouble deflected

The darkest moment came when Benitah walked off the job. Harris asked him three times if he wanted to go home and he answered yes. “I said, ’Okay then, come back on Monday with a counselor and your parents. But I must tell you, if you leave here you’re finished. I can’t go through this all the time, worrying that you’re going to run off.’ Monday he was back very nervous and contrite. It was the one and only time that happened.”

At one point the manager suggested that the company stop the experiment. Harris objected. “Please let it go. I’m not giving up on him.” It was the same comment he used to make to continued on page 7
Spill the Beans ... continued from page 1

In families where the understanding of mental illness is limited and prejudice is common, the choice is not so clear. Disclosure might lead to judgment and social exclusion. Situations like these often bring on shame, loneliness, depression and diminished personal safety. The risk of suicide is known to be an elevated danger following a psychiatric diagnosis.

These same benefits and drawbacks also apply to romantic relationships. By openly discussing a psychiatric diagnosis, both partners are able to explore what the illness means for each individually and for both as a couple. It’s the time for the two to decide whether there’s a strong enough commitment for the relationship to survive the impact of the new burden. Once again, discussing the illness’s repercussions helps people gain a better understanding of out-of-character behavior and reduces the possibility of difficult actions and reactions incurring offense.

If you’re working

Disclosure in the workplace can’t be reduced to a simple yes or no. It largely depends on the nature of the job and the type of mental illness. Does your condition have an impact on how you perform your duties? Could your medication slow your reflexes or interfere with your ability to concentrate?

To follow the general guidelines: Should your job be safety-sensitive — truck driver or airline pilot, for instance — it only makes sense that you speak up about your illness. If you’re doing office or retail work, the area becomes grayer and most likely telling isn’t mandatory.

But what if you’re being interviewed for a job and the question is put to you? Should you hide the truth? Disclosure can help to explain any awkward gaps in your employment history. And if you conceal, you might pay the price later on, especially if your illness affects your ability to work.

Under the Quebec Charter of Human Rights and Freedoms, mental illness is considered a handicap and consequently discrimination is prohibited. So legally your employer has a duty to provide you with necessary accommodations. These may include adjusted or limited work hours and a modified work environment (such as an office instead of an open workspace to reduce the impact of distractions and extraneous noise). Other employees may resent the fact that individual differences sometimes necessitate uncommon treatment in order to achieve equity, but the law is the law. The employer’s obligation would extend only up to the point of “undue hardship.”

How to decide

In the end, it’s up to you. You may choose to open up to some friends or family members and not others. At work, you may draw the line at revealing only some details.

If you’re still not certain, do take your time. Just don’t come to associate a sense of shame with your hesitancy. See it instead as several options available that need reflection before you choose the one that feels right. Because once the cat’s out of the bag, it’s out for good.

Adapted from “To tell or not to tell — considerations in disclosing a diagnosis of mental illness” by Sabrina Hassan, Moods Magazine, Winter 2014.

Harris ... continued from page 6

Benitah: “I will never give up on you as long as you don’t give up on yourself.”

Those trying times are long over. In fact, things are going so well that Richards has taken on a second employee with mental illness. Ted Tryer, 62, who suffers from bipolar disorder, works in the warehouse with Benitah. Even though the two often pretend they don’t like each other, Harris knows it’s a game they play. Tryer has a paternal affection for his co-worker. When one is away it’s clear that the other misses him. And when they’re both on the job, they work well together.

Benitah loves his work and says so regularly. The company returns the affection. “You can’t not love him,” says Harris. “He’s friendly, caring, polite, the classiest guy I’ve ever met in my life. And he’s much more self-confident now. I can’t say anything bad about him.”

As our talk was winding down, Harris disclosed that his brother suffered from schizophrenia but rejected all their father’s efforts to get him help. “You can’t force a guy,” he says. “It makes me feel good to be helping someone now.”

TRIBUTES & MEMORIALS

| In honor of Blanche Moskovici | In memory of Doug Richardson |
| Beverly Kravitz | Kay Simpson |
| In honor of Benjamin Librowicz | In memory of Debbie Richardson |
| Oro Librowicz | Kay Simpson |
| In memory of Sara Katz | In memory of Sarah Gropper |
| Fran and Howard Brenhouse | Kay Simpson |
| In memory of Sandra Katz | In memory of Lynda Percival |
| Kathryn Kines | Martin J. Done |
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| Kay Simpson | Judy Phillipson |
| In memory of Pieter Boudens | In memory of Herbert Herman |
| Kay Simpson | Marylin Block |
| In memory of Liliane Durand McQueen | Banque de Développement du Canada |
| In memory of Michael, Evelyn and Judy Ortenberg | Louise and Edgar Goldstein |
| In memory of Gino Motafferi | Helena Casey |
| In memory of Anita Miller | Frank Kagan and Elsa Kisber |
| In memory of Michael Shaffer MSW | Saul Friedman |
| In memory of Mary Quinlan | Katherine Stern |

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Jean Claude Benitah, President
Anna Beth Doyle, Vice President
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Share&Care is a grassroots organization, committed to helping family caregivers manage the effects of mental illness through support, education, guidance and advocacy. By promoting understanding, we work to dispel the stigma still surrounding mental illness, thereby helping to create communities that offer new hope for meaningful lives.

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We never share, trade or sell donor information.

Benitah ... continued from page 5

body whistling. Now he’s the one who whistles.”

In Quebec City there’s a pilot project called Clé en main. When a patient leaves the hospital, the organization takes over, finds the person a comfortable place to live and makes sure services are available. A full follow-up team of professional care providers is in place. Once everything is on the rails, the hunt for work begins. The project is reportedly doing well and the aim is to eventually expand it to other areas of Quebec.

While no two mental illness situations are identical, it’s clear to the Benitahs what made the difference for their son. They convinced him from the get-go that nothing was more important than taking his medication regularly. Otherwise he could wind up back in the hospital and any ideas of working would be over. That prospect was sufficient to keep him compliant.

Second, Alain needed a happy place to live. “At the beginning,” says Jean Claude, “we were often told what a mistake it was to let him stay at home, that he had to learn to fend for himself. But we knew our son and worried that living on his own he’d risk relapsing. After 20 years, we know we made the right choice. Even Alain’s doctor agrees. ‘Don’t change anything,’ he advised us. ‘Alain is one of my success stories and I don’t have that many.’”

Stella interrupted. “Don’t forget patience and love. Even if something bad happens, parents have to be supportive and understanding. Their child needs to feel appreciated.”

Parental caregiving may not come with a salary or working hours, but if that’s not a job, what is? ☐