



BC's
Mental
Health &
Addictions
Journal

Visions

Families





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bc partners | Seven provincial mental health and addictions agencies are working together in a collective known as the BC Partners for Mental Health and Addictions Information. We represent the Anxiety Disorders Association of BC, Awareness and Networking around Disordered Eating, British Columbia Schizophrenia Society, Canadian Mental Health Association's BC Division, Centre for Addictions Research of BC, FORCE Society for Kids' Mental Health Care, and the Mood Disorders Association of BC. Our reason for coming together is that we recognize that a number of groups need to have access to accurate, standard and timely information on mental health, mental disorders and addictions, including information on evidence-based services, supports and self-management.

visions | Published quarterly, *Visions* is a nationally award-winning journal which provides a forum for the voices of people living with a mental disorder or substance use problem, their family and friends, and service providers in BC. *Visions* is written by and for people who have used mental health or addictions services (also known as consumers), family and friends, mental health and addictions service providers, providers from various other sectors, and leaders and decision-makers in the field. It creates a place where many perspectives on mental health and addictions issues can be heard. To that end, we invite readers' comments and concerns regarding the articles and opinions expressed in this journal.



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In this issue of *Visions*, we take a closer look at the family. We look at the impact of mental illness within the family, and on its various relationships. We explore how strengthening family relationships and caregiving skills can contribute to the recovery of the person with mental illness. We also take a look at how families of people with mental illness can help each other and, in particular, at the potential for fathers to play a more active role as caregivers and advocates.

In planning this issue, Guest Editors Nicole Chovil and Keli Anderson – family members themselves – felt that it was important to focus our attention on families of young people, as the majority of mental illness first appears either in childhood, adolescence or young adulthood. It is also during these years that the family’s role is most important, and when family support and involvement plays a crucial role in successfully managing the illness.

The families whose stories appear within these pages attest to the value of this role: in helping engage the young person into care in the first place, in fostering dialogue and eventual acceptance of the illness, in providing support on a day-to-day basis, and in making change for the better throughout the mental health system, even in the face of tragedy.

To play this role, however, families need support: they need advice about how to encourage their sons and daughters to seek treatment when needed and they need education about the illness and how to deal with it. They also need understanding from professionals within the mental health system, but also from other places, like the school system.

As many of our articles describe, the support families need can come from a variety of approaches: through family education courses, through ongoing support groups, and through tools and information available on the internet. Regardless of the vehicle for providing support, the starting point for strengthening the family is within the treatment relationship itself, where families need to be respected as allies within the treatment team and as potential experts in their own right.

Eric Macnaughton

The BC Partners are grateful to the Provincial Health Services Authority for providing financial support for the production of Visions

subscriptions and advertising | If you have personal experience with mental health or substance use problems as a consumer of services or a family member, or provide mental health or addictions services in the public or voluntary sector, and you reside in BC, you are entitled to receive *Visions* free of charge. You may also be receiving *Visions* as a member of one of the seven provincial agencies that make up the BC Partners. For all others, subscriptions are \$25 for four issues. Back issues are \$7 for hard copies, or are freely available from our website at www.heretohelp.bc.ca/publications. Contact us via any of the means listed below to inquire about receiving, writing for, or advertising in the journal. Advertising rates and deadlines are also online.

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The opinions expressed in this journal are those of the writers and do not necessarily reflect the views of the member agencies of the BC Partners for Mental Health and Addictions Information or any of their branch offices

I am an addictions counsellor and I would like to say that I thoroughly enjoy your booklet, *Visions*. I received the Concurrent Disorders issue in March and find the information very helpful. I just received the one on Parenting and will read it next. Keep up the good work.

Benita Chapdelaine, Terrace

I just received a copy of *Visions*, and appreciate the good work seen here. It's good to see the government spending our tax dollars on mental health issues. My input is regarding a lack of balance. As I read these three specific articles, I thought great! You are covering gender specific topics, but was disappointed to see that these valuable resources are not being spent on my gender. Not a single article? Why is this? Page 15: "Substance Use by *Girls and Young Women*." Page 29: "Woman's Pain". Page 56: "New Programs for *Women and Youth*." To be fair, this issue is the first I've received, and therefore I can't fairly form an opinion. I'll be looking forward to reading further such resources that include a focus on boys and men's issues.

Dan deMunck, Maple Ridge

I read with interest, and a little anxiety, my copy of your *Visions* magazine. Although I am relieved that the mental health industry in BC is finally affirming the reality that many people with drug addiction problems also suffer from other or 'concurrent' mental health disorders – like bipolar disorder and depression – I noticed that the link between both addiction and mental health disorders and early childhood trauma was noticeably absent. Many people who were traumatized/tortured in early childhood go on to develop mental illness like bipolar disorder and depression, psychosis etc. There is a lot of information coming from the US linking post-traumatic stress disorder from early childhood trauma to drug addiction and mental illness in adulthood. It's time that BC did the same. I look forward to your forthcoming issues and eagerly anticipate the linking of drug addiction and mental illness in adulthood with early childhood trauma/torture.

Anonymous

Your Winter issue, in my opinion, failed to adequately cover the increasing societal consumption of marijuana. As a former pot-consumer, I can attest to the permanent damage that marijuana can cause to the consumer's body and mind.

Scientific proof of such potential damage? For one, there are the startling facts published in an article last September 17th, in London's *Guardian* newspaper, authored by a Professor at the Institute of Psychiatry, Robin Murray: research that people with schizophrenia who consumed a lot of cannabis had a much worse outcome than those who didn't. Murray goes on to say: "This was confirmed by other studies, including a four-

year follow-up at the Maudsley Hospital. Those who continued to smoke cannabis were three times more likely to develop a chronic illness than those who did not consume the drug. Why does cannabis exacerbate psychosis? In schizophrenia, the hallucinations result from an excess of a brain chemical called dopamine. All of the drugs that cause psychosis – amphetamines, cocaine and cannabis – increase the release of dopamine in the brain. In this way, they are distinct from illicit drugs such as heroin or morphine, which do not make psychosis worse."

If pro-pot people propose legalizing marijuana for practical reasons – e.g., less pressure on already-overburdened law-enforcement and justice systems – that's a clear and perhaps practical motive; but there's simply way too much of the media-propagated misinformation out there telling our impressionable youth that pot is harmless.

Frank G. Sterle, Jr., White Rock

Re: your *Visions* issue on Parenting. We're doing some things in Squamish that might be of interest to your readers, as part of the Communities that Care project.

- 1 We're using a population health model to help the community learn to assess science-based risk and protective factors that are common to the development of five major adolescent health and behaviour problems: substance abuse, pregnancy, school failure, violence and delinquency
- 2 We have a huge community coalition that has moved through the steps of assessing the community, prioritizing risk and protective factors of particular interest in Squamish and then through community forums, and identifying evidence-based programs that would be a good fit for Squamish
- 3 We have finished implementation for year one of one of the evidence-based programs (The Strengthening Families Program) and are in the first year of implementation of a second (The High Scope Program). (The Strengthening Families Program combines a Children's Skills Group, Parent Skills Training Group and a Family Skills Group. To remove barriers to parents' attendance, we provide a meal, child-care and transportation)

The model has been evaluated as a very effective prevention program by the Substance Abuse and Mental Health Services Administration in the US, is one of the 'best practices' on Health Canada's website, and is the subject of a huge trial in Ontario by the Centre for Addiction and Mental Health. Please contact us for more information or visit us at www.ctcsquamish.com.

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*If you have a comment about something you've read in *Visions* that you'd like to share, please email us at bcpartners@heretohelp.bc.ca with 'Visions letter' in the subject line. Or fax us at 604-688-3236. Or mail your letter to the address on page 3.*

Letters should be no longer than 300 words and may be edited for length and/or clarity. Please include your name and city of residence.

All letters are read. Your likelihood of being published will depend on the number of submissions we receive.

Visions Survey Results

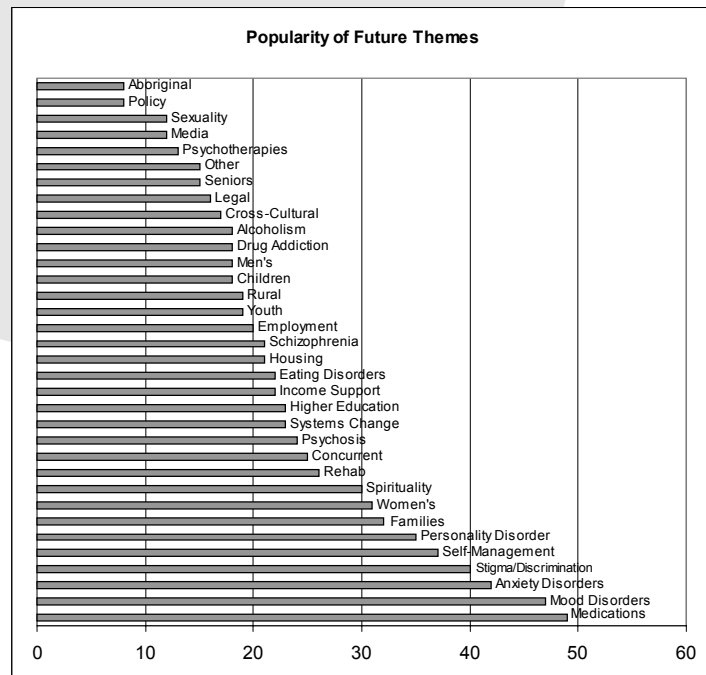
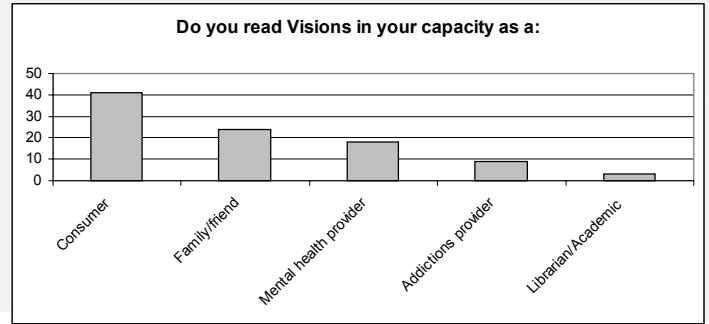
Two issues of *Visions* ago, the BC Partners for Mental Health and Addictions Information included a survey to help gauge what our readers like and don't like about *Visions* as well as what they'd like to see in the future. The response was better than we had hoped, with nearly 100 people mailing in from all over the province. Trevor W. Jackson of Port Alberni was the winner of the \$50 prize, who in turn graciously donated it to the New Horizons clubhouse run by the Canadian Mental Health Association Port Alberni Branch. Thanks, Trevor!

You like us, you really like us!

According to our survey, 69% of all respondents find *Visions* very valuable, with 97% giving us a ranking in the 'very valuable' or 'valuable' range. Most of you tend to keep *Visions* around to make reference to later. You tend to like the magazine as is, with most of you liking the current design and quarterly production schedule. Two-thirds of you have even used a resource listed in the journal and three-quarters of you share your *Visions* with at least several other people.

Our Readers

Our readers come from a variety of backgrounds and expertise. While more than half of our survey respondents are either a person affected by mental health or addictions or a family member or friend of such a person, the rest are mental health and addictions professionals working in the field (see chart above). *Visions* is a proven way to reach both audiences and bring them closer together. Three-quarters of those responding to the survey were women and an overwhelming majority of respondents were between the ages of 36 and 65.



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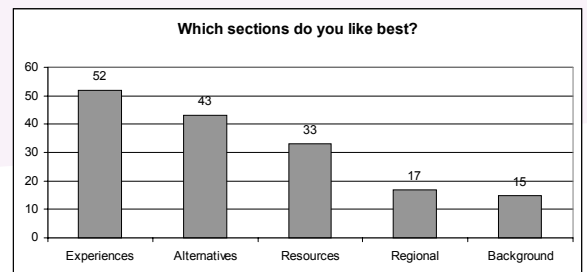
The Magazine

The bar graph to the left shows that the most popular topic themes relate to medications, mood and anxiety disorders, stigma/discrimination, and self-management. The survey also showed that readers are eager to see previously-covered topics in *Visions* revisited.

Respondents also made it clear that the sections on Experiences and Perspectives and Alternatives and Approaches were the most appreciated, with other categories not far behind. 57% of respondents read the magazine cover to cover with 74% of you reading the editor's message or guest editorial.

All in all, we are encouraged by the replies and look

forward to building an even greater journal: BC's only Mental Health and Addictions Journal with its unique focus on the consumer, family and mental health and addictions professional. Missed the survey and want to give your input? We always welcome feedback on *Visions* (see our contact information on page 3). The *Visions* survey is also online at www.heretohelp.bc.ca/publications/visions where, as always, you can check out all our back issues.



Families as Partners for Mental Health



Nicole Chovil, PhD,
and Keli Anderson



Nicole is Director of Education for the BC Schizophrenia Society



Keli is a parent of a teen with bipolar disorder. She is also a founding member and Executive Director of The FORCE Society for Kids Mental Health Care. The FORCE (Families Organized for Recognition and Care Equality) is a non-profit society that was formed in 2000 by a group of mothers who wanted to ensure that mental health care, services and information was provided to families of children and youth

When a serious illness strikes a family member, it sends shockwaves throughout the whole family. Shock, disbelief, sadness and confusion are often some of the first emotions to be felt by family members. When the illness is a mental or substance use disorder, the effects can be particularly dramatic. Although intellectually we know that mental illness strikes many families, when it happens in our own, we're often not prepared. Learning that something is wrong with your child can be a frightening experience.

Mental illnesses impact families in many ways. Families may face difficult decisions about treatment and hospitalization. They may face the anxiety and stress of an uncertain future. The additional demands of care and attention their child needs may lead to burnout and reduced time and energy for other family members. Many families deal with the fear that they may have somehow caused the illness. The cost of medication, time off work and extra support can create a financial burden for families. And finally, the stigma and prejudice attached to mental illness can isolate the family from its community and social support networks.

Many families find that joining a support group has helped them tremendously in dealing with the illness. A typical mental illness support group meets once a month and is free of charge. Support groups provide comfort and an opportunity to be with others who have first-hand experience with mental illness. In addition, support groups can assist with concrete information about managing symptoms, finding help within the community, and the latest treatments available. Support groups offer a safe setting to share experiences and provide an opportunity to learn from others.

All family members – including the ill young person – must work through the emotions that are generated by the illness and arrive at a place where they can accept what has happened. This does not mean passively accepting one's fate. By utilizing the strengths of the family, there is much that can be done to ensure that the illness does not take over their lives. The family's discovery of these strengths and skills often gives rise to changes that improve the quality of life for everyone in the family, including the ill family member.

This issue of *Visions* is devoted to instilling hope in families – for although the road may be bumpy and full of potholes, you and your loved ones can survive and prosper in spite of the mental illness. Over and over again, families have shown us their incredible strength,

courage, resourcefulness and dedication in supporting their ill family member to wellness. In this issue, readers will find courageous stories told by families who have struggled with mental illness. These personal accounts help us to see the human side of mental illness and confirm our belief that we can succeed, even in our darkest hours.

No one should ever have to face a mental illness on their own. Families are often the main support network for a person who may be struggling to manage and recover from a mental or substance use disorder. They are the ones who deal with the illness on a daily basis. Research tells us that when families are given the knowledge and skills to deal with a mental illness, the ill person is better able to cope and has a higher quality of life.

In this issue, we present a variety of perspectives from different family members as well as perspectives from those who work with families of a child, adolescent or young adult family member who is dealing with a mental or substance use disorder. We've chosen to focus on this group as many disorders have their onset in childhood or young adulthood.

children who go untreated suffer, cannot learn and may not form healthy relationships with peers and family. some children are placed on a trajectory for jail rather than college at a very early age.

Youth in a Difficult World
National Institute of Mental Health (2001)

A 2002 analysis of mental illness prevalence studies concluded that 15% or 140,500 children and youth in BC “experience mental disorders causing significant distress and impairing their functioning at home, at school, with peers or in the community.”¹ When detected and treated early, however, the majority of young people can successfully manage and have a fulfilling life. We also know that young people with mental illness are at increased risk for suicide and therefore early detection and treatment of mental illness in young people may help to prevent suicide.

The high rate of hospitalization among young adults between 15 and 24 years of age attests to the impact of mental illnesses on young people. Mental health and drug and alcohol problems – especially among adolescents – frequently occur together. Mental and substance use disorders can affect educational achievement, occupational or career opportunities and successes, and the formation and nature of personal relationships. Left untreated, a childhood mental illness may develop into a much more serious illness in adulthood. Receiving effective treatment, learning what’s needed to manage a mental illness, having strong social supports, and access to resources that maximize educational opportunities are essential to minimizing the impact of mental illness on a young person’s life. Quality information on mental and substance use problems is also key to ensuring that families can support their child.

In the past, families have not always been accorded the respect and involvement that is needed in the care of their child’s mental illness. The need for collaboration between professionals and the family is now being recognized and implemented as a key part of evidence-based practice.

the most useful things a provider ever said (to a parent):

- o “It’s not your fault! You are not powerful enough to have caused the kinds of problems your child has”
- o “Believe in your instincts. You’re the expert on your child.”
- o “I value your input.”
- o “What do you need for yourself?”
- o “I don’t know.”
- o “I don’t know what caused this problem, but I’m willing to work with you to make things better for your son/daughter and family.”

Friesen, B.J. (2002). *Family and Youth Perspectives in Mental Health Services and Research.*

Children, youth, young adults and their families:

- should be involved in designing their treatment plans
- should have treatment plans based on the strengths and resources of the ill person and the family
- should have treatment plans that acknowledge the family as a resource and that empower the family system to operate effectively

The BC Partners for Mental Health and Addictions Information are committed to ensuring that families are given the recognition and support they need and deserve. We are very excited about a new resource for families that will be available in the near future (see ad, page 48). We are also working to create other resources for families. As representatives of two provincial organizations that provide support, education and a voice for families dealing with mental illness, we see this issue of *Visions* as a demonstration of the progress that is possible by the hard work, dedication and continuing hope shown to us by families in British Columbia. ■

footnote

¹ Waddell, C. & Sheppard, C. (2002). *Prevalence of mental disorders in children and youth.* Mental Health Community Consultation and Evaluation Unit, Department of Psychiatry, University of British Columbia

family-to-family

education program

The Family-to-Family Education Program of the BC Schizophrenia Society and National Alliance for the Mentally Ill is a psychoeducational course for families who have a relative with a severe mental illness. The classes are co-led by family member volunteers trained to carry out the curriculum.

The course is a comprehensive package of information about all aspects of mental illness and imparts information and techniques to help family members cope and to help them support the ones they love. The focus is on major psychiatric illnesses (schizophrenia, bipolar disorder, major depression, panic disorder and obsessive-compulsive disorder) and emphasizes the clinical treatment of these illnesses and the knowledge and skills that family members need when faced with the challenges of mental illness.

The structure – consisting of 12 weekly classes of two and a half hours duration – enables family members to tell their own stories, relate to each other’s problems and get to know each other. It includes discussions of medications, handling crises, and empathizing with the ill family member, with an emphasis on effective communication. The course also stresses self-care and rehabilitation, and encourages advocacy and fighting of stigma.

The Family-to Family Education Program was designed by Joyce Burland, PhD, a family member and clinical psychologist, and was introduced into BC in 1995. To date, more than 1,500 family members in 37 communities have completed the course.

For more information about the program, contact the British Columbia Schizophrenia Society at bcss.prov@telus.net, 604 270 7841 or toll free at 1 888 888 0029

For Better or Worse

The impact of a child's mental disorder on the family – A review of the literature –

Sarah Hamid-Balma

Sarah is the Director of Public Education and Communications for the BC Division of the Canadian Mental Health Association, and Visions' Production Editor. She is also a consumer of mental health services

Learning that one's child has been diagnosed with a mental disorder can be a shock to any parent's system, which can affect untold relationships within the family, from child-sibling to child-parent, to the relationship between the parents themselves. Although it's a more common scenario than most may realize – 15 % of kids will be affected by mental illness, touching as many as 140,000 families in BC alone – social science researchers have actually spent very little time studying the impact of a child or young person's mental illness on family relationships.

Although relatively little research has looked at this question specifically, there is relevant research we can learn from, including a literature on the family impacts of chronic illnesses and physical disabilities in children. There is also helpful research on adult psychiatric disorders and family relationships, although some of this work has been criticized for a 'family-blaming' bias, that is, for looking at how the parents' relationship contributes to an offspring's problems, without also considering how the challenges of having mental illness in the family might impact on family relationships in the first place.

Taken together, these

findings provide hope and suggest that while some families can be immobilized by such a life event, others cope well, especially when certain positive features are present to help buffer the stress caused by mental illness in the families' midst. In this article, we'll look first at some of the overall impacts that the family may experience, then look specifically at the potential impacts on marital relationships, and consider why certain families may fare better than others when faced with this situation. Finally, we'll look at some of the interventions that may help families minimize the impact of the illness on their relationships and help them be more effective caregivers and parents.

When considering the research and making generalizations, it's important to keep in mind that certain limitations are common to many of the studies reviewed. These include a lack of longitudinal data (i.e., studies which study families both before, during and after the onset of the illness), and a lack of random sampling (e.g. studying primarily mothers and parents who participate in support groups may not accurately represent all parents dealing with these issues). As already mentioned, we also have to keep in mind that

the research looks at many different chronic conditions, and not specifically at mental illness. While limitations such as these and others prevent us from drawing firm conclusions, the findings do help us gain insight into the issue of the relationship between children's mental illness and family relationships.

Potential Impacts of Mental Illness on Parents (and Families)

The following list reflects just a few of the overall ar-

reas where negative effects are possible for the family:

- **financial strain** both from direct costs, such as specialized treatment services, and indirect costs, such as having to leave employment to do part-time/flex work
- **a reduced sense of confidence** in managing day-to-day difficulties (also known as 'mastery')
- **social isolation** both from child-care demands and friends being lost due to stigma
- **dealing with resentment** from siblings of the child/

stages of mourning

Coming to terms with a diagnosis of a chronic illness (including mental illness) for a child can involve feelings of grief for many families. Family members may actually go through some or all of the classic stages of mourning including denial, bargaining, anger, detachment, depression and acceptance.

Although it's hardly the neat and perfect end that it sounds like, 'acceptance' is achieved when parents demonstrate some of the following characteristics:

- o ability to discuss their child's shortcomings with relative ease
- o striking a balance between encouraging independence and showing love
- o ability to collaborate with professionals to make realistic short and long-term plans
- o pursuit of personal interests unrelated to their child
- o disciplining appropriately without undue guilt
- o abandoning overprotective or unduly harsh behavioural patterns toward their child

Since families aren't all the same, not all parents or families will show all stages and/or may rapidly cycle through or spend long periods of time in one or more stages.

SOURCE: Seligman (1999)

youth

- difficulty finding time to spend away from children
- residual guilt for failing to recognize symptoms or seek help early enough
- potential strains on the family's relationship with their extended family, friends and neighbours
- difficulty participating in social activities as a family
- fathers report greater stress in relation to finances and emotional attachment to the child, while mothers report more stress from managing daily routines and medical regimens
- elevated health and psychological problems, particularly in mothers¹
- frequent reporting by parents of general worries, depression, tiredness, feelings of incompetence and restrictions on personal activities (more so than parents in general)

Effects on the Parents' Marriage

The question of the effects on marriage and marital satisfaction of having a child diagnosed with a chronic health condition (including a mental disorder) is an interesting one. From the point of view of the parent, all of the items listed above (e.g. financial stress, social isolation, etc.) have the potential to add stress and strain to the parents' marriage. Since caregiving for a child with an ongoing illness is generally acknowledged to be a major stressor, it might be assumed that the impact on the marriage must always be negative. However, the research paints a mixed picture, showing

divorce or remarriage

Although there is no evidence that divorce rates are higher among families with a child with mental illness, the impact of divorce raises unique issues. The literature documents, not surprisingly, that divorces leading to single parenthood lead to greater responsibilities for that parent, also to feelings of isolation and status in community and rejection by relatives, friends and neighbours.

Remarriage by one or more of the parents can result in new rules and roles needing to be adopted, problems and issues around loyalties and authority, new or varied financial responsibilities, new resentments by step-siblings, and issues of who does the primary caregiving. Researchers are quick to point out, of course, that divorce or remarriage will not have the same impact on all family members and its impact will also depend on its timing within the family life cycle and the degree of problems before the marital breakup.

SOURCE: Seligman (1999)

negative effects in some cases, no effects in others, and positive effects in still other situations, such as increased closeness and support developing within the couple.

Overall, while these couples may not experience greater divorce rates, they are at risk for marital distress. Such risk areas and effects include but are not limited to the following:

- communication problems
- increased relationship conflict
- increased role strain, particularly the following four areas:
 - practical stressors related to the parenting role, including caregiving activities
 - expectations and disappointments about the division of labour
 - disagreements between parents regarding strategies and for dealing with the illness and the responsibilities of each parent
 - giving and receiving of affection
- decreased relationship satisfaction
- lack of intimacy
- sexual difficulties
- temporary separations

In the end, we must re-

member that these effects are possible but not inevitable. As we considered above, in some cases, the marital relationship may in fact be strengthened in some ways. Also, we need to keep in mind that in those cases where significant impacts on the relationship are experienced, the stress related to caring for a child might have been the turning point for a relationship that was on the edge of distress anyway. As one researcher aptly puts it:

"A family's focus on a child with a disability as the source of family problems may in fact be a 'red herring' that leads parents away from more fundamental issues about their relationship. It is important that professionals discriminate between family problems related to the stress of coping with childhood disability and those that would have arisen under any circumstances. However, problematic marital relationships can be made considerably worse by the birth of a child with a disability. It is probably not true that such a child or any child for that matter can bring a troubled marriage together."²

So why do Some Families Fare Better Than Others?

Despite all this research, still unanswered is why some marriages and families cope well in the face of a child's illness and others don't. A popular theory among advocates is that families don't cope well because of poor or non-existent services. It is certainly true that the presence of accessible, quality services can make things considerably easier on families and their relationships. However, faced with potential stressors such as service barriers and other experiences related to the illness, some families still cope better than others. Things that can buffer potential stressors include:

- experience of parents – for example, the impact may be greater with new parents (of course, parents with other children may still face the challenge of balancing the needs of all children)
- age of the child – developmentally, children vary in their ability to understand their illness and participate in their own care, so the impact on the parents will vary
- parents' resolution of diagnosis, or the way in which the family frames

footnote

¹ specifically, mothers may also show more effects because they are more willing to report symptoms when asked and because of their role as primary caretaker and main representative of the child to the health care provider

² Seligman. (1999). pp. 121-122

its situation and the parents' belief in their capacity to influence life events

- degree of family empowerment – a sense of competence and confidence in their ability to deal with problems, shown by one study to be the only variable associated with 'enrichment' (experiencing positive rewards from caregiving) and less stress
- support of immediate family members
- availability of social supports from family, friends, neighbours
- amount of time for leisure pursuits
- division of caregiving duties
- religious/spiritual involvement
- financial resources
- employment – although a working parent may feel additional stress in juggling work and home duties, studies have consistently shown that having multiple roles including a work role may be an additional source of social support and self-esteem
- physical health of parents
- spouse or partner's level of depression — in one study, the best predictor of both mothers' and fathers' emotional and social functioning one year later was the spouse's level of depression
- amount of helpful information and practical advice available on coping with everyday difficulties

Interventions:

What Helps?

Some of the most helpful things for parents have

been mentioned above, such as access to practical advice and information about how to deal with the illness and access to quality services for their child. In addition, the family may also benefit from practical support having to do with finances or from services that offer respite for their duties as caregivers. They may also benefit from support groups that help them gain access to the wisdom and experience of other parents who have successfully dealt with similar situations. As pointed out by Dr. Don Duncan in the following article, regardless of whether the illness contributes to parenting or relationship challenges (or vice versa), some parents may also benefit from interventions that help strengthen their skills as parents or from supports aimed at strengthening their relationship as a couple. Emotionally Focused Therapy, for instance, is a promising approach for couples with children living with ongoing health conditions. Its effectiveness in this context relates to its focus on communication difficulties, intimacy and emotional problems, and repairing attachment bonds (since adults, like children, have an increased need for attachment during times of stress).

As for parenting interventions, professionals and researchers suggest that parents may find guidance and skills-training around discipline much needed: "Children with chronic illness are foremost children and thus experience the full range of developmental challenges common to all children," write Gaither,

Bingen and Hopkins (2000). Parents may be hesitant to enforce developmentally-appropriate discipline out of fear of what it will do to the child's emotional state, out of guilt, out of a desire to keep their child's life free of further stress, and out of a desire to reduce stress on themselves by potentially avoiding conflict with the child.

Conclusion

Knussen & Sloper (1992) have noted that professionals often underestimate parents' coping abilities and overestimate the negative impact of the child. Believing otherwise may be a self-fulfilling prophecy that just sets one up for failure. It may be most helpful to learn from those parents whose relationships and marriages survive and can even thrive in the face of challenges, from young people who can participate in their own self-care with support, and from families that can rally together and emphasize their collective strengths and coping resources. **ii**

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Give the Relationship Some Oxygen



My theory about what has held my husband, Dave, and I together for 16 years is that we met each other in our late 20s, at a time in both our lives when we were mature, had enough experience to know the difference between love and infatuation and, as we still do now, absolutely believed in committing to each other to make our marriage last.

This love has been more tested than we could ever have imagined. The tests began when we were told that we would not be able to have children, and we put our names on the In-Vitro fertilization program at UBC. Four months after this, when I got pregnant with James, I instinctively knew then that the child I was carrying must be one determined kid.

We entered into parenting thinking that it was the most important job we would take on as a couple. We also entered in knowing that we would have differences of opinion on how to parent our children. What we didn't enter in knowing was how much energy, time and emotion it would take to parent our child, James, who turned out to have bipolar disorder.

I can't speak for my husband, but when people ask me if there were early signs of James' disorder, or at what point did we know there was a problem, I can answer, "when he was a baby." I knew from when he was an infant that he wasn't the same as my friend's babies – when I had to leave coffee get-togethers early because James had problems staying and getting along with the other children; when I would get him into his car seat, pull away from the house, and pull over and cry when he finally fell asleep. I never told my husband these stories because I didn't want to seem like a 'cry-baby' or have him tell me that I was 'overreacting.' I just wanted to be able to enjoy what the other moms were enjoying.

I remember when we had to hospitalize our son when he was 10 years old at the psychiatric ward of BC Children's Hospital. We were allowed to visit from 4pm to 8pm each day during the week. I remember meeting my husband at the hospital at 4pm every day and the almost unbearable pain we felt as we drove away at 8pm every night, watching him pressed against the window waving to us. We saw that having a child on that ward was unlike having one on any other ward. There were no fancy curtains or nicely-coloured walls. There were strict rules and a stark interior, where sometimes a child was restrained and put into the padded seclusion room.

We never talked about how it felt to leave him there, as it was just too painful, and I think the challenge for parents is that most moms want to talk about it and most dads don't. Another challenge was that I was sometimes so caught up in getting James the treatment and support he needed, that I forgot about the impact of the diagnosis on my husband and our relationship. James' disorder became our life.

It helped to have a therapist talk to us, both together and separately. My husband once said to our therapist: "I just want to spend some time with Keli." I then realized that I had begun to look at my husband as just another person needing something from me, instead of looking at him as someone who loved me and someone who just wanted some quality time with me. Life is so overscheduled, over-structured and demanding that it's easy to fall into the rut of thinking of our loved ones as just another thing needing something from us.

Sometimes all that's really needed is some unstructured time for being together. I've discovered that it's not important that Dave and I talk about everything going on with our son; in fact, it's more important that we don't talk about it all the time and that we just forget about it sometimes. Time for marriages and relationships needs to be scheduled in. We now try to get away for a night every couple of months without our children, where we have dinner, stay overnight, and don't talk about James' problems. We need to connect on the level that brought us together in the first place.

I used to think that my children's needs had to be met before my own or those of my marriage. I'm slowly realizing that if I'm healthy and if my husband and I are together and happy, then we are better able to meet our children's needs. After all, remember what they tell you on the plane, in the event of an emergency, if you want to help your children, you give yourselves oxygen first. ■

Keli Anderson

Keli is a parent of a teen with bipolar disorder. She is also a founding member and Executive Director of The FORCE. Society for Kids Mental Health Care (see their website bckidsmentalhealth.org)

Beyond the Blues: Child and Youth Depression is a new Knowledge Network documentary that looks at the problem of depression in youth and helps BC families learn symptoms to identify a child or youth who is in need of professional help. It first airs September 27th, 2004. Check your local listings for times or see www.knowledgenetwork.ca. An online learning component will also be available on the air date under the 'Knowledge Tools' section of the Knowledge Network site. This documentary is the first of a three-part series on child and youth mental health

Is ‘Bad Parenting’ the Chicken or the Egg?

Don Duncan

Dr. Duncan is Medical Director of Mental Health Services for the Okanagan region of Interior Health. He practices Child and Adolescent Psychiatry in Kelowna, BC and speaks frequently to public and professional audiences on issues related to children's mental health

After years of resisting referral to a mental health professional for her son's difficulties, the child psychiatrist uttered the very words she was avoiding: “Mrs. Johnson, I think your son is suffering from a mental illness and I want to refer you and your husband to a local parenting class.”

The ‘mental illness’ part was not a surprise. She and her husband had known all along that there was something unique about their son's struggles. It was the ‘parenting class’ part that twisted the knife she had felt sitting in her heart for years.

These innocent words may not have been felt so strongly by others. For Mrs. Johnson, however, they only served to confirm the shaming opinions of friends, family and the countless strangers in grocery stores that her inadequate parenting skills were the cause of her son's mood problems and disruptive behaviour.

We've all seen it: an angry, tight-jawed mother yanking on the arm of a screaming, flailing child in the grocery store. We scurry to the next aisle out of social embarrassment. And then, we've all thought it: “No wonder the child is like that, look at that stressed-out mother.”

Sadly, the experience of Mrs. Johnson in the professional's office is played out

many times every day in the offices of mental health professionals across North America. The parenting class recommendation itself is not necessarily the problem. It's the implied message: the suggestion that ‘bad kids’ are made by ‘bad parents,’ that flattens the hopes of parents already struggling to preserve slivers of self-esteem. Yes, I know, the suggestion is very consistent with our cultural beliefs and very consistent with clinical lore. But does it have scientific merit?

To be sure, parenting patterns can have a significant impact on children's functioning and well-being. There is no scientific doubt here. But what do we make of the strong resilience literature that demonstrates most kids survive bad parenting with little significant pathology. This seems to fly in the face of the unsubstantiated, often assumed, and all-too-commonly implied theory that any child in the presence of a bad parent (Mrs. Johnson hears “your parenting”) will develop mental illness. This is simply not true.

The clinical implications are clear then. What are the chances that the mental illness-related problems being experienced by this child in my office were ‘caused’ by this parent? Possible – but unlikely! The corollary follows. What are

the chances, therefore, that fixing the parent will fix the child? Don't bet the farm.

So what do we do with parenting skills then? Why would we spend precious limited resources on family assessments and family therapy? Why include expensive family interventions in our toolbox? Should we ignore the family and focus on the child as an isolated individual? We'll get to that later, but first let's discuss the relationship between child dysfunction and parental distress further.

Common clinical lore suggests that parents who are stressed by life circumstances (finances, life events, low education, family size, etc.) bring that stress to the parenting role and inflict psychological harm on their children through dysfunctional interactions and poor parenting styles. Good theory. It's just not true.

For example, Vitanza (1999) demonstrated that the strongest predictor of parental stress in mothers of children with mental illness was not the environmental stressors but the level of challenging behaviours in their children. So it does not seem to be the case that stressed parents bring their stress to the parenting role. Rather, it is the parenting of challenging children itself that causes parents' stress. Bad parents don't cause bad kids. It's the other way

around. Challenging children bring out the worst in their caregivers, teachers, doctors and nurses.

Interestingly, other factors that predicted mother's stress more than environmental stressors included her level of self-esteem, the presence of depressive symptoms and interpersonal sensitivity (being more easily hurt than the average person).

Interpersonal sensitivity is an important factor for professionals to keep in mind. Parents' historic experiences with blame and shame will make it easier for them to misunderstand our communication. Extra care must therefore be taken to ensure we are just as clear about what we are *not* saying as we are about what we *are* saying.

Barkley and others have studied mothers of children with attention-deficit hyperactivity disorder and found that they were more negative in their interactions and were more likely to utter commands than other mothers were. However, it is interesting to follow the research further. When the children are treated, these mothers become just like every other mother. Again, the ‘bad moms’ don't create the problem. Rather, it looks like the problem creates the ‘bad moms.’

Vitanza showed further that some positive environmental factors (like the

presence of social supports) can reduce the parental stress experienced by these parents and may actually protect mothers from the stressful effects of parenting a difficult child. Unfortunately, having a difficult-to-manage child often leads to increased social isolation and a reduction in social supports, thereby magnifying the effects of the child's challenging behaviour.

Back to parenting classes. Do I recommend parenting classes? Absolutely. In fact, I recommend them often. And I've taken some myself. This may seem inconsistent with my previous comments and criticisms, so let me explain.

The difference between my recommendation that parents attend skills classes and what I believe to be a typical recommendation lies in the theory behind the recommendation, the expected outcome of the recommendation, and the implied (or sometimes explicit) message around the recommendation.

Professionals often, even if unintentionally, send the message to struggling parents (whose sensitivity is already heightened to criticism) that they are failing as parents and that their failure is a primary cause of their child's problems. Thus, we not only miss a prime opportunity to assist the family, we increase parental stress and actually worsen the very problem we are attempting to treat.

Regardless of the clinician's actual intentions, parents often hear the following:

"Mrs. Johnson, your

son has a mental illness. If you weren't so stressed-out, or if you had better parenting skills (and most parents do), your child would not be experiencing the problems you are asking me to fix. You have to stop focusing on your child's difficulties as an excuse for your stress (and failing marriage) and accept responsibility for your part in this. I am sending you to some classes so that you will learn that this is so, and so that you will change your ways. If you do as I say, attend the classes, and improve your parenting skills to at least 'average,' I believe your son's difficulties will resolve and my services will not be required."

The appropriate message, which must be stated explicitly so that there is no room for misunderstanding, follows logically by contrasting the above message:

"Mrs. Johnson, your son has a mental illness. I have a few recommendations for you. I want you to listen very carefully to what I am about to say because it will be very easy for you to hear me saying something that I do not intend.

"I do not believe you have caused your son's problems. I can guess that you have heard others suggest that you have, or that you have had those thoughts and fears yourself. But the kinds of difficulties your son is having are not caused by parenting. And because you did not cause the problem, I do not believe you can do anything in particular to fix the problem. I'm sure you would have done that by now if you could.

"In fact, my experience with struggling children and their families allows me to guess that your son's difficulties are a significant source of stress for you and your family. The research shows that children with these difficulties are very difficult to parent and place you at risk of burning out.

"The problem is, when you get stressed, it becomes harder to be the parent you want to be and to be the parent your child needs you to be. You see, it's not that I think your parenting is below average. Rather, it's that your child's difficulties place unusual demands on you so it is essential that you have better-than-average parenting skills.

"Nobody is born with these skills. But they can be learned. Your son needs you to be the best possible parent you can be. And I believe learning these additional skills and hearing from other parents who are experiencing the same struggles you are will make parenting a little easier for you too.

"Thus, I am recommending you attend some parenting classes to fine tune your skills and ensure we are doing something to help protect you from the stressful effects of parenting a difficult child. This is in your son's best interest as well, because he can't afford to have you burning out. We need you in there for the long haul."

In summary, I have not found it helpful or valid to assume that I (as the professional) have a positive goal for this child and that the parents (as the problem) must be 'treated' to make them less of a prob-

lem. When I see 'dysfunctional' parents in my office, I immediately ask myself 'what kind of world must they be living in to make them so stressed?' Next I ask, 'what can we do to assist them achieve our shared goals for this child and for their family?'

This shift in perspective may seem subtle, but the effect it has on my communication, on the parents, on the intervention process, and ultimately on the child are enormous. In my experience, bad parents are simply good parents who need less blaming and shaming and more encouragement and reassurance. They are trying to do the same things I am, they've just been at it a lot longer. ■



it is the parenting of challenging children itself that causes parents' stress. bad parents don't cause bad kids. It's the other way around

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Learning to Be a Different Kind of Parent

Susan Inman

Susan has worked for many years as an English and drama teacher at a secondary school in Vancouver

For over 20 years, my husband and I enjoyed participating in and witnessing the miraculous process of child development. Our two daughters brought great love, intriguing challenges and immeasurable enrichment to our lives. They still do. However, for the more than four years that our younger daughter has suffered from severe mental illness, the nature of the challenges has changed profoundly. I'd like to talk about some of the things that have made a difference for us as we faced those challenges and how, in attempting to deal with them, we've been learning how we can be involved in issues that affect other families who are parenting children with mental illnesses.

Resources that Make a Difference

We've been luckier than many families. Medications do help our daughter although, like many people, she must continue to deal with a shifting array of symptoms and side effects. We've also been fortunate that our daughter has had access for three years to a unique program in Vancouver called Hamber House. Funded by the Vancouver School Board, BC Children's Hospital and various provincial ministries, this facility is for 12 adolescents who suffer from serious mental illnesses. Most of the students have schizophrenia, mood disorders or severe anxiety disorders. At Hamber House, they work on the BC curriculum or GED (high school equivalency exam) preparation at their own pace, and receive intensive therapeutic support to learn about and manage their disorders.

We've also been fortunate that our daughter has received excellent psychiatric care. Despite having disorders that have proved to be very complicated to treat, she has had psychiatrists who have been dedicated to helping her receive the best possible help. These psychiatrists have also been very willing to establish good communication with us and have been careful to listen to our observations and suggestions about her treatment.

Another fortunate aspect of our situation is that we have had access to excellent family education programs. The family education program that developed out of UBC's Schizophrenia Rehabilitation Day Program provided us with a crucial foundation, and the BC Schizophrenia Society's family education program (see ad, page 7) extended this foundation to let us understand even more about the predictable journeys that families make when their children become ill. There are also several family support groups that the local community mental health teams provide; the Vancouver West Side

Team, for example, welcomed us with support and information even though we are not registered with their team. (This is because using team services means people must give up their private psychiatrists.) I've also discovered that family members can attend numerous professional conferences to learn about recent discoveries in the mental health field.

Currently, the most meaningful help for me has been a support group I started last year for 10 mothers whose children all suffer from serious neurobiological disorders (mental illnesses). Because of the knowledgeable and skillful support this group provides, we can explore in depth the unplanned and life-altering effects of our children's illnesses. We also continue to share information and resources for handling the recurring crises that all of us must confront.

Common Challenges for Families

Despite these excellent resources, managing our daughter's illness has presented challenges far beyond anything we had previously known. We understand that much of our daughter's future depends on the discoveries that neuroscientists have yet to make. However, there are many difficulties that consumers and their families face, beyond the limits of current medications and therapeutic practices. One of these difficulties is ignorance. Another significant one, which I'll talk about later, is lack of rehabilitation services.

Ignorance

For most of the 20th century, psychiatrists and psychologists blamed families for mental illness. While a relatively recent paradigm shift brought by brain research has changed this perspective, mental health professionals trained in outdated theories continue to do damage.

As we did, many families find private counsellors and therapists for their children when they first exhibit bizarre and inexplicable behaviours. In our case, a very high-profile therapist had been working with our daughter for several years before her first major psychotic break and had convinced her that her various symptoms were manifestations of a dark family secret that needed to be uncovered. By the time we finally found a psychiatrist who understood mental illness, he not only had to deal with our daughter's psychiatric illness but with, in his words, the 'brainwashing' that she'd experienced from her therapist.

I know from my own extensive work with families

that our shocking experiences are very common. Family blaming is not only ignorant, it undermines families' abilities to provide the kind of support that research tells us is crucial in achieving the best outcome. In our case, my daughter's initial belief that we were somehow responsible for her symptoms made the onset of her disorder more agonizing and dangerous for her and us.

Ignorance in other aspects of our society is equally devastating, and most of us are astonishingly uninformed about mental illnesses until a family member becomes ill. Although I'm a teacher, and my husband is a university professor, and although we are aware of many important social issues, we had never really learned about mental illnesses.

This lack of public knowledge makes adjustment for families much harder than it needs to be if a family member becomes ill. Not only are families trying to manage these stressful illnesses, they are also trying to educate themselves about these very complicated disorders at the same time. Having an educated public would mean that families wouldn't face such a difficult situation. It would also mean that consumers and families could receive much more sensitive responses from our communities. A step in the right direction is occurring in the US, where an increasing number of schools are including mental illness content in their curricula.

Lack of rehabilitation services

Another serious problem faced by families is lack of rehabilitation services to help their loved ones with their recovery. Next year, our daughter will be able to attend the UBC Schizophrenia Rehabilitation Day Program. While she's there, she'll be part of a stimulating therapeutic community, but after that, options for her growth and development are meagre. This year, I've worked with a multi-agency committee under the auspices of Vancouver Community Mental Health Services. We've worked to map out educational, vocational and recreational services that are available for youth and young adults who live with serious mental illnesses. We've also identified gaps in services. The map is small and the gaps are enormous.

Becoming Active and Making a Difference

At this stage in our parenting, we increasingly realize that in order to help our daughter have the best possible life, we must become more active in the wider community. Gradually, I am learning more about the process of becoming an advocate to improve services within the mental health system. I know that making the case for change goes beyond the moral and ethical arguments that should compel society to offer better services to consumers. The case also involves marshalling the research that shows us that when people receive adequate support services, they become less of an economic burden to society; or studies that show that supported housing costs less than hospitals and prisons; or that if consumers also have appropriately-

suggestions to parents on making a difference

I've been thinking a lot lately about what we parents can do to improve services for our children. Here are some ideas:

- **Request that educational institutions develop expertise in the area of mental illness:** Universities are not adequately training counselors and teachers to understand mental illnesses; training is usually minimal if it exists at all. Ask your schools and school boards about the kind of training staff have concerning mental illnesses. Once this foundation is in place and staff are trained, these institutions can move on to address the issues that are currently missing from the educational agenda.
- **Request that more special programs be created to meet the educational needs of consumers:** Education departments need to be investigating the best educational strategies for meeting the unique learning needs of students living with these disorders. Recently, a committee I work with helped to organize an Open House for mental health consumers. During the event, we talked about the current educational options and discussed what would be needed in an ideal program specifically designed for consumers to complete high school. The deans who attended were surprised and impressed by the very large turnout of consumers, their advocates and interested mental health professionals. We in this community know that the numbers requiring services are large, and we need to help educational institutions realize how many more people could use their resources if they were appropriately adapted.
- **Speak out about inaccurate representations of mental illness in the media:** We are constantly surrounded by inaccurate representations of the mentally ill in the media. The National Alliance for the Mentally Ill in the US is the largest advocacy group in the world for people with mental illness (www.nami.org). One program they've created is called Stigmabusters. Through their listserve, I am regularly notified about offensive media references to people with mental illness and about whom to write to to complain. I've been amazed at the results these coordinated efforts have achieved. The more we speak out, the more likely it is that change will occur.
- **Join forces:** Parenting a son or daughter with mental illness can be an overwhelmingly stressful and isolating experience. The BC Schizophrenia Society has chapters around BC that help people living with all kinds of disorders, not just schizophrenia. The CMHA has branches that can become even more helpful in meeting the needs of consumers and their families, but first we have to make them aware of our concerns. For example, the task force I mentioned earlier requested that the local CMHA branch organize a special event once a month for young adults. They have since begun to do this!

funded, evidence-based, supported education and employment programs, then they can have the same opportunities as people with other disabilities.

Since my daughter became ill, I've had to confront what little power we have to control some of the most significant events of our lives. There wasn't anything I could do to prevent her from becoming ill; I am learning, however, that there are actions I can take to make her illness more bearable for her and for us. Listed above are ideas about some of the ways that we family members can work to make a difference. ■

recommended reading

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Men and Support Groups

Howard Fluxgold

Howard is a freelance journalist

When I was asked to write about what men wanted from a support group, I was truly dumbfounded. I didn't understand the question. My jaw dropped, my eyes glazed and I spluttered, "I dunno what men want."

Why should men be singled out? What specific needs could they possibly have?

As I pondered these questions, I recalled my Family-to-Family course with three men and 10 women. One day in class, when I was the only male in attendance, I had noted the lack of men and wondered aloud if anyone knew why. There was silence in the room. Quietly, the woman beside me confided that her husband didn't want

Maybe there are differing needs, I thought.

When the class ended, I started going to a support group, but once again it was almost all women who attended. The group arranged interesting and informative speakers. The more you know about mental illness and the mental illness system, the more you can cope with both; and in a way, that is support. Knowledge is power. Still, I was one of only two men.

To fill in the time when speakers were unavailable, our group leader (a woman) asked us to tell our stories. The stories were similar, however. They were sad tales of how these women had been victimized by the system.

and bureaucratic incompetence.

In all the support groups and classes I have attended over the last 18 months, I have received information on how the illness works, but never on how the system works. After almost two years, I'm not sure how someone is involuntarily committed or why. I don't know why or how hospitals decide to release their mental patients, because they are obviously not well when they are discharged. I don't know how an extended leave order works, and I strongly suspect that those working in the system don't either. I don't know how the legal system works when it deals with a mentally ill person. I don't

would provide information on how the system works, as well as how the illness works. They would be designed to exchange experiences and information. The group would decide – and they would be asked their preference. My first speaker would be an expert on how men handle mental illness, someone who could tell us why there are so many who behave like ostriches.

I would also create a crisis help-line where group members could phone one another for advice and support when they need it most. My experience has been that in a crisis, there is no one to turn to for advice. You muddle along as best you can until someone provides you with the needed information. I would suggest that we play golf, go bowling, or skiing or hiking – do some male bonding.

In the meantime, I haven't gone to my support group since the winter. I have been lucky that my extended health benefits include 12 visits each year to a psychologist. I find it very supportive going once every two months to discuss whatever is on my mind. I get his viewpoint and expertise, sometimes about myself and sometimes about schizophrenia or the system. He also says I can call him in a crisis, which is a great comfort.

Right now we're between crises. ❏

If I were king, my first support group speaker would be an expert on how men handle mental illness, someone who could tell us why there are so many who behave like ostriches.

anything to do with mental health or mental illness. She was on her own, trying to learn about the ravages of schizophrenia to help her teenage nephew living in the Okanagan.

Maybe there was something I didn't understand.

I started wondering whether men approached this tragedy differently from women. In the class, I remembered that whenever there was a call to arms – a suggestion that we demand better services from the government – the men (all three of us) always volunteered. We were joined by a few reluctant women.

The stories taught me mostly that things could get worse, that misery loves company and, what I already had figured out: if you sit there and take it, you're sure to get it.

For the women who came regularly, I think it was some sort of support in that they could complain to someone and have a social hour or two with like-minded friends. For me, it was no support at all. Frankly, I don't need or want support on a daily, or weekly basis. I don't want to keep repeating the same story of broken dreams, bizarre behaviour

know what a disability allowance is, or about what the different kinds of supported housing that is available – like what a SIL is or what a super SIL is. I have no literature on any of this. Maybe no one really knows. Maybe things are changing so rapidly that no one can keep track of which service has been dropped or morphed into something else.

If I were king and could wave my magic wand, I would form a support group of socially compatible people. It would meet 10 times a year – never in the summer. The meetings

for more thoughts on support groups (for any gender), you might want to check out two related articles on 'mixed support groups' and 'picking the right support group' at www.heretohelp.bc.ca/articles

Dear Dad

When Elizabeth, the Executive Director of ANAD, asked me if I would write a letter to you about our relationship during my illness, I said yes right away without even thinking about it. I have gotten to know her over the past few months. She showed me previous editions of *Visions* and said that she was looking for a personal story of a young person's communication with her dad about her disordered eating.

This was going to be easy, right? Well, Dad, it hasn't been. I have written over 15 different letters over the past three weeks and thrown them away. I have drawn pictures, and paced the floor. I have finally ended up with this. I took so many tries to get it right because it was the first time that I dug so deep for you to understand me, and for me to understand you. This letter has been great therapy for me. I hope you see it that way.

In writing this, I thought of all of the fun times we had together when I was little. You taught me how to ski and made me laugh more than anyone I have ever known. You traveled a lot when I was small, but whenever Mom took me to the airport to pick you up, it felt like Christmas. I think I was about 14 when I started to feel you didn't care or you just couldn't be bothered with me anymore. Fitting into my life seemed to be a big bother to you. Then the fights started over the clothes I wore and how embarrassing it was for you to be seen with me. Dad, I acted tough and stood up to you. I'd go too far and we couldn't make up for days. I'd go to bed wanting to say sorry, but too proud to give in.

It was the strangest thing to me that you were the one to confront me about my eating disorder. When did you notice? When did you care? Why did you do it without Mom? I've never asked you this before. Maybe you thought she was protecting me. Dad, I'm glad it was you. I have never told you this before. I think if it were Mom who confronted me, I would have lied. I actually used to get mad that she was not complimenting me on how great I was looking as I became thin-

ner. But, when you said that one sentence, "Are you starving yourself or throwing up?", I knew I couldn't hide it anymore.

Dad, I wish you could understand what I went through for four years after that. We went back to not talking much. When I was well, you were more involved with me – you got me through algebra! But, when I was sick, you tuned out. You and Mom fought a lot, and I felt guiltier and guiltier. You'd make me angry, but I couldn't be bothered arguing back with you. You just didn't get it. No, Dad, I couldn't just go and eat something. No, I couldn't find myself a passionate interest overnight to "take my mind off of 'it'."

Dad, for the past two years, I have been in the best health that I can ever remember. Writing this letter has made me think about you more than I have ever done before. I am so grateful that you made me face my illness when I did, as who knows where I would have ended up. The irony is that after you made me face it, you seemed to be in denial. I felt like I let you down. You rarely took me places. I used to think that you thought my illness was a reflection on you as my dad. You didn't want people to think you caused this. What if someone stared at my thinness when we were out together? Dad, as I get a bit older, I don't think this anymore. I think you were too scared and in so much pain that you couldn't control, that you tuned out. I think the pain of seeing me so sick broke your heart. I think you and Mom just couldn't work out the pain together.

Dad, this letter is your gift for Father's Day. The truth is you were there for me when I needed you the most. Your strength got me to face the truth. We are off to a good start, as long as you know I am likely to slip back. This time, I expect you and me to handle things differently.

Love,
Christine ❖

Christine

Christine is a 19 year-old Lower Mainland college student whose struggle began with eating disorders at the age of 12. She has written this letter to her father for the readers of Visions. Writing a "Dear Dad" letter is an approach used by ANAD (Awareness and Networking around Disordered Eating) to help consumers and families develop mutual understanding about eating disorders and how to provide effective support

i have written over 15 different letters over the past three weeks and thrown them away. it was so hard because it was the first time that i dug so deep for you to understand me and for me to understand you



Psychosis

A parent's perspective

Mike Singleton

Mike is from White Rock and is actively involved with the South Fraser Early Psychosis Intervention program (EPI) parent group known as PSPOPS, or Peer Support for Parents of Psychosis Sufferers. He is balancing a career in the aviation industry with caring for his daughter, facilitating support meetings and looking after the PSPOPS website. For alternate frustration, Mike plays golf, and for solitude and relaxation he paddles solo in his sea kayak

All parents have a special bond with their children. They conceive and then nurture them, helping them grow toward adulthood. This bond strengthens over the years as both the parents and the children develop dreams, hopes and aspirations for the future. It also strengthens as adversity or disagreements test the relationship.

Unfortunately, life does not always unfold as one expects or wishes. Psychosis can steal children away from their parents, creating a hurt that – because of the bond between parent and child – is deeper than any other hurt possible. Psychosis hurtles individuals and families into a whole different world – from normalcy to total devastation almost overnight. There is no pain that can compare to the pain of seeing your fragile, scared teenager experiencing a horror over which they have no control.

This is my perspective after two and a half years of dealing with an illness that changed my life, even though I was not the one experiencing the illness. In our case, the illness came on with a ‘psychotic episode,’ a term to which I was totally oblivious prior to the event. It is a term, however, which I was to become very familiar with – as I struggled to help my daughter as she experi-

enced the psychosis, and as I did everything I could to understand what this chemical imbalance in the brain was all about.

I soon found out how resilient we have to be as life throws these curve balls at us. We have to

adapt to changing circumstances. We have to carry on with the mundane tasks of life. We have to change our existing philosophies, and sometimes even change our friends as we find they are unable or unwilling to understand and

support us when mental illness enters the picture.

As a single father (widowed), I was devastated when my daughter became ill. “WHY ME?” was my first response, soon followed by anger, frustration, disappointment and a host of other negative emotions. It didn’t take long however to realize that this was not about me, it was about an illness that was scaring my innocent sixteen year-old daughter to death. My emotions quickly changed to sadness and empathy with a tremendous need to do something to help.

I was very fortunate that my daughter was accepted into the South Fraser Early Psychosis Intervention (EPI) Program. This EPI program taught me that “psychosis is treatable and recovery is to be expected.” It also taught me that I was an integral part of the recovery process; this made so much sense to me. The professionals would spend an hour or two each month with my daughter; I would spend a hundred times that as I tried to keep life as normal as possible and help her to understand what was happening. I read books, took courses, searched the internet and became totally involved in learning as much as I could about my daughter’s illness. The more I learned, the more I came to under-

“I soon found out how resilient we have to be as life throws these curve balls at us. We have to adapt to changing circumstances. We have to carry on with the mundane tasks of life.”



A new Knowledge Network documentary looks at the problem of early psychosis in youth and helps BC families learn symptoms to identify a child or youth who is in need of professional help. It first airs November 22nd, 2004.

Check your local listings for times or see www.knowledgenetwork.ca.

An online learning component will also be available on the air date under the ‘Knowledge Tools’ section of the Knowledge Network site. This documentary is the third of a three-part series on child and youth mental health

stand how much the medical profession had advanced over recent years. Medications, knowledge, support structures and attitudes have all improved tremendously.

Unfortunately, the more I learned, the more I came to understand how difficult it is to deal with mental illness in society. Past stigma, media hype, incorrect representations and lack of understanding make people nervous or fearful. In some cases, people are downright ignorant and hurtful because they just don't 'get it.' They either don't understand the illness – and don't even realize that they don't understand – or they feel that they know, even better than the parent, just what the answers are.

My daughter had one math teacher who told her that she had a poor work ethic and that this was detracting from her self-esteem. Now, equating 'self-esteem' with 'work ethic' is possibly not too outrageous a concept for someone coaching competitive sports, but it is totally off-base when dealing with a young person struggling with psychosis. The 'poor work ethic' was actually her inability to figure out, learn new math concepts and remember old ones due to the slow recovery of 'executive skills' affected by the illness.

It's not the teacher's fault though. Specific training in handling brain illnesses is not part of the average teacher's background. However, the experience was still a tremendous slap in the face for my daughter who was working her hardest,

struggling every day to stay healthy and to reintegrate into society. Sad as it may seem, incidents like this are not necessarily limited to people outside the immediate family – for example, it might be a sibling who refuses to accept the illness and suggests to the person that the doctors have 'convinced' them they are sick. This kind of thing does not help the person learn recovery strategies or to fully trust anyone. Incidents like the two mentioned above are not just insensitive and hurtful, they show how much education is needed.

As my daughter and I continue to work on her recovery with the experts in the EPI program, I find that I occasionally experience circumstances where I can introduce people to the modern world of brain illnesses and help to reduce the stigma long associated with mental illness. I am just one person, however, and we need each and every person who does 'get it,' to help those who don't. Society needs to understand and be compassionate in its handling of people with brain disease, just as it does with other more socially acceptable diseases. We need to adjust sensitivities, attitudes and actions in line with modern medical progress and with more up-to-date knowledge about brain diseases.

For more information about mental illness, see the Peer Support for Parents of Psychosis Sufferers website (PSPOPS) at www.psychosissupport.com. †

www.cmha.vancouver.ca



CANADIAN MENTAL
HEALTH ASSOCIATION
L'ASSOCIATION CANADIENNE
POUR LA SANTÉ MENTALE
VANCOUVER-BURNABY BRANCH

Youth, the Family and Mental Illness Series

September 23rd

Dear Mom and Dad – Children and their parents talk about what helped them through mental illness and how it affects family relationships

September 30th

Is it a phase or is it something more? Recognizing potential mental illness in children and youth and early intervention

October 7th

Depression in children and youth: do antidepressants help or harm? How to cope with depression in children and youth and resources you can access

October 14th

Coping with suicide and loss, attempted suicide and preventing children and youth suicide

October 21st

Managing anxiety in children and youth. How to cope with anxiety in children and youth and resources you can access

October 28th

Youthspeak – youth speak about their experiences with eating disorders, substance abuse, psychosis and how they were supported to get help and what keeps them healthy

November 4th

The future of child and youth mental health services in BC: the New Provincial MCFD Plan

Evenings will have a panel of speakers including parents, youth and clinicians. There will also be organizations present to offer resources relevant to the topic.

All evenings will be held at G.F. Strong Rehab Centre in Vancouver at 4255 Laurel Street (@ King Edward) from 7-9 pm. **Register through CMHA Vancouver-Burnaby at 604-872-4902. The cost is \$10 per evening or \$50 for the entire series.** Subsidies are available for the unwaged or low-waged. A certificate is issued to those who attend all sessions.

Holding On While Letting Go

The contradictions of teenage mental illness

Our 16 year-old son had just emerged from his bedroom. For most of the day, he had been agitated and uncommunicative. At one point, he was aggressive and intimidating. By the evening, I needed to take a drive to help me think clearly about whether we needed immediate intervention for the safety and well-being of our family. This usually meant calling emergency mental health services, who were familiar with us by now.

Pam
Pam's family
lives in
Victoria

On this night, I had reached my limit of endurance. I needed to know whether our son was a danger to myself or another member of our family and whether he would abide by the rules of our home. When I returned from my drive, I conferred with my husband in our bedroom about a strategy to address our current problem. We mutually agreed on a plan and sat down to ask our son for clear, simple answers to some short, direct questions. He said he would not physically harm anyone in our home and would abide by the rules.

Our frankness seemed to open the door to new communication with our son. As I write, he is distributing a few resumes in search of a part-time job (a monumental effort — and though I have my doubts that he is ready, it at least has him looking to the future and engaging in a positive activity).

Our journey began several months ago, when after a breakup with a girlfriend, our son cut an arm and a leg in a criss-cross pattern over a large area. A knowledgeable friend assured us that self-harm and suicide were different matters and directed us to find some support.

We visited our GP, who decided that our son was depressed (after a very few questions) and prescribed 30 days worth of Prozac. He said he would see him again in 30 days. When I asked for a referral to mental health care, he told us that we would find resources in the community. Our next GP did not like antidepressants and reduced our son's dose by half. He talked of a psychiatric referral, but never followed through.

After the frustration of watching my son's health decline and of being told, "I don't have time for this," I asked my husband to accompany us to the next visit, so that we could express the concerns we shared more clearly. But as soon as the physician saw my husband and I standing in the room with our son, he became defensive and promptly told us he was not comfortable with adolescent psychiatry. He said he felt that he was not the doctor for us.

During this time, our son had been cutting himself deeper and more frequently. Rather than hide the cuts,

he would stand in the open with blood running down his face, arm or leg. At times, he was blank and distant. His suicidal notions became apparent now, and he was determined that he would die. We became involved with Project Alive, and found a worker who became our greatest advocate. She saw the need for immediate treatment, but it took Emergency Mental Health, an urgent psychiatric assessment, and a few visits to emergency before our son was finally admitted. I had slept in the living room with him for at least three weeks before he was hospitalized. It was hell.

Our son spent almost five weeks in a youth psychiatric facility. He was diagnosed as having major depression and was released with a prescribed antidepressant and no follow-up. While there was a half-hearted effort to recommend follow-up therapy, our son refused the notion of any kind of therapy.

Back at home, things went fairly well for the first week, though we have noticed some odd behaviours. Some of the distressing behaviour occurred towards the end of his hospital stay when he initially did not want to come home. He also directed most of his anger towards me, which added to my distress. Since then, his behaviours have become increasingly odd and entrenched. He has begun to exhibit some risky behaviours, such as shoplifting and hypersexuality.

Thankfully, he has now agreed to additional psychiatric help, and we are waiting for his referral to be processed. Our wonderful Project Alive worker had the foresight to keep our file open a while longer and has continued to be an advocate. My husband and I are attending a psychoeducational course and have joined a family support group, both of which are invaluable resources. We are looking into a class or support group for our 13 year-old son, though there don't appear to be many resources for siblings in this age group.

Our family is tired and stressed. We don't live day by day; we live hour by hour, and minute by minute. In an unpredictable world, we have to be prepared for anything during the course of a day. Some of the greatest frustrations we have encountered so far, however, are the bureaucratic roadblocks and the health care professionals who neither take the time to get to know the family as a whole, nor listen thoroughly, objectively and empathetically to their concerns and observations.

Judgments and assumptions are still alive around mental health issues. There is no greater feeling of helplessness and hopelessness than having the people you most need to trust dismiss or minimize your con-

cerns, leaving you to flounder through the system on your own. It is equally distressing to watch your child become replaced by a stranger, while each day begins in hope and ends in grief. Will our journey end in acceptance or recovery, or will it end at all?

Of course, although we've had frustrations with professionals, I do have to note that all the emergency services – aside from one particular ER doctor – have been fantastic. The problems generally lie on the other side of the crisis. Though we have been told our son has major depression – and certainly depression was a piece of the puzzle – what we see now is that when the mood is stable, what is going on does not look like simple depression. He had been on antipsychotic medication when in care, and this was tapered off as the doctor felt the medication may have been doing our son more harm than good. He finished his last dose when we brought him home and though he seemed more 'normal,' we have watched him slide every day since then.

The trick is getting people to listen now that he is not suicidal. Now that he has a diagnosis of major depression, it seems that anything I tell the doctor and certain professionals about the symptoms he is experiencing is met with the 'hysterical mother' wall. (Again, emergency health and some other advocates listen to us, and can see). I find the doctors typically listen better to my husband than to me – and though this must sound stereotypical, it truly has been my experience. Because of all the work my husband has missed attending appointments, and me being at home, we are pretty tight financially. We can't afford for him to miss a lot more work, and I could not leave our son at home all day if I went to work.

We are trying to find a day program, and he is being ping-ponged around in the meantime. We're told by the community support people that he is still in crisis and not ready for the program. He is on a wait list for a psychiatrist, and he just doesn't 'fit' anywhere right now. For now, he is involved in a youth program that he attended pre-illness.

He quit his band and has not been playing his instrument. He becomes bored with his friends very quickly, aside from a young lady who exhibits very risky behaviour. It is difficult to keep him occupied, especially during the day-time hours. Some days he sleeps a lot. Then we pay, as he won't sleep at night. There are other days when he is agitated, when dealing with him requires a great deal of tact and energy from us.

I miss our son. I want nothing more than to make him soup and make his problems go away. I am learning that all the love in the world likely makes a difference to him, but doesn't cure him and, at times, feels painfully futile. I am learning that there are moments that give you hope and sustenance. A genuine hug from our son at the end of a few hellish days seems to erase pain and revitalize energy.

We are getting to know him as he has become, and

I am feeling myself begin the grieving process for the person we've left behind. He had so much promise, and I am trying to reframe my feelings so I can see that he still has promise, though sometimes it is hard to shift gears. He is very artistic and very bright. He was a high-functioning 16-year-old before he got sick, so he has a bank of skills to draw on.

But he can't seem to learn anything new. He doesn't read anymore, although he will listen to books on tape. He can't do his schoolwork, but he does remember most of what he had learned scholastically prior to his illness. In other ways he has regressed. He is learning about the pain of cruel comments from people about his 'weird' antics. We experience the pain along with him. We keep encouraging him and loving him and advocating for him – and that's all we can do. He will be an adult soon, and we are trying to maximize the window of time we know we have to be most helpful to him, to give him every chance possible.

I am grateful for the help our son and our family has received so far, but sometimes it is hard to express gratitude when you feel 'beat up on' and unheard by some of your encounters. I guess we are all vulnerable right now, so those feelings are greatly intensified. We advocate for our son, but as this is all new to us, we fall short with our lack of knowledge. This is why we are working so hard to learn as much as we can. It is an overwhelming task at times. We try to make hay when there are good days, but that also comes with all the other tasks that have been sliding and thus building. We are practicing — it's a big life change **i**.

I miss our son. I want nothing more than to make him soup and make his problems go away. I am learning that all the love in the world doesn't cure him. I am learning there are moments that give you



My Son Sam

He may have inherited more than he bargained for

Tara lives in Mission and is grateful for the support she has received as a member of the Mood Disorders Association of BC

I have fraternal twin boys about to turn seventeen. Being sons of mine may turn out to be the most difficult experience they will ever have to go through. These boys are intelligent, good-looking and artistic. They are also excellent athletes. To meet them, you would likely comment on how polite or well adjusted they are – that is, of course, if you were unaware of the home life they have had to endure, by no choice of their own.

Children often take on various genetic qualities of previous generations. I inherited mental illness from my father and his parents before him. Now, one of my sons appears to have inherited some of the illness as well. When we saw the first ultrasound, I remember one of them being very peaceful, just floating along, while the other one was highly active. Throughout the pregnancy, the active one kept the three of us awake many nights before he even entered the world. After he was born, he suffered colic for quite some time and we didn't witness his first smile until he was three months of age.

I was a nervous, first-time mother with two babies and soon after their birth, began to have intense anxiety attacks. Try-

I would love to protect him and keep him cushioned from all the unpleasant experiences he may go through

ing to be a 'perfect' mother, I would clean the house and the infants constantly. Having been raised in a very dysfunctional family – with an abusive, alcoholic, (undiagnosed) bipolar father and a mother who left when I was 11 – I intended to do better.

The boys were given lots of love and attention from the start. I remained at home, while my husband worked long hours to save for a down payment on our first house. Shane was a relatively peaceful child, while Sam was highly active, very impatient and unable to sit still for longer than a few minutes.

The boys attended school and were generally happy. From an early age, Sam was able to mimic me and do everything he put his hand to, not unlike me as a child. I believed that with positive reinforcement and attention instead of abuse and criticism, he would fair far better than I had.

At twelve years of age, however, he had his first

bout of depression. The boys were now in Grade Seven and at a new school. Shane began to excel, but Sam broke his collarbone and missed a great deal of school. When he went back, he was far behind and became overwhelmed. He cried every night and became extremely depressed.

Upon the doctor's advice, he was put on an antidepressant that unfortunately caused him to become psychotic and violent. He ended up in Children's Hospital and became increasingly worse with the various medications they tried. Even though we live over an hour from Vancouver, either my husband or I would be there with him for several hours every day. In the end, we removed him entirely from the hospital environment, took him off all of the medications and gave him Chinese herbs prescribed through the Dean of the College of Chinese Medicine. Within a few weeks, he was like his old self.

Sam developed anger issues that we tried to get him to address in counseling, but he has always been very private about his feelings and wouldn't willingly talk to the people who tried to help him.

Two and a half years ago, I became manic for the first time in over 20 years and left my husband and children. Shortly thereafter, I spent a period of time on a psychiatric ward. The boys, who were 14 at the time, were scared, confused and angry. There is a great deal of stigma surrounding anyone with a mental illness within high school, so I am pretty sure they didn't talk to too many people about what they were going through. Upon my return, it took several months for me to recover and then try to carry on where we had left off.

Over a year later, with a number of stressors in my life, I experienced another breakdown, but this time the boys did not visit me in the hospital, and my husband sent me to live in Vancouver for several months. Upon my return this last September, I noticed a great deal of change in both boys. Shane had emotionally distanced himself from me. Sam was struggling with his anger towards me, using marijuana regularly and blaming me for everything

To read more from Tara, visit www.heretohelp.bc.ca experiences and click on the story called 'Perennials'

that was not going right in his life. His grades began to slip, and although he is trying to quit weed, he finds it to be a relaxant. Sam will be entering Grade 12 next year, and he has some catching up to do since he has only been doing one course this semester. Like I was, he is not comfortable sitting in class for many hours.

As he tries to find his first paying job, I worry a great deal about whether or not Sam will be able to cope or if he will follow my pattern of more serious mental illness as the stressors in his life increase. I would love to protect him and keep him cushioned from all the unpleasant experiences he may go through, but he adamantly insists that I don't know how hard it is for him and he is unwilling to talk to me without blame. He also refuses to take medication even though he did take an antidepressant to help him sleep when I was away. I have apologetically taken the blame for all of my children's ups and downs for many years. Unfortunately, it is virtually out of my hands now as they are almost ready to head out on their own.

This hereditary illness – that my father, his siblings and my own sister all have – still needs a great deal more research and funding before we can correct the chemical imbalances involved. We also need to get to the bottom of the other contributing factors so we can learn to cope with them better and perhaps break the cycle of stress and illness before it leads to worse experiences. ■

Two Views of a Cup of Juice

I vividly remember my wife pouring me the cup of homemade grape juice that morning. We sat together in the hospital psych ward, where I had been admitted the previous night.

"Poison," I said.

Michelle stared at me, her mouth open. "It's only grape juice. Just drink a little." We sat. "I'll drink it then," she said, and reached for the cup.

"NO!" I grabbed her forearm. "No... Please, don't!"

She pulled back her arms, and tears appeared in her eyes. The cup remained between us. "It's just grape juice. We just thought you'd appreciate something from home."

I looked at the jar. Indeed, at our wedding, we had drunk juice extracted from grapes that grew on her family's property, canned by her parents. It often appeared at special dinners. But here? At the hospital, a jar from home? Sealed, and resealed? Because, undiluted, the juice had a thick flavour that could mask that of any chemical poured into it.

I could understand why Michelle and her parents wanted me dead. That made sense: they had figured things out now, based on my suicide attempt, knew that I had set into motion a chain of events that would end in a great conflagration, and that they, being the closest people to me, would bear the brunt of the outrage from the general public and world at large as disaster approached. They understood and wanted me dead.

I could understand that, I really could, but should I let them do it? Cosmic ramifications were very much on my mind, and I was unsure whether I should let them go through with this, because killing me would have repercussions, too. I didn't know – dilemmas like this had arisen before me many times in the past two days and I often found myself unsure. I looked at the cup. Michelle's eyes were red, and she took out a frayed Kleenex from her purse to dab at them. I should let her decide, at least.

"All right," I said. "If you really want me to drink this, I will."

I took the cup. I paused, with the Styrofoam lip at my own. Drank. I finished it.

"There," she said. "Do you want more?"

"I'll just go lie down now."

"Are you still tired?"

I nodded.

"Don't forget your bag."

Poisoned, I took the duffel bag she'd brought me, maintaining the charade, and made my way down the hallway. In my room, I didn't bother changing out of my clothes, just lay atop the bed with my hands folded on my chest: a suitable pose for someone about to slip away from the world. How long would it take for the poison to circulate through my body and begin disrupting vital functions? What would I notice first? Would it be painful? Would it start with a seizure, and end with me curling into a ball, face frozen in rictus? I accepted my fate, but I did worry about what might happen to Michelle and her family as a result. Not be prosecuted for my death, hopefully. Maybe sleep would be the first thing. Felt drowsy again...

Jan Lars Jensen

Jan was born and raised in the Fraser Valley of BC and currently lives in Calgary, Alberta, with his wife Michelle. His book Nervous System: Or, Losing my Mind in Literature, was recently published by Raincoast Books



A couple of hours later I woke. Unpoisoned. I sat up. Maybe it *had* been only grape juice.

Michelle, I learned, intended the juice only to serve as a reminder of home and family, of happier times, and of the many people concerned about me during this abrupt, downward turn in my mental health. But my thinking had become so delusional that such an explanation didn't occur to me. I could only frame events according to my new, highly paranoid view of my situation. A cup of grape juice was an invitation to poison myself. Michelle's parents were suddenly people who might want to kill me.

The scene above is excerpted from my book about that period in my life, called *Nervous System: Or, Losing my Mind in Literature*. Going through the book now, I realize how much family factored into the whole experience: as I imagined terrible events befalling those closest to me, because of me; as those very people aided in my recovery; and as I searched, afterward, for an explanation as to why this had happened, only to find depression extending far back in my family tree, seed-

ing my mother's own dark, difficult days.

When I hesitated with that cup of grape juice in my hand, my family was actually no different. My thoughts only revealed how different I had become. I sometimes wonder what the view was like from the other side, as Michelle looked at me, so suddenly changed from the person welcomed at countless family dinners and celebrations. Who is this? she might have asked herself. Thankfully, I didn't stay changed in this way.

The experience taught me that family does influence who we are: not just genetic tendencies toward stability or delusion, passed down through generations, but also who we are while coping with a breakdown. My wife and her family played a significant role in my becoming well again. I'm not the same person I was before this happened, but, if I'm improved in any ways, I owe much to the family members who helped me rebuild.

That's something for which I'm thankful enough to toast (maybe even with homemade grape juice) 🍷

The Mad Muslim

A South Asian, East African, Middle Eastern perspective on mental illness, abuse and family

“Madness comes from the refusal to develop, to adjust, to dilute one's true self in the sordid mush of the world. If we want to find the true self in each of us, we must go to the county lunatic asylum.”

Farah Tejani,
BA, MFA

Farah is a writer, teacher, singer and comedian. She performs at literary cafes and bookstores at the heart of Vancouver's art scene. She is compiling a collection of short stories titled *Make Your Own Chai, Mama's Boy!* and has a novel in progress: *Raw Angel: Diary of a Real Live Madwoman*. Farah sells her books by donation, giving half of the proceeds to CMHA Richmond's Pathways Clubhouse

With culture comes thousands of unwritten rules and regulations that other cultures are bound to be confused by. I have seen all kinds of cultures and customs. I have pulled all-nighters at clubs in Knightsbridge. I can say my prayers in Arabic and English. I speak three languages. I have stayed in group homes and women's crisis centres and I have stayed at a shelter on

Hastings Street in one of the seediest areas of Vancouver's downtown core. I have smoked pot to relieve the pain of my past and taken wake-up pills to study for exams at university. I have had a Muslim friend commit suicide because she was not accepted by her community and I have many times almost been that Muslim girl.

Many articles about mental illness are written

from the outsider's perspective, looking in. I would like to go beyond the scientific and clinical perspectives made by the medical health professionals and offer the reader a chance to explore the clashing, contradictory, cultural expectations of one East African born, Indo-Canadian, 'mentally ill' Muslim woman.

Welcome to my mind. It's a bit crowded in here, but you'll get used to it.

My name is Farah Tejani, and I was diagnosed with bipolar disorder seven years ago at the University of British Columbia's Detweiller Pavilion Mood Disorder Clinic. In the same year, this very same university awarded me my Master of Fine Arts degree with High Honours. Interesting? I think so. Here, on the one hand, I was being commended for my skills in English, writing and the

Brennan, G. (1977). *A Holiday by the Sea*

creative arts, while just blocks away on the other side of campus, I was being diagnosed as mentally ill... technically insane.

Now, you may never truly understand what it was like for me, but I can tell you that after those nine years of diligently educating myself with my peers and honing my skills to hopefully one day be an inspirational and dedicated professor of the creative arts, I never imagined that I would one day be sitting here, inside my house for days, sometimes even for weeks, riddled with anxiety and pain, fear and anger. I was sure I knew where I was going in life, but in 1997, my life started going on without me.

I have been locked up by my own family 36 times over the last seven years for being different. Or shall I say, for not being quite what they wanted me to be. I was a westernized Indian girl. I have never before revealed my story to anyone. But today, for my Muslim, Hindu, and Sikh sisters everywhere, the time is now. Someone has to say something, and I'm not going to wait for that someone.

Sexual and physical abuse towards South Asian girls and women runs rampant. I believe that a large percentage of women with mental illness have been exposed to one or the other, or like me, to both. It is quite common in my community for a father's friend to be called 'uncle.' This creation of 'insta-uncles' is one of the leading factors leading to young girls being abused by so-called family members (not to mention the real ones).

And it is this insta-uncle umbrella that South Asian families ignorantly provide that protects and safeguards Indian men from being caught. A certain amount of trust comes with the word 'uncle,' and when this title is given out freely, with no discretion, this leaves young Indian women vulnerable and defenceless at the hands of strangers.

I dedicate this article to the brave families who will read on from here. I realize that this might be difficult and that some will choose to perpetuate the illusion that 'Indian girls don't get sexually abused or mentally ill.' I also believe that there are a large number of people who are suffering or know of others who are suffering, who will read on to help find some answers as to what we can do from here.

Let's start with some of the most serious misconceptions about mental illness in the South Asian community. Mental illness is not caused by spirits possessing your body or by the *Nazr* (the evil eye) from jealous relatives or friends. It is not curable by holy water or special prayers. And mental illness is most definitely not the punishment for ill deeds of a past life.

I was nine years old when the first 'friend' of my dad tried to rape me. (There were more to follow). I had called this man Amin (Uncle) for many years because that is what I was told to do. My own real uncles and cousins have sexually abused me, and although the family knows about it, to this day nothing has been done. I

never spoke of the first abuse until six years later, at age fifteen, and instead of being protected and consoled, I was severely beaten in front of my mother, brother and cousin for making up such a story. No one helped. I then learned to keep things to myself.

Many years later, it was discovered that I was, in fact, abused. But by this time it was too late and so much easier to lock me away every time I tried to speak about it. It was so much easier to discredit me in order to protect the name of the family. I was branded 'pagal' (crazy), and most likely unfit for marriage. This is another common response made by Indian culture: "Quick! Find a husband for her, or you'll be stuck with her." Nonetheless, I did my own searching, and after boyfriends and betrayals, I was always left in the same place... with a family and community that have chosen to disrespect and discredit me, rather than coming to terms with the severe damage my upbringing might have caused me.

My family hand-picked a Muslim psychiatrist who did his best to convince me that I was being melodramatic and dishonest about what happened to me when I was young. He assigned me zombifying medications that made me feel confused, unclear and unresponsive.

It wasn't until a few years ago, when I realized that I could see another psychiatrist, that I was finally set free. After taking the time to know my story, she held a family meeting where all the members

were asked if I had been abused in the way in which I claimed – and they confessed. And that was it... so many years later. I just needed to be believed. Many South Asian girls feel that they will be blamed or not believed at all. This has got to change. There are more and more support services for us these days, and I only hope that they are used.

Today, I humbly but happily live (with my black dog, Sabbath) in a basement suite that is a small castle to me. These days I write and do comedy. It's ironic how easily I can perform in front of a

“ We now feel that we can cure the patient without his fully understanding what made him sick. We are no longer so interested in peeling the onion as in changing it. ”

Dr. Franz Alexander, *Time*, May 19, 1961

large group of strangers who adore me, while I can barely sit in a room with my relatives. I go out rarely and usually only when I am with someone or have a performance. I live with the much-appreciated assistance of the Canadian Mental Health Supported Housing program and I receive some financial assistance from disability benefits. In appreciation for what the CMHA has done for me, I sell copies of my self-published collection of

My Recovery

Safety, freedom and friends

Caroline Fei-Yeng Kwok

*Caroline was born in Hong Kong. Her education includes a degree in English from the University of Minnesota, a Master's degree in Education from the Ontario Institute for Studies in Education at the University of Toronto, and studies in creative writing at Yale University. She has published a memoir, *The Tormented Mind*, and is currently teaching English as a Second Language and literacy to immigrant psychiatric survivors at Across Boundaries in Toronto. Caroline was awarded the 2001 Courage to Come Back award by the Centre for Addiction and Mental Health in Toronto*

As a Chinese woman who suffers from manic-depression (bipolar disorder), I feel that there is a strong social stigma around mental illness within the Chinese community. Often, mental illness is considered a taboo, a family shame that is better to be kept within the family. Together with the lack of knowledge of and education about the different kinds of medications, the family may not give the right support to the ill person.

I come from a traditional Chinese family with over-protective parents and had my high school education in a girls' school in Hong Kong where academic excellence was highly valued. In 1972, I returned to Hong Kong after studying English literature at the University of Minnesota and after travelling to Europe for two months on my own. I took the Diploma of Education Course at the University of Hong Kong while, at the same time, I worked as an English teacher at the Language Centre of the same university.

I faced many cultural adjustments coming back to the city of my birth. At that time, my friends in Hong Kong had never been abroad. My parents could not understand that I had changed. They could not accept that I had grown up and become independent.

At the time, I was totally ignorant of sex, relationships and marriage. I naively believed that I should marry my first boyfriend, whom I met after I returned to Hong Kong. In April 1973, when I was about to take the examination for my diploma course, I had a minor fight with him. A doctor at the university's health centre prescribed some pills for me and I was able to sleep and concentrate on my studies.

However, not knowing much about medication, my mother snatched away the pills and would not let me take them. After that, I could not sleep and I lost my temper, yelling in English. My mother called a Chinese

psychiatrist who could not communicate well in English.

Against my will, I was sent to the psychiatric ward of a general hospital for a two-week observation period. My telephone line was cut. My constant visitors were my boyfriend, my parents and my nanny. My friends were told by my mother not to interfere.

After my hospitalization, my mother went to see the psychiatrist on my behalf. At the time, the medications were necessary; however, after my immigration to Toronto in 1974, I was able to survive very well without them.

My next episode occurred in 1978, when I had emotional trouble with my boyfriend, who by now had become my husband. Being new to Canada, holding down two teaching jobs, and taking a graduate course at the same time, I did not have any friends to confide in. It was during this 1978 episode that a psychiatrist gave me a diagnosis of manic-depression and prescribed lithium for me.

Another episode occurred in 1980 after a trip to Hong Kong. After having conflicts with my parents and my husband, I decided to come back to Toronto by myself and signed myself into the North York General Hospital. A psychiatrist there gave me lithium, methotrimeprazine, sodium amytal, haloperidol, and chlorpromazine. Yet he wrote that my "behaviour remained very active, uncooperative, and demanding," that I had a good relationship with my parents, and that my husband appeared to be extremely tolerant and supportive. He did not notice that I was unhappy in my marriage, friendless and alienated from my family. I divorced my husband in 1982.

My next major episode occurred in 1992, when my intimate relationship with a coloured colleague ended abruptly – a relationship that my mother had disapproved of all along. At that time, I was hospitalized at ►

Mad Muslim | *continued from previous page*

short stories (*Make Your Own Chai, Mama's Boy!*) and give a portion of the money to the CMHA. I have always been blessed. No matter what, I've learned to never give up on me.

In the meantime, I take life day by day, and I have found an excellent psychi-

atrist who knows of other cases like mine and who has found the perfect chemical cocktail to help stabilize me and ease the pain of all that I have been through. I take the medication and I do my part. But most importantly, I live my truth.

I offer my story to other South Asian women like me who are in similar circumstances. Reach out and don't be scared – you will find the help you need. People can be cruel. They will come to the hospital when you break your leg, but no one comes to the

hospital with flowers or cards when your mind is broken. Mental illness is not contagious, and stigma kills. Please speak up, or help someone you know and do something about it. We have to come together. ■

Mount Sinai Hospital and given heavy tranquilizers and, after discharge, was essentially deserted by my mother. I had a brother in Toronto, but there was not much support from him either. I was left in the hands of the Public Trustee after my brother refused to be my Power of Attorney.

In 1999, I was in a coma for two weeks as a result of receiving the wrong combination of neuroleptic medications from a psychiatrist at Mount Sinai. I recovered with no brain damage, except that my handwriting has become illegible.

In August 2002, I faced a tremendous emotional trauma, yet I survived very well without having to take any tranquilizers. I was receiving a minimum dosage of divalproex (600 mg. a day). I functioned well, continued teaching part-time, traveled to Hong Kong alone, and did not lose any sleep. At present, I am only taking 250 mg. of divalproex a day as a preventative against any further hospitalization.

Why the change? Why is it that I do not have to take so many psychiatric medications now and am able to survive so well? There are several reasons for this change. They are what Professor John Nash is reputed to have attributed his own recovery to in the biography written about him, *A Beautiful Mind*. They are: "safety, freedom and friends." Safety, freedom and friends have made a lot of my dreams come true.

I have an understanding psychiatrist, Dr. John Kluckach at the Centre for Addiction and Mental Health in Toronto, whom I see regularly. He appreciates my creativity and is encouraging and supportive. My family physician is equally understanding. I go to the gym and am vigilant about my diet, especially since I am also a diabetic.

My memoir, *The Tormented Mind*, was self-published in 2000, describing my experience as a Chinese woman who has survived mental illness. This memoir has opened many avenues for me. All my friends have accepted me once again. I am also making new friends – including understanding psychiatrists, social workers and survivors – who have provided me with positive emotional support and understanding.

Three universities in Toronto have used my book as their course text in social work and disability courses. The Director of Asian American Studies at the University of California at Davis has also used the book in his clinical psychology course. This year, I will be giving presentations to psychiatrists and mental health workers in the cultural training program at the Centre for Addiction and Mental Health.

My attitude to life events has changed for the better in that, since my coma and the terrorist attacks of September 11, 2001, I am more mindful of the unpredictability of life and treasure it to the fullest. I enjoy going to operas and concerts once again – a passion that I had lost as a result of heavy tranquilizers and my misconceived notion that my contacts with the arts would worsen my illness. I have also become a member of

the Art Gallery of Ontario and the Royal Ontario Museum and I have traveled to Montreal and Cuba on my own.

Had there been more education about mental illness and the different kinds of medication available, my family would have shown more understanding of my illness. My recovery would have been less painful.

Thus, it is my hope that this article will make families or friends realize the importance of giving positive support to psychiatric consumers/survivors in helping them to recover and function well in society again.

Jessie's Hope



I have difficulty saying the word suicide. I have difficulty writing the word.

Before my daughter Jessie took her own life in February 2002, I had personally known only one other person who had died by suicide. That was some 25 years ago. He had been a student at university. His parents, neighbours of my family, were shocked and devastated. They had had no prior indication of his mental turmoil. I remember thinking at the time that to lose a child to suicide must be the most painful thing that could befall a parent. It seemed unfathomable.

Our own circumstances differed in that we watched our daughter battle her demons for six years and through two previous attempts of suicide. So we knew the possibilities and because of that, I felt that some little corner of my mind had to prepare itself for that worst possible of outcomes. Even so, the mind plays strange games with us. Following her second unsuccessful attempt, I had a giddy, euphoric sense of optimism. This was such a low that I felt that it was our turning point. I thought that things couldn't get any worse, so it would be a steady road

Diana Budden

Diana is Jessie's mother. Jessie committed suicide after her long battle with disordered eating and depression. Diana is the President of Awareness and Networking Around Disordered Eating (ANAD). 'Jessie's Hope' is the name of ANAD's annual fundraiser and poster campaign

to improvement from then on. Somehow this same feeling didn't occur to Jessie.

I watched her try. I saw her beg for relief from her mental exhaustion. I sat with her in the emergency ward for days, waiting for a bed in an overcrowded psych ward where there were not adequate facilities or staff to deal with her depressed, suicidal, bulimic condition. I sat waiting in another emergency ward, waiting to have her self-inflicted arm cuts stitched, as she was humiliated by the doctor who told

her she was 'wasting their time' by doing this to herself. I tried to keep up to date on the variety of medications she went through – antidepressants, anti-anxiety and sleeping medications – meanwhile asking myself how the medication could work while she binged and vomited several times a day. Alcohol joined in the mix over the last year.

I am left with an indescribable sense of emptiness. I know that the sad, lonely, mentally and physically exhausted child that I lived with was just one of

so many others that live in our communities. I have so many unanswered questions, so much anger for the inadequacies of a medical system that wasn't able to treat my Jessie as an individual with her own unique needs.

Tell me why it is that when we have parents suffering with dementia or Alzheimer's, we can confer with their caregivers, but when I live with my 20-year-old daughter who is not capable of making rational decisions around her own health and life, I can not confer with her caregivers. Tell me why four separate caregivers cannot confer with each other regularly. Tell me why one of her counsellors knew that Jessie was hoarding her medication for several weeks before her death, but didn't share the information with me or the other caregivers.

Jessie suffered with shame and guilt, and there continues to be an aura of denial and shame around speaking openly about mental health issues. It remains an area crying out for increased awareness and for improved steps toward prevention. I weep for the wasted years of each individual caught in their own dark dungeons and for the lost innocence of children debilitated with depression, unable to reach out to find the comfort and peace they seek.

Like so many of those left behind after a suicide, I will endlessly wonder why our love was not enough to help Jessie rediscover a love of life and of herself. I will continue to work toward improving the outlook for others who walk

the lonely path of the suicidal. I believe we should be doing a far better job of supporting those individuals caught in the web of depression and yet, at the same time, I find that I hold a huge respect for Jessie's choice to end her own torment. As much as it has been heartbreaking to have lost our battle, it was equally heartbreaking to watch her suffer through it. I wish her peace.

'Jessie's Hope' is the name of ANAD's annual poster campaign. It is a poster design competition aimed at youth in BC during which teachers are supplied with a curriculum outline and suggested guidelines for leading a classroom on issues related to disordered eating. We encourage teachers to help students talk about self-esteem, healthy relationships with food, acceptance of our diverse body shapes, and the influences of fashion and diet industry media images and messages. Each year a different theme is chosen, and students design a poster on this theme. In December, one design is chosen to be printed, distributed and sold province-wide as a fundraiser for ANAD.

It had been Jessie's hope, upon her own recovery, to be able to help others suffering with disordered eating and depression. She did not want anyone else to go through the pain and anguish which she experienced. I am proud to have Jessie's name associated with ANAD's campaign ■

Parent? Teen? Family Member?

Are you a parent, teen or family member interested in sharing your personal experience with kids' mental health or substance use issues? The BC Partners are looking for kids and families from all walks of life to help raise awareness about these important aspects of health. There is nothing more powerful than learning from the first-hand experiences of real kids and families – whether they are coping with adversity or not. Maybe you can share how your family is handling the stressful transition back to school this fall? Perhaps you are one of the many families facing mental illness or substance use issues among your children or teens? If you are interested in being profiled as part of our media campaign, we would love to hear from you. For more information:

▶ **Sarah Newth**

Anxiety Disorders Association of BC
Tel: 604.525.7566

All participating families will receive a small honorarium.



Gavin's Suicide

A mum's memorial and hope to understand a horrible and secret condition

I write about Gavin, the storyteller, full of wit and intelligence – a passionate gobbler of knowledge and the kind defender of everyone. Gavin was my son who had a killing disease called depression. Although he was much more than this, I am telling his story through a particular lens. I will share what I know about depression and, by association, guess at Gavin's inner life.

The reason I am proceeding this way is that for me, imagining what it is like to be another is at the centre of our humanity. It is the essence of compassion and it is the beginning of morality. Suicide has left me few clues to enable such empathy, but this is the last task Gavin has left us. By attempting this endeavour, I hope to be a little wiser about the horrible and secret disease that claimed him and, accordingly, to understand.

Although shaken to the core by Gavin's suicide, I wasn't surprised. Gavin was sick once before. All of us who loved him watched and asked with care and fear ever after. But apparently suicide can't be held at bay by conversations full of love and promise. I knew that even as he was surrounded by vigilance, he was especially vulnerable. People who have a major depressive episode and have made a suicide attempt have a 50%

positive steps out of grief

Lloyd and Heather Craig have spearheaded a unique campaign. The University of British Columbia Hospital Mood Disorders Centre, in partnership with the Vancouver General Hospital and UBC Hospital Foundation, the UBC Department of Psychiatry, and the UBC Brain Research Centre, are raising funds for an endowed Chair in Depression Research and a Centre of Excellence in Depression.

The Chair in Depression Research will attract new research dollars to Vancouver, build on existing relationships and establish new ties with professional colleagues and interested stakeholders across Canada and around the world. Together, they will build a critical mass of knowledge and understanding in depression that will make Vancouver and UBC a Centre of Excellence in depression research, treatment, education and care.

In only a few short months, over \$4.5 million has been raised, and a commitment for a major donation is forthcoming. For more information, visit www.psychiatry.ubc.ca/mood/chair.htm

chance of getting sick again.

He first got sick in 1995. He lost some weight, couldn't sleep and was irrational and anxious. I found it hard to get my mind around the possibility that something was amiss. He was always a happy, stable, successful, balanced person. Whatever was happening, the doctors couldn't see. They opined on his intelligence and on how articulate he was or about the fact that he was just 20. In desperation, Gavin tried to stop the misery by taking pills.

Effective treatments for depression are beginning to be developed, but there are few diseases that are as mistreated. Research tells us that only half of the people who are depressed even search for treatment. Of those that do, most go to their family physician, who often have little training in either recognition of depression or about the most appropriate interventions. As a result, the illness is diagnosed only 40% of the time, and even among those who are diagnosed, under half will get treatment. Fewer still will receive appropriate treatment, with one study estimating that only about 2% of people with depression get optimal care.¹

Gavin tried to be well, but depression has the ability to outmanoeuvre, weaken and obliterate. Suicide became the only solution to an unendurable level of mental pain. He made another major attempt on his life, resulting in broken bones and head injury. After rehabilitation and psychotherapy, along with medication, he returned to life and all of his passions.

Why do people get depressed? The literature is replete with ideas that include a composite of genetic, neurological, environmental and chemical reasons. Recent research claims almost 3% of the population suffers from chronic depression at any one time. Depression is the leading cause of disability and accounts for more of the world disease burden than anything other than heart disease. Depression claims to take away more years from our lives than war, cancer and AIDS put together. Other diseases mask depression and if you include alcoholism, for example, depression may be the biggest killer on earth.

Gavin had five more years of success. He completed an undergraduate degree in his beloved mathematics and went on to graduate school. However, successes were not enough to keep depression away, nor were caring friends, colleagues and family. Gavin had all those in abundance. Unbeknownst to any of us, the depression came back.

Heather Craig

Heather is a volunteer staff member of the BC Business and Economic Roundtable on Mental Health (www.bcmentalhealthworks.ca) and is responsible for research and communications with a special focus on outreach to the health professions. She graduated from the University of British Columbia in 1969 with a Bachelor of Science in Nursing and worked as a nurse in various capacities until 1989. Since 1990 she has worked as an artist, with arts degrees from Emily Carr Institute of Art and Design and Simon Fraser University. Her husband, Lloyd Craig, is Chair of the roundtable and CEO of Coast Capital Savings, Canada's second largest credit union

My Role as a Teacher-Mother (Or is it Mother-Teacher?)



Donna Murphy

Donna Murphy is the secondary Special Education Teacher for the Surrey School District. Since the death by suicide of her son, Kelly, in 1997, Donna has worked as a member of the FORCE Society for Kids' Mental Health Care to ensure that quality of care is available to all families in BC

Throughout my life, I have had two main loves. One has been my son, Kelly, who died by suicide in 1997 after a three-year battle with obsessive-compulsive disorder and depression. The other love has been my teaching and the students and families whose lives I have touched. Everything I am today has been influenced by these two most important factors in my life.

As a young teacher, I was full of enthusiasm and energy and ready to take on and change the world. I taught children and worked with their families. However, it was not until I became a mother that I truly experienced respect for the learning process of children and for the role that parents play in this process. As Kelly grew, he began to struggle at school. Although he loved his friends, and recess was his favourite subject, he often had a difficult time settling into classroom routines and could become frustrated with learning.

Most of his teachers seemed able to cope and he moved along through the primary grades. In his intermediate grades, he met with some very strict, unbending teachers who put academics first and children second. Kelly began to dislike going to school, and I had to become creative as a parent to get him there. When he was in Grade Six, I went to the Fall parent-teacher interview expecting to hear the usual litany, that he would never be able to go to college and that he was often disruptive to the class. I will never forget his sixth-grade teacher. This wonderful lady told me about his sense of humour, his kind nature and how much she had appreciated having him in her class. I

walked out of the interview with tears in my eyes, having learned an amazing lesson. It was not any harder for the teacher to emphasize Kelly's accomplishments, yet it was much more positive for me as a parent.

I took this lesson to school with me, vowing to always start from the positive, and to look for strengths in the students I teach. It also made me realize that parents love their children and want the best for them. Parents all have various degrees of skills, and it is up to the professionals to team up with them to help children reach their full potential. My days of criticism were over. I began to teach and treat children the way I wanted my own treated. And I began to take great joy in teaching and working with families.

My career took a turn when I went into Special Education and began teaching conduct- and behaviour-disordered children in the Social Development Classes in Surrey. I opened a program in an elementary school and based my teaching on respect. I worked as part of a team and at the end of the day, we always felt that we had worked for the best interest of the children. Were they challenging? You know they were, and each came with their own prob-

Gavin's Suicide | *cont'd from previous page*

What happened? According to Kay Jamison, a researcher in depression and suicide: "depression paralyzes all of the otherwise vital forces that make us human, leaving instead a bleak, despairing, desperate and deadened state. It is a barren, fatiguing and agitated condition; one without hope or capacity.... All bearings are lost; all things are dark then drained of feeling. The slippage into futility is first gradual, then utter. Thought, which is as pervasively affected by depression's mood is morbid, confused and stuporous. It is also vacillating, ruminative, indecisive, and self-castigating. The body is bone weary; there is no will; nothing is that is not an effort and nothing at all seems worth it. Sleep is fragmented, elusive, or all consuming. Like an unstable gas, an irritable exhaustion seeps into every crevice of thought and action."²

About 15% of depressed people commit suicide, and Gavin was one of those. Jamison's description help make sense of the end: it is neither selfish nor unselfish, but rather it is a giving in to being unable to bear any more. Gavin's amazing persona was unbreakable as the gap between private pain and public expression was absolute. Gavin was able to make his pact with death and not show any of us a sign.

Gavin's illness and death is not the sum of his life. But imagining his depression seems necessary for me to clearly remember his life. I do understand, and I will miss my beautiful son forever. †

footnotes

¹ Parikh, SV, Lesage, AD, Kennedy, SH, Goering, PN. (1999). Depression in Ontario: Under treatment and factors associated with antidepressant use. *Journal of Affective Disorders*, 52, 1-3, 67-76.

² Jamison, K. (2000). *Night falls fast: Understanding suicide*. Vintage Books. p. 104.

lems and learning styles. But we based our program on strengths and worked towards transitioning students back to their home school.

When Kelly became sick, I felt that he should have the same respect shown to him as we showed to the children in the Social Development classes. I had learned from my teaching not to engage him when he was in a rage. I knew that I should not personalize everything he said, although that was often difficult. I also had many connections in the professional community. Despite all this, it was very difficult for me to obtain the help I needed for him. I knew that he was very ill, and yet I heard over and over again that he was looking for attention. I also doubted myself when I needed to advocate for him at school.

When Kelly was in Grade 12, he found his way into an alternate program. This was the first time since his Grade Six year that he felt happy at school. Once again, he had the acceptance, respect and support he needed in the school setting. As well, I felt that I was being heard, respected and included as part of the team. Kelly was loved as a bright, funny, honest student who spoke openly about his illness and who accepted everyone for his or her strengths.

Kelly's death has given me an opportunity to once again look at my teaching style and make the changes necessary to help students be successful. How we base the word 'success' is individual to each child. I hope that after I

have worked with students, they will have positive self-esteem and a positive attitude towards learning. I hope they will remember the time spent with me as a positive part of their life and in future years will be able to smile when remembering these school years.

Kelly once said to me that I can be sure that I have a positive influence on the kids I teach. He told me this when he was gravely ill, and it was one of the greatest compliments he ever paid me. I learned many lessons from my son and use them every day in my teaching. Recently, a good friend of mine told me that by doing this, I bring a little bit of Kelly to school with me every day.

As a Mom and a teacher, I have been able to take my two great loves of my life and intertwine them to make a difference for other children and families. I hope to be able to continue to do this and to one day influence new teachers and changes in the way education is provided.

We need to celebrate the positive influences in the teaching profession and be proactive towards making change for our future. As well, we need to continue to work towards what we know to be right – that is, promoting self-esteem in all students and encouraging parents of kids with mental illness to speak out for their children and to ensure they are receiving the best support possible in the school system. ■

For more on Kelly's story, see Donna's article in *Visions Journal*, Vol. 1 #11 at www.cmha-bc.org/visions

Engaging a Young Person in Care

Recovery from psychosis and other mental illnesses is associated with early intervention, optimal medical treatment and with appropriate psychosocial support. All of these things, in turn, depend on successfully engaging a young person in care, something that may be in some cases extremely difficult for families and professionals alike.

What is 'Engagement'?

Engaging the young person in care involves negotiating the successful entry of the individual into care, building active involvement in the treatment process and maintaining that involvement over time. Promoting engagement in care is a key aspect of recovery from early psychosis and other serious mental illnesses. Lack of engagement in care is associated with increased possibility of relapse which, in turn, is associated with slower and less complete recovery from the illness.

For various reasons, many young people with serious mental illness remain out of contact with the mental health system. Promoting successful engagement depends on a positive first contact with care, humanizing or 'putting a face' on the treatment, developing specific strategies to promote ongoing medication adherence, and providing proactive support that is consistent with the needs and preferences of young people.

Ensuring a Positive First Contact with the Mental Health System

While a positive first experience with the mental health system can set the stage for successful engagement in care, a common theme underlying young people's first contact is trauma. Although trauma can be associated with the illness symptoms, it is often associated with the various phases of the first experience including police involvement, the emergency ward, seclusion and aspects of the regular hospital ward environment.

"I didn't appreciate the mental health centre calling the police because I felt I would have gone to the hospital, instead of putting me under that embarrassment."

It is important for families to do whatever they can to minimize these kinds of experiences for young people, so that they will be encouraged to reach out for help if and when it is needed in the future. Families need to be

This article is adapted from the "Engagement" fact sheet, from the 2002 series The Psychosocial Aspects of Recovery from Early Psychosis, produced by the Canadian Mental Health Association's BC Division with a grant from the Ministry of Health Services

aware of what resources exist to help deal with a mental health crisis or emergency in the least threatening manner. For instance, in many regions in BC, families can phone the early psychosis contact person or the mental health emergency team in their area (a province-wide list of early psychosis contacts is available at www.psychosissupport.com; call the Mental Health Information Line at 1-800-661-2121 to find the number for the general mental health emergency response team in your area). By taking advantage of these resources, parents in many areas of the province can talk to a person who can help provide advice about obtaining an assessment in an environment that is as safe as possible for the young person.

Demystifying and Humanizing Treatment

People experiencing psychotic illness may be more willing to accept help if efforts are made to demystify and humanize the treatment setting, that is, to provide some initial explanations and reassurance to the individual about the illness and its treatment, and about what will happen within the treatment setting.

"I think the major thing is to have caring, compassionate people, people who are non-threatening when the young person first comes in, and who are understanding of the families' point of view."

As the comment suggests, in the initial stages, young people will benefit from some basic information and reassurance about the illness and its treatment. Professionals must assure the individual and the family that they understand what is going on, that it is an illness or a condition with a biological component and that the condition will probably respond well to treatment, especially with early intervention. Families need to be aware that from the perspective of a young person in crisis, a simple but powerful means for promoting engagement in care is to find a mental health professional who pays sufficient attention to the young person and who communicates concern, compassion and reassurance for his or her well-being.

Promoting Ongoing Adherence to the Treatment Plan

After the initial phase of treatment has been completed and the individual has reached some degree of recovery from the acute stage of the illness, a negotiation about ongoing treatment adherence needs to take place. This discussion should be grounded in a thorough exploration and understanding of the young person's attitudes towards treatment, which will impact on adherence. To some extent, attitudes to treatment will be impacted by the individual's knowledge and attitudes about the illness itself. What follows is an outline of the key issues identified in the literature that impact on ongoing treatment adherence, together with strategies for addressing them.

Fear and Stigma about Medication

Some individuals may discontinue their treatment because they fear becoming dependent or addicted to the medication. Such individuals may have a generalized stigma against taking any kind of medication, as reflected by comments like "I don't even like to take aspirin." To address these feelings, the family can help the young person frame treatment as a mutual exploration process, whereby the professional and consumer, together with his or her family, search for the best medication within the context of a treatment approach that includes other forms of support. In this way, the individual can begin to see taking medication as 'an act of control,' rather than one of dependence or failure. At the same time, misconceptions about addiction to the treatment should be addressed.

A closely related issue is that some young people refuse to take medication because they associate taking medication with 'being ill,' rather than 'getting better.' In the same vein, they may also talk about going off their medication because they want to 'get a life.' These feelings should be addressed by helping the individual to see medication as a necessary part of an overall strategy aimed at her or him achieving or regaining their valued life goals, such as going back to school or building healthy relationships. In other words, the treatment should be negotiated within the framework of illness management or as a way of helping the individual live successfully with the illness rather than the 'treatment compliance' framework, where taking medication is seen and communicated simply as an end in itself. Again, the family can help promote and maintain engagement with a treatment plan by reinforcing these messages.

Finally, some young people may have fear or stigma associated with the idea of taking a specific treatment, such as the same medication taken by a relative who had a negative experience with a particular medication or with mental illness in general. If this is the case, the feelings towards the family member in question should be explored and addressed; the young person must be helped to realize that a bad experience of a parent, for instance, doesn't mean he or she should expect a similar fate.

Perceptions that Medication is Ineffective or Unnecessary

In some cases, side effects – either actual side effects or fears about them – will negatively affect treatment adherence. In order to address fears about side effects, the individual must be given the information needed to recognize them if and when they occur. The treating professional must also be open to negotiating treatment which minimizes actual side effects, especially dysphoria (subjective negative feelings caused by the treatment), weight gain, and side effects related to hindered role functioning (e.g., vocational or sexual).

In other cases, the young person may discontinue

the treatment because of a concern that the medication doesn't make a difference. In order to address this issue, the individual must be helped to see the relationship between treatment adherence and increased well-being. For example, the clinician or the family may help the individual chart the improvements in moods or symptoms that occur as the treatment is continued. At the same time, professionals must be alert to the possibility that the medication does not work as well as should be expected and should be open to negotiating a new treatment strategy. The family can help by sharing their perspective on the treatment with their son or daughter's doctor or other mental health professional.

It is important to help young people – particularly those who are not yet convinced of the benefits of medication – to learn the connection between medication discontinuation and relapse. The increased possibility of relapse must be communicated to individuals considering going off their medication, by both professionals and their families. And in the event of a non-compliance-related relapse, this opportunity should be taken to stress the connection between treatment adherence and vulnerability to future episodes. In this sense, a relapse can be communicated as an opportunity for learning.

It is common for young people who have made some degree of recovery to discontinue medication because they are feeling better and no longer see the need for treatment. In anticipation of this situation, professionals and families should communicate a clear message to the young person: despite the sense of improvement that they may feel, he or she possesses an underlying vulnerability to developing a long-term illness, this vulnerability may be increased each time the individual has a relapse of the illness, and medication is an essential part of a strategy to reduce the risk of a relapse.

Memory or Logistical Problems Impacting on the Medication Routine

A final reason for treatment non-compliance is the difficulty of remembering to take the medication. Because of this, prescribing overly-complicated medication regimes which require the person to take multiple medications should be avoided. As well, interventions aimed at promoting treatment adherence should include a behavioural element. That is, they should feature aspects like developing a regular medication schedule that is interwoven with the individual's daily routine intervals – e.g., at mealtime or bedtime – building in reminders such as calendars or alarms, and by enlisting the support of others such as family members, peers or professionals to help maintain the medication routine.



Cross Cultural Considerations on Treatment Adherence

As already mentioned, when negotiating engagement in care and ongoing adherence to treatment, it is important to explore an individual's ideas and attitudes about the nature of the problem and towards the proposed care plan. This is particularly important for individuals from various ethnocultural backgrounds who may be more likely to have divergent ideas about the source of the problem and who may have expectations for treatment that are inconsistent with the Western medical model.

To address this issue, the cross cultural psychiatrist Kleinman has developed an assessment process to elicit an individual's 'explanatory health model.' It proposes a series of questions to explore with the individual and the family, such as:

- What do you call your problem?
- What do you think has caused the problem?
- What do you think your illness does to you (and) will it have a long or a short course?
- What do you fear most about your sickness/problem?
- What are the chief problems your sickness/problem has caused for you?
- What kind of treatment do you think you should get?
- What are the most important results you hope to receive from the treatment?
- Do you think the problem is similar to those of anyone else that you know (such as a friend or relative)?

All of these issues may impact on the individual's attitudes to the illness and its treatment; exploring them is, therefore, a necessary foundation for dialogue and negotiation about the proposed treatment plan and about any complementary or alternative therapies that the individual or family may wish to pursue. It should be noted that while this assessment process was developed in the context of cross cultural psychiatry, it will be helpful for individuals from any background.

Summary and Conclusion

Engaging a young person in care depends on promoting a positive first contact with the mental health system, understanding the importance of a compassionate treatment environment, developing strategies to promote ongoing treatment adherence and providing ongoing care in a proactive manner that is consistent with the preferences of young people dealing with psychosis or other serious mental illnesses. Promoting engagement on an ongoing basis entails helping young people see the treatment as a means for control and a vehicle for achieving recovery. The family can help promote this by learning about available resources, advocating for effective care that promotes engagement and by reinforcing messages that can help a young person stay engaged with an ongoing treatment plan. **i**

How to Deal with your Drug-Abusing Child?

Try reversing roles

Jeff Thompson
MEd, RCC

How can you help your drug-using youth who appears unmotivated to change? In responding to that question, a role-reversal may be useful to promote insight and compassion, allowing us to ask: How to deal with parents (caregivers) who try to control your drug use?

a note for the adults, before you read on:

This article does not want to minimize the excruciating pain and helplessness one may experience as a caregiver when precious loved ones appear to be destroying themselves. It's not acceptable. The intent of this article is to join together the creative efforts of many who need to find solutions. It is hoped you might draw something you can use from this article.

Jeff has been a therapist for 10 years, specializing in group therapy with psychodrama, and has worked at the Addiction Research Foundation, the Maple Ridge Treatment Centre and the Orchard Recovery Centre. He currently works as a clinical supervisor with Watari in the Downtown Eastside. Jeff also authored the Problem Substance Use Workbook on behalf of the Kaiser Foundation. The workbook is also useful for family members and can be downloaded for free at www.heretohelp.bc.ca/helpmewith

Have compassion for yourself...and them. It must be tough for them to see you growing up and forming your own life and independence. They probably mean well. And if you've found yourself harsh and cold toward your parents, know that they probably deserve it...ahem...I mean know it is a common experience to break away and have space to form your own identity. Indeed, your drug use may be one way for you to reject 'their' rules as you create your own values. To ensure you break from an unfitting path, you might feel an appetite to wander in the forest. Just watch out for wolves in granny clothes!

You may be in an extremely difficult stage of life right now. How to negotiate freedom and autonomy while having support? It's not whether we should or shouldn't need connection and support...we just do. It's part of being human. Health is being connected to people who are good for us versus people who bring us down.

Remind them whose life it is and the freedom of choice that comes with having a life... yeah yeah... choices have consequences and every choice impacts others... blah blah blah, 'talk to the hand,' preferably not mine.

Keep your freedom. Don't let their demands for you to change your drug use stop you from exercising your own freedom to make changes you want. If you're at a restaurant and a stranger tells you to eat... there may be an urge not to eat to spite them, however, you can still retain your freedom to decide whether you're hungry or not. The stranger may feel self-satisfied when you are munching and smiling, but you can know your choice to eat or not eat was not controlled by them; you stayed true to what you wanted.

Continue to dream. You might be hiding your dreams from others and

are your caregivers/parents control freaks?

1. On at least one occasion my caregivers/parents took all my clothes from the house before they left for work, thinking my nakedness would keep me imprisoned for the day Y/N
2. My parents/caregivers ask me what I want to do with my life Y/N
3. My caregivers/parents want to give me a piss-test (for drug use) Y/N
4. My parents/caregivers have snuck into my room and gone through my personal belongings Y/N
5. My caregivers/parents say I am going to waste my life Y/N
6. My parents/caregivers say I have to quit using drugs Y/N
7. My caregivers/parents told me I need to go to a treatment centre Y/N
8. My parents'/caregivers' crusade against my habits allows them to ignore their personal problems Y/N
9. My caregivers/parents want to know what I am doing when I go out Y/N
10. My parents/caregivers want to know what I plan to do about my drug use Y/N
11. My caregivers/parents suggestion for dealing with emotional stuff I have to deal with is "get over it" Y/N

How did they rate? Personally, I believe if a parent/caregiver scored one YES, then you might be experiencing them as control freaks, although questions #2 and #9 may be exceptions. You might want to help them clarify their intentions.

even yourself these days. Trust they will surface when you invite them into support and safety.

"They might grow out of it." Most parents do let go of some of their controlling and demeaning ways.

There may be a time where you can forgive them and yourself for your reactions to them. Allow space for your relationship to change.

What can you do? Not much, if they're not moti-

vated to change. Sound familiar? But that doesn't mean they're a lost cause!

- Help them recognize the impact of their behaviour and healthy alternative ways to express their love and fears that might help.
- Asking them to share their perceived pros and cons of them continuing their controlling efforts may help bring change.
- Suggesting they talk to others who have reduced their 'control freak'-edness might improve things; you could also suggest that www.heretohelp.bc.ca and professional counselling can help.
- And, if you are wanting to explore your psychoactive substance use (which is any substance used to impact mood or behaviour):
 - Knowledge can be powerful. Check out the Alcohol and Other Drugs page at heretohelp.bc.ca.
 - Changing from harmful patterns of psychoactive substance use is common and possible! Successful change from problematic use often includes considering change, commitment to change, support and connection, new activities, specific plans to deal with difficult situations, and rewarding changes.
 - To find out about available services, visit www.addictioninfo.ca or call the Alcohol and Drug Information and Referral Line at 604-660-9382 (Lower Mainland) or 1-800-663-1441 (elsewhere in BC). ■

The Dance of Caring

Motivating young people to be involved in treatment

“Everything in the universe has rhythm. Everything dances.” So says Maya Angelou and from my perspective as a school counsellor, I think she has perfectly described the process of engaging young people into care. Working with adolescents and their families, I have found that there are definite steps to the dance we call ‘a continuum of care.’

Like a dance, all the players need to know the steps and anticipate what comes next. The dance begins with building bridges of understanding and creating relationships with the student, the family and the school and health community. Through the trust they build with students, school counsellors provide families with the support they need to navigate medical and mental health services. We also need to be aware of the cultural beliefs about mental health that provide the background music to all the conversations we may have with families. All of these things – creating a safe place for families to explore, question and problem-solve, awareness of cultural issues related to mental health, and providing families with connection to the services they need – is what makes the dance flow.

A case example will serve to illustrate this process when it works well. I worked with a young man last year who was experiencing symptoms of early psychosis. His family did not speak English. They had never heard of psychosis, but they were frightened and bewildered about the behaviour their child was presenting. Our first meetings were about getting to know this family, not trying to problem-solve or diagnose.

Through an interpreter, we talked about their life before they came to Canada, their other children, and about their hopes and dreams for this particular child. Connections were made with a social worker who spoke the first language of the family. Appointments for assessment and the subsequent planning after a diagnosis was made involved several more meetings and weekly phone conferences through an interpreter. Education regarding the nature of psychosis was provided to the family in the first language. The ongoing case management of this student became not only my responsibility as the school counsellor, but that of our whole school community. For example, when the young man was having a difficult day and hearing voices, teachers allowed him to wear his headphones in the classroom since listening to classical music helped him to cope more positively. In another case, a student who was diagnosed with severe depression was able to use the art studio in our school to paint as a way of coping with the bad days. Flexibility, creativity and compassion are needed by all to create a community of caring.

Challenges abound in this work of supporting families. Lack of resources, access issues, and mixed messages given to young people about behaviour and expectations – all of these things serve to create missteps in the dance of engaging a young person into care. Parents struggle with long wait times, self-medicating teenagers and misdiagnosis. Teachers struggle with inappropriate behaviour and needy students in large classes with little support. Communication is the key to opening up misconceptions and closed minds. For example, one student I worked



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MA, RCC

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Family Education

This article is adapted from the BC Early Intervention Study and from "Psychoeducation," a fact sheet in the 2002 series The Psychosocial Aspects of Recovery from Early Psychosis, produced by the Canadian Mental Health Association's BC Division with a grant from the Ministry of Health Services

The first part of this article looks at some of the common needs and challenges faced by young people and families as they attempt to learn and deal successfully with a mental illness in its early phases. The second part of the article looks at the kind of information that consumers and families find helpful and includes some additional helpful resources.

The Need for Education

Despite evidence showing its value for both consumers and families alike, a common challenge for both is to gain adequate information about their illness during the early phases of the illness. Professional factors, such as confidentiality, 'family-blaming,' and failure to ask the consumer's permission explains some of this gap.

Families may also struggle to be involved due to logistical reasons (e.g., lack of time), lack of assertiveness, lack of awareness of the importance of their involvement, or resistance.

While many families do receive some information, they often lack specific and practical information that can be used to cope with their own situations. In the absence of specific information, families may develop expectations that are either unrealistically high, or overly pessimistic about the chances of recovery. While this is beginning to change, historically when families received information, it was often through their own initiative, rather than through a proactive attempt to involve them. Families desire an educational approach that is proactive, inclusive of all family members (such as

siblings, spouses and children of parents with mental illness) and sensitive to their emotional reaction to the first experience of illness.

Without a sensitive, hopeful approach to delivering information, families may be devastated when receiving a diagnosis or may experience widely divergent reactions among the members. Fathers are particularly likely to react more negatively and deny the illness. As with young people with mental illness, first-time families need individual counselling that helps them understand and come to terms with the illness on a one-to-one basis and helps them to contribute emotionally and practically to the recovery process.

After this is offered, families often want the opportunity to learn from

other families in similar situations. Learning from other families offers a greater opportunity to understand the practicalities of coping with the illness, to learn about available resources, as well as a great opportunity to feel understood. Families also benefit greatly from direct dialogue with the person with the illness, as this can build mutual understanding and support and avoid blame. Despite the value of open communication, families have difficulty knowing how and when to broach the subject, and consumers, too, have difficulty opening up about the illness.

Encouragement from professionals would help set the stage or increase the possibilities for communication. If this is not possible, families identify other valuable ways of gaining an experiential ►

The Dance of Caring | *continued from previous page*

with suffered from a severe anxiety disorder and paranoia. Working with her teachers, we managed to change their experience of what they saw as whining and helped her develop some self-talk that helped this young lady identify what was making her anxious. Then the job became one of having her keep a journal and write about her anxiety triggers, instead of verbalizing her fears.

Despite the challenges, we continue to look for ways to support our students. Young people struggling with mental illness need to know that their school counsellor is an advocate who will help them navigate the day-to-day rhythms of their condition. There is a role for the school counsellor in providing ongoing support, and the stigma attached to counselling and medication can be overcome when we help the young person frame

them as a method of coping and caring. Families need help to let go of expectations that may not be realistic and require support to create new hopes and dreams. For parents, daily frustrations – such as dealing with an adolescent with a sleep disorder or managing medication side effects – can become overwhelming without someone to call who can just listen while they vent. With the circle of support created around a student in place, families can turn to taking care of each other instead of being focused only on the young person. While crisis may mark the beginning of the process of engaging a young person into care, it is the ongoing dance – of support, assessment, medication and lifestyle stress management – that provides young people with a mental illness the framework for success in adolescence, both academically and personally. ¶

understanding of the illness through articles, stories, and meeting other people with mental illness who have recovered. A benefit of meeting recovered consumers is that it is a powerful way of building families' hope for recovery for their relative.

Psychoeducation: Frameworks for Delivering Information

The Stress-Vulnerability Model

Up until now, we've concentrated more on the barriers to and the value of illness-related education for the individual and for the family. Now, we'll go on to talk more about the kinds of information that are valuable to both consumers and members of their family. One generally-accepted information delivery framework is the 'stress/vulnerability' model. Within this framework, the person's experience can be explained as being due to an underlying biological vulnerability which is also influenced by psychosocial factors or stressors.

In this context, the information given to the young person and to his or her family can suggest both biological strategies –

i.e., adhering to medication and avoiding substance abuse – and psychosocial strategies to reduce the vulnerability associated with the illness and prevent a possible recurrence of an acute episode. Psychosocial strategies include managing interpersonal conflict, making use of peer support, identifying and managing environmental stressors, learning the early warning signs of the illness, and planning proactive coping and help-seeking strategies. Drawing analogies to the management of other ongoing health issues that fit this framework, such as diabetes or asthma, can help normalize the experience of mental illness for the young person.

The Recovery Model

Another important organizing framework for presenting information is the recovery process and how this is experienced by others. (For the present purposes, we'll define recovery as "the process of learning to live a meaningful life with the illness.") By presenting recovery as a process that occurs in documented, recognizable stages, the individual and family can be helped to normalize their own pain-

ful experiences, to see they are not alone in having them, and to realize they are a necessary step to healing. They are also given hope that recovery is possible and, indeed, what is expected. Information of this kind can be delivered through professionally-based interventions or with peer-driven approaches such as BRIDGES and its family education counterpart known originally as The Journey of Hope and now as Family-to-Family (see ad on page 7).

Summary and Conclusion

Education about the illness or 'psychoeducation' is crucial to the recovery process of young people and their families who are dealing with early psychosis or any serious mental illness. Despite its importance, certain barriers – such as the stage of illness, uncertainty about diagnosis, views about patient confidentiality, and cross cultural communication difficulties — hinder its delivery in many instances. Information must be given in a way that is sensitive, thorough, and which enables individuals and their families to cope with symptoms and prevent a possible relapse, irrespective of what the diagnosis is. The stress/vulnerability framework and the recovery process are key information delivery frameworks.

By educating young people and their families about both biological and psychosocial causes, families can begin to gain a sense of control over the illness,

and learn to manage the effects of the illness as they attempt to resume their day-to-day lives. Also, by learning about the experiences and successes of others in similar situations, individuals and family members can gain a sense that they are not alone, along with hope for recovery. Psychoeducation must be seen not only as information delivery but also as a form of counselling that helps young people and their families come to terms emotionally with the prospects of living successfully with mental illness. †

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relevant resources

www.heretohelp.bc.ca/helpmewith – a website from the BC Partners, which includes the Family Toolkit and the Mental Disorders Toolkit among others. Each toolkit contains extensive information and also contains worksheets for developing an 'early warning strategy' to prevent illness relapse.

Psychoeducation in Early Psychosis. Early Psychosis Manual 1. (1997). Produced by Australia's Early Psychosis and Intervention Centre. To order, see www.eppic.org.au

Early Psychosis: A Care Guide. (2002). "Psychoeducation" section. Produced by the Early Psychosis Initiative. Mental Health Evaluation and Clinical Consultation Unit, University of BC. See www.mheccu.ubc.ca/cy

Storm Breaking: An Anthology of First Experiences through Mental Illness and Into Recovery. (2002). Produced by the Canadian Mental Health Association, BC Division. Online at www.cmha-bc.org or call 604-688-3234 or 1-800-555-8222 (toll-free in BC).

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Emotional Impact Series

By Adolph J. Moser, EdD; Illustrated by David Melton

Landmark Editions, Inc., 1996; full-colour; 40-60 pages each; hardcover; \$15.95 each

Editor's Note: All of the materials reviewed below help families deal with an important topic: how to help their son or daughter learn and talk about mental health and mental illness at a level that is appropriate to their age.

Review by Jennifer Quan

Jennifer is a Communications Co-op Student at the Canadian Mental Health Association's BC Division

The Emotional Impact Series of children's books was written by a registered clinical child psychologist and designed to help teach children about their emotions and positive ways to deal with them. With titles such as *Don't Rant and Rave on Wednesdays!: The children's anger-control book*, and *Don't Pop Your Cork on Mondays!: The children's anti-stress book*, the seven-book series covers the topics of stress, self-esteem, anger, grief, lying, divorce and violence.

The large-type books are easy to read and filled with lots of colourful cartoon-style illustrations. The language is simple to understand, and the pictures are fun and lively. Though the reading level is described as for ages 9-12, I think that younger children would especially enjoy and benefit from the books when read together with an adult.

Each of the books begins with a playful description of the topic and problems that can arise from not dealing with the situation or emotion in a positive way. The second half of each book describes positive ways of dealing with the topic of concern and offers fun exercises that the children can do on their own or with their parents. The exercises range from relaxation techniques and communication skills-building to art projects that help readers understand and organize their feelings.

Though the books are aimed more at promoting general mental wellness and positive behaviours than dealing with specific disorders and illnesses, the themes and principles taught could also be applied to help relieve various illness-specific symptoms as well. For example, in *Don't Feed the Monster on Tuesdays!: The children's self-esteem book*, children are encouraged to think of negative thoughts as the products of a little green monster who lives inside their heads and grows larger the more they believe the negative thoughts. Children are told that as the monster grows, he takes bites out of your self-esteem. To defeat the monster, you must refuse to listen to his negative thoughts, think

good things about yourself and others, and accept mistakes as okay. If applied to helping kids deal with specific mental illnesses, this concept could be a helpful way for children to conceptualize, for example, strange, disruptive or obsessive thoughts, compulsions, anxieties or negative thoughts tied to depression or disordered eating and body image.

Overall, I found the books entertaining, filled with great illustrations and good tips for anyone – children and adults alike – to put things in perspective and to work through the emotional challenges of life.

This series may be available at your local library or bookstore and are also available for ordering from Landmark Editions (www.landmarkeditions.com or 1-800-653-2665), Chapters Indigo or Amazon.

more books for kids and teens

Most of the following books should be available at your local library or bookstore.

books for younger children

- Abramovitz, M and Abramovitz, M (2002). *Schizophrenia (diseases and disorders)*. Lucent. Ages 9-12. Information on the causes, treatment, prevention.
- Benedek, EP and Rosmillia, P (Illu.). (1984). *The Secret Worry*. Human Sciences Press. Ages 4-8. A little girl's secret worry makes her sad and cross with her family and friends until the worry doctor helps her understand her worries and herself. Describes play therapy.
- Bode, J. (1997). *Food Fight: A guide to eating disorders for preteens and their parents*. Simon & Schuster. Grades 4-7. Stories of preteens suffering from anorexia and bulimia. Symptoms, causes and ways of dealing with disorders, written for preteens.
- Grass, G. (2001). *Catch a Falling Star: A tale from the Iris the Dragon series*. Stoddart Kids. Grade 3-5. Illustrated fairy tale about a friendly dragon educating young children showing signs of mental illness.
- Holmes, MM, Mudlaff, SJ, and Pillo, C (Illu.). (2000). *A Terrible Thing Happened*. Magination. Ages 4-8. After Sherman sees something terrible happen, he becomes anxious and then angry, but when a counsellor

helps him talk about these emotions, he feels better.

- Jabonsky, J, Moritz, EK, and Geary, R. (Illu.). (2001). *Blink, Blink, Clop, Clop: Why do we do things we can't stop?* Childswork/Childsplay. Barnyard characters depict the common types of obsessive-compulsive disorder (OCD). OCD is represented by the obnoxious "O.C. Flea," who is banished from the barn as the animals learn to change their behaviour.
- Lite, L and Hartigan, M (Illu.). (1996). *A Boy and a Bear: The children's relaxation book*. Specialty Press. Ages 4-8. A boy meets a polar bear on a snow-covered mountain. Teaches young children how to calm and relax themselves through breathing exercises.
- Pinto, A and Jutton, PA. (2000). *Up and Down the Worry Hill: A children's book about obsessive-compulsive disorder and its treatment*. Lighthouse Press. Ages 4-8. Tells the story of Casey's initial struggle with OCD, his sense of hope when he learns about treatment, his relief that neither he nor his parents are to blame, and eventually, his victory over OCD.
- Silverman, J. (1999). *Help Me Say Goodbye: Activities for helping kids cope when a special person dies*. Fairview Press. An art therapy activity book encouraging kids to express their feelings in words or pictures.

books for older children

- Parker, S. (1990). *The Brain and Nervous System*. Franklin Watts. Grades 5-8. An easy-to-read, illustrated overview of the components, functions, and disorders of the nervous system.
- Sherrow, V. (1996). *Mental Illness* (Lucent overview series). Lucent. Ages 9-12. An illustrated historical overview of mental illness, treatments and related social and political issues.

books for teens

- Carlston, D and Nicklaus, C. (1977). *Where's Your Head: Psychology for teenagers*. Atheneum. Discusses the common psychiatric problems of young people and how to deal with them and gives a brief history of psychiatry.
- Cobain, B. (1998). *When Nothing Matters Anymore: The survival guide for depressed teens*. Free Spirit. Written by Kurt Cobain's mother. A teenager's guide to understanding and coping with depression, discussing the different types, how and why the condition begins, how it may be linked to substance use or suicide, and how to get help.
- Copeland, ME and Copans, S. (2002). *Recovering from Depression: A workbook for teens*. Brookes Publishing. Interactive workbook exploring suicidal thinking, negative behaviours, reaching out, problem-solving stress, substance use and triggers.
- Covey, S. (1998). *The Seven Habits of Highly Effective Teens*. Simon & Schuster. A step-by-step guide filled with cartoons, ideas, quotes and stories to help teens

achieve their goals and build self-esteem, positive relationships and self-image.

- Friedman, MS. (2000). *Everything You Need To Know about Schizophrenia* (Need to Know library). Rosen. Clearly-written basics of causes, symptoms and treatments. Part of the Need to Know series which also includes books on addiction, eating disorders, smoking and alcohol.
- Garland, EJ. (1998). *Depression is the Pits, but I'm Getting Better: A guide for adolescents*. Magination. By BC's own head of the Children's Hospital Mood and Anxiety Clinic. Understanding, gaining control, helping yourself (with medications or psychotherapy), post-depression steps, personal stories and resources.
- Holmes, A et al. (1999). *Cutting the Pain Away: Understanding self-mutilation*. Chelsea House. Understanding, talking about, treating, and helping yourself or someone you know who self-injures.
- Jovinelly, J. (2001). *Coping With Bipolar Disorder and Manic-Depressive Illness*. Rosen. A book in the Coping series, which also includes books on depression, police encounters, self-mutilation, gambling and schizophrenia, among others.
- Miller, M. (2000). *Drugs and Mental Illness* (Drug abuse prevention library). Rosen. Relationships between drugs, both therapeutic and harmful, and mental illness.
- Rosenthal, H. (1988). *Not Without My Life I Don't: Preventing your suicide and that of others*. Accelerated Development. Behaviour, causes and prevention of suicide.
- Vavricheck, SM et al. (2000). *The Hair Pulling Habit and You: How to solve the trichotillomania puzzle*. Writer's Cooperative of Greater Washington. A friendly, illustrated, step-by-step workbook for recovery.

fiction: fun and education

- Bennett, JW. (1990). *I Can Hear The Morning Dove*. Houghton Mifflin. An uplifting and often funny novel about a 16-year-old girl who struggles to survive after her recent suicide attempt.
- Dorce, D. (2000). *Loving Penny*. Writer's Club. 13-year-old Penny begins to deal with her depression by binge eating, before gaining the strength to regain her self-esteem and learn to love herself.
- Green, H. (1989). *I Never Promised You A Rose Garden*. New American Library. A captivating chronicle of the three-year battle of a mentally ill, but perceptive, teenage girl against schizophrenia, emphasizing her relationship with the doctor who gave her the self-understanding with which to help herself.
- Hesser, TS. (1998). *Kissing Doorknobs*. Delacorte Press. 14-year-old Tara first encounters her compulsive behaviour at age 11 when she hears of the sidewalk game "Step on a crack, break your mother's back." An inspiring account of her experiences with obsessive-compulsive disorder. ■

web resources

www.kidshealth.org
health articles for kids, teens and adults on three different age-appropriate sites.

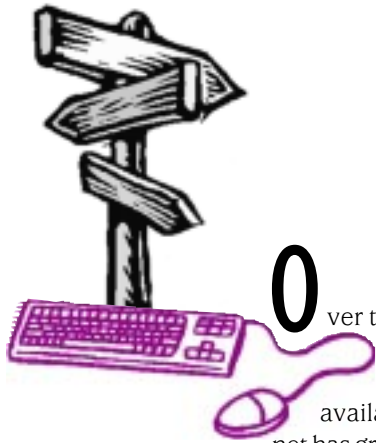
facetheissue.com
a mental health and addictions information website for youth, delivered in a hip format.

www.zoot2.com
from Alberta, information and interactivity for youth 13-17 on alcohol, drugs, gambling, personal development and recovery.



NOTE
other than the Emotional Impact Series featured in the review, the rest of the books in this article are suggestions based solely on summaries. Each book has not been read in full or independently evaluated for clinical appropriateness

Finding Useful Health Information Online



Mykle Ludvigsen

Mykle is a Communications Officer at the Canadian Mental Health Association's BC Division

Over the last ten years, the amount of information available on the internet has grown exponentially. As anyone who has been online can attest, the information can range from the useful to the downright dangerous. Unlike most health books or journals, not all health information on the internet is written or checked by a reputable source, whether that be a health professional or a consumer or family member with extensive first-hand experience.

Some websites with comprehensive information on mental health and addictions will have contradicting information. That's why it's critical to pay careful attention to see where your information is coming from. A key rule of thumb when evaluating health resources on the internet is to judge a site by the following six key criteria:

Authority: As a browser, you should make careful note of whether the author of the material is clearly identified and what their level of expertise and training might be. Is he or she a doctor or counsellor? A person with first-hand knowledge of mental health or addictions issues? Someone with relevant personal experience as a friend or family member? In these cases, it is advis-

able to have at least partial contact information where a person can be reached. In cases where no author is listed, look carefully to see who published the information – government, a non-profit, an association of treatment professionals, an individual, or perhaps a pharmaceutical company? Do you trust these sources? The people supporting this material should be reputable, familiar, and have a track record in dealing with the issues they are covering.

Accuracy: Accuracy is important; bad health information can cause serious damage to your health if you take the wrong advice. Some key points to consider include checking to ensure that the article has a list of references where you can see the supporting information, whether the article has explained the research method used to obtain data, and if this information is easy to find.

Objectivity: Ask yourself a question after you finish reading some information: was this a marketing pitch, or was this presented in an objective manner? Is the purpose of this website to sell or promote a particular product or philosophy or to simply provide information that I can use to make my own decision? An objective website will provide

many sides of the issue, including downsides, in order for you to make an informed decision. Sponsorship information should also be clearly presented if the website was funded or sponsored by any third party. Websites promoting 'quick fixes' to anything health related should be disregarded.

Coverage: Another important question to ask is whether a particular site provides comprehensive information on the particular condition you are researching. For example, if you are searching for information on depression, does the site include links to information about anxiety, or different types of depression? Does it discuss both pharmaceutical and cognitive-behavioural therapies? What about the misuse of alcohol or other drugs in addition to depression? Or about how families can help a person with depression? You should also look for any innovations such as online self-tests, worksheets or message boards. The BC Partners for Mental Health and Addictions Information website at heretohelp.bc.ca is a good example of a site with broad coverage, linkages to information all over the web, and interactive features and tools.

Currency: It's essential that any health information

site that you use has the latest information available. Somewhere on the page should be an indication when the material was written and last updated. Links on the page should also be kept up to date. A vast number of websites launched are never updated, meaning some information on the web could be more than 10 years old.

Design: The site should be clearly organized, separated into individual pages on different issues or linked in such a way that you can click on a link and scroll to a part in the page where the information is located. The site should be easy to understand. There should be a search function available and visual elements should enhance and not detract from the resource. The interactive features should increase usability, and the site should be accessible without downloading special plug-ins or viewers.

It is always important to discuss any health information you find online with your mental health professional. The web often acts as a platform for various causes or ideas and it is important to make sure you are getting the best information. Used properly, however, the web is an invaluable information resource that can help you gain more information about a diagnosis. ¶

references

Simply Stated: Disease Information You Can Trust. "Evaluating Health Information Online" at www.simplystated.com/info/tools/evaluating_health_info.jsp. Accessed May 20/04

Healthlinks, University of Washington. "Finding Health Information Online" at healthlinks.washington.edu/howto/finding_healthinfo.html. Accessed May 20/04

How Families Can Help Children Manage Problems with Anxiety

Excessive anxiety is a dilemma faced by many kids and families. Anxiety disorders are the most common form of mental health problem, with over 65,000 children and youth in BC coping with at least one anxiety disorder. Fortunately, anxiety disorders are highly treatable with cognitive-behavioural therapy, select medications or a combination of both. Parents and families can play an extremely important role in helping kids manage excessive anxiety and associated problems.

There are many different causes of anxiety problems in children. Understanding the preliminary causes of a child's anxiety is of limited value as the causes are either not directly changeable (e.g., genetic vulnerability to anxiety) or they originate in the past (e.g., a traumatic or stressful event).

Fortunately, with your assistance, your child can learn to manage their anxiety without having to understand and resolve the initial cause!

The important next step in managing anxiety is identifying what maintains the anxiety or what keeps the anxiety high when the cause or trigger has passed. After years of research, we now know that a child's anxiety is maintained through several different factors including the way the child

1 thinks – anxious kids tend to see the world as dangerous and threatening

2 copes – anxious kids tend to avoid and run away from scary or challenging situations

3 interacts with their family – sometimes families respond in a helpful way, but other times families can get drawn into unhelpful responses

Parents can help their anxious child with each of these areas. The first step is deciding to address the problem and seeking out 'evidence-based' assessment and treatment, that is, strategies shown to work through well-conducted research studies. Both you and your child must be fully on board with the decision to seek treatment as many of the strategies and techniques require hard work over a number of weeks or months. Fortunately, this hard work pays off, with approximately 80% of kids and families experiencing benefits from an evidence-based management plan.

To increase motivation, you and your child can sit down and brainstorm the problems anxiety brings to their life and the benefits they will experience once they have mastered their anxiety.

Deciding to begin an evidence-based program such as cognitive-behavioural therapy can bring both the family and child enormous rewards. The child struggling with anxiety will soon experience increased self-esteem, greater confidence and improved levels of personal happiness. The family will notice decreased conflict and worry, and increased family cohesiveness.

Implementing an Evidence-Based Management Program

Some points parents may want to cover with their child:

- Anxiety is a normal feeling and lots of other kids have the same difficulties (normalize, normalize, normalize!)
- You will be doing this together with your child every step of the way (studies show kids do best when their parents are able to provide encouragement and coach them in the use of helpful anxiety management strategies)
- Your child will never be forced to do anything they do not wish to do
- Challenges and new skills will be tackled at their own pace by breaking them down into manageable steps
- Getting better can be fun and very rewarding

Helpful Ways of Dealing with Your Child's Anxiety

Reward Brave, Non-Anxious Behaviour

Whenever you see your child doing something brave, make a big fuss. Set up a plan so that whenever your child faces a situation she or he finds challenging, they will receive a reward (e.g., special time with parent or friend, sticker, treat, etc.).

Ignore Behaviours You Don't Want

Don't give your child your attention when they are engaging in anxious behaviours (e.g. having an upset stomach before a birthday party) and praise your child when the behaviour has

Melanie O'Neill, PhD

Melanie is a Registered Psychologist with the University of British Columbia and Malaspina University College

helping anxious children checklist

- Get an assessment from a trained expert
- Get informed and educated about anxiety
- Teach tools to relax
- Teach tools to cope with worrying
- Encourage your child to take risks
- Break down feared tasks into manageable chunks
- Use a firm and consistent parenting style
- Establish daily routines
- Plan for homework and projects
- Model and teach healthy self-care (e.g., diet, sleep, exercise)
- Problem-solve life stressors (both yours and your child)

Adapted from Anxiety Disorders Association of BC's Helping Anxious Children brochure: anxietybc.com

references

March, J.S. (1995). *Anxiety disorders in children and adolescents*. New York: Guilford Press.

Rapee, R.M., Wignall, A., Hudson, J.L., Schniering, C.A. (2000). *Treating anxious children and adolescents: An evidence-based approach*. Oakland, CA: New Harbinger.

stopped and they move on to a more helpful way of coping (e.g., brainstorming what they will do to cope at the birthday party).

Preventing Avoidance

We now know that running away from anxiety-provoking situations is one of the key maintaining factors in childhood anxiety problems. By avoiding a feared situation, your child never gets to learn there was nothing to fear in the first place. Encourage your child to gradually and slowly face challenging situations when you know they are capable of being successful in that situation.

Empathize and Understand

Ensure that your child knows that you understand their anxiety (you've felt it before!) and how hard facing your fear can be (provide an example from your own life). They will be much more willing to follow your lead as their anxiety coach!

Encourage Constructive Coping

Prompting your child to come up with their own helpful coping options in a scary situation – rather than telling them how to cope – is a great way to foster self-esteem in your child. This also shows your child that you have faith in their ability to manage their anxiety.

Model Non-Anxious Behaviour

Your child watches you face challenging situations. Ensure you are modelling brave coping whenever you enter a situations that scary for you.

Parents and families often get pulled into well-intended but unhelpful responses when coping with an anxious child. These responses may help lower the child's anxiety in the short-term, but usually make anxiety worse in the long-term; examples include providing excessive reassurance, taking over or being too directive, encouraging avoidance, becoming impatient, or participating in the child's safety behaviours or rituals. **i**

your child is very anxious...

what can you do?

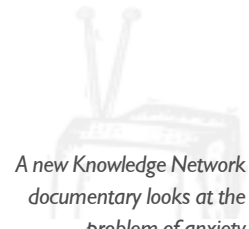
Remember we all feel anxiety from time to time. The goal as parents is to help your child cope with scary situations and learn how to master excessive feelings of anxiety.

- Summarize what your child has shared with you in a supportive and understanding way. Make sure you really know what they're concerned about.
- Present some choices and break down the scary task into manageable chunks. This sets up kids for success and allows them to discover they can choose to do something active to cope with their anxiety.
- Brainstorm potential strategies (e.g. problem-solve) for dealing with their situation. Let your child take the lead in this exercise.
- Examine each strategy and their most likely consequences. "What would happen if you go to school today? What would happen if you stay home and miss class?" etc.
- Encourage your child to select a strategy that works best for the current situation.

Adapted from Rapee et al. (2000). Helping Your Anxious Child: A step-by-step guide for parents. New Harbinger: Oakland, CA.

recommended readings

- *Taming the Worry Dragon* series (Includes workbooks and videos for kids and families). Available at Odin Books in Vancouver: Call 1-800-223-6346 or visit www.odinbooks.ca.
- Rapee, R M, Spence, SH, Cobham, V, & Wignall, A. (2000). *Helping Your Anxious Child: A step-by-step guide for parents*. New Harbinger: Oakland, CA.
- *Anxiety Disorders in Children and Youth*. Past issue of Visions Journal (No. 14, Spring 2002). For a free printable copy visit www.cmha-bc.org/visions



A new Knowledge Network documentary looks at the problem of anxiety disorders in youth and helps BC families learn symptoms to identify a child or youth who is in need of professional help. It first airs October 18th, 2004.

Check your local listings for times or see www.knowledgenetwork.ca.

An online learning component will also be available on the air date under the 'Knowledge Tools' section of the Knowledge Network site. This documentary is the second of a three-part series on child and youth mental health

A Family Story

An insider's look at growing up in a family unaware of mental illness and alcoholism

Murphy Kennedy

Murphy is Executive Director of the Canadian Mental Health Association, Kamloops Branch

As far back as I can remember, I felt like an outsider, both within my family, and out there in what seemed to me like an unsafe world. I have spoken to many who have experienced mental illness in their childhood who felt exactly the same way.

Many children go through a stage of shyness in early life. Some may even keep this trait

throughout their childhood and into adulthood. Most of us remember hiding behind mom or dad's leg for a short while, until we got used to a new person in our surroundings; however, an anxiety disorder is quite different.

I recall an afternoon in Peterborough, Ontario. I was three years old. While busy playing in the upstairs of our farmhouse, I heard

my uncle and aunt arriving at our front door on a visit from Hamilton. I was terrified. I climbed into an old clothes chest until they and my parents came looking for me. My body trembled as I heard them coming up the stairs, their voices getting louder, with my mother's becoming more stressed as her concern for my whereabouts increased. As they got closer to my hideout, my fear intensified until they eventually found me.

Thirty-seven years later, I still vividly remember the power of that fear which filled my entire being. This was not shyness: this was mental illness, and neither my parents nor I had any idea what was going on inside my head. This unintentional ignorance on everyone's part would last another 26 years, until the pain of social anxiety disorder and depression convinced me to seek help.

Soon after this incident, I discovered alcohol. It was never too far out of reach in our Irish family home. The bottle of Canadian Club whiskey was always prominent on top of the fridge. "That's Dad's medicine!" would be my mother's answer to my quizzical musings. "Medicine," I thought. "That's what makes a person feel better, isn't it? Hmmm, maybe it would work for me. I'll have to give it a go."

My adventure into self-medicating with alcohol began early. Six years old is my first recollection of being looped. It took 20 years filled with drunken mishaps and physical

cont'd next page

When Someone You Love Is Depressed

How to help your loved one without losing yourself

By Laura E. Rosen and Xavier F. Amador

When *Someone You Love Is Depressed* came about as a result of the authors' work. As psychologists, Rosen and Amador were often approached by friends or relatives of the depressed people who were their clients. Beyond the questions about the illness, most had concerns about how to best deal with their loved one while continuing to maintain a healthy relationship.

The authors include real-life stories and use them as examples to teach methods you and your loved one can use to protect yourselves and your relationship while dealing with depression. Specific chapters are included that deal with your partner, child, parent or friend when they are depressed, giving you step-by-step suggestions and a questionnaire to assess how you are coping in the relationship.

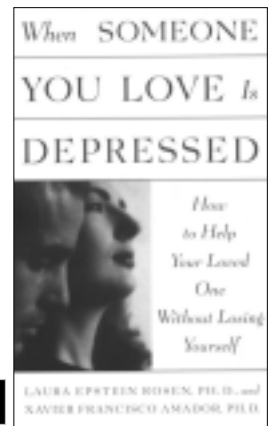
The title of the first chapter, "How Does Your Loved One's Depression Affect You," is an important beginning to understanding relationships and the effect a mental illness has on those relationships. It is not uncommon, but often not recognized, for the parent, spouse, friend or child of the person living with depression to feel his or her own anger, frustration, despair and sometimes even physical symptoms as well. This book provides education, support and direction for the healthy member of the relationship that can only produce beneficial results for the depressed person as well. There is an oft-repeated message throughout the book that the support person must remember their own needs and pay attention to signs that they are becoming overburdened.

The focus on the importance of communication and working as a team is a common thread throughout the book. Communication problems are not uncommon in relationships, but adding a mental illness to that relationship increases the possibility of a communication breakdown. One chapter is devoted entirely to communication, entitled "Constructive Communication." After reading it you will have less of a feeling of hopelessness or helplessness and more of an optimistic outlook on ways of improving communication.

Some important areas covered throughout the book include:

- the stages relationships go through in their adaptation to depression
- how to avoid pitfalls common in relationships with depressed people
- communicating effectively with the opposite sex (gender can make a difference)
- dealing with substance abuse and depression
- guidelines for dealing with a loved one who is suicidal
- ways of encouraging a person to seek treatment

This book was originally suggested as a resource by the partner of a Mood Disorders Association of BC member who found it in the library where she worked. She found that the book answered some questions about her partner and confirmed her suspicion that he was suffering with depression. Learning how to communicate with him and also deal with her own feelings helped their relationship survive. Although initially you might read the specific chapter which you feel is most closely related to your situation, a quick browse of the topics covered in the other chapters will soon have you reading the entire book. ■



Free Press, 1997
272 pages; \$13

Review by Pat Merrett

Pat is Executive Assistant for the Mood Disorders Association of BC

Chinese Family Support Groups In Vancouver

Sophia Woo, MSW and Raymond Li, RPN

Sophia is a Multicultural Mental Health Liaison worker for Vancouver Community Mental Health services, Vancouver Coastal Health. Sophia can be reached at the Grandview Woodlands Mental Health Team, (604) 251-2264

Raymond is a Case Manager for the Northeast Mental Health Team, Vancouver Coastal Health. Sophia and Raymond co-facilitate all four Chinese family support groups in Vancouver. Raymond can be reached at (604) 253-5353

The need to incorporate families of persons with an acute or chronic mental illness as a part of the treatment team is gaining recognition among mental health professionals, and a sizable literature has developed in the area. Literature on certain major mental illnesses such as schizophrenia supports the fact that empowering family members and consumers can increase their problem-solving skills and coping behaviours which, in turn, enhances recovery. Professionally-facilitated or self-help groups for families, including education and mutual support, have formed throughout North America. However, in the early 1990s, most of these groups were conducted in English and have been underutilized by families of other cultures. Historically, Canada promoted a multicultural policy, yet there were few successful efforts to meet the needs of one of the largest ethnically-diverse populations: the Chinese.

In the spring of 1993, the Northeast Mental Health Team of Vancouver Community Mental Health Services embarked on a couple of culturally-specific family psychoeducational projects. One project targeted Cantonese-speaking families in the Northeast Team catchment area, where over 30% of the population is of Chinese origin. The Team's case managers had identified that the Chinese families in the community suf-

fered the same problems of burden and isolation as the English-speaking families. However, they were not readily accessing available resources due to language and cultural barriers. The goal of the project was to provide a setting which was linguistically and culturally comfortable in order to meet the universal needs of such families, namely to:

- provide education on mental illness and information about other supporting resources
- empower families in managing their loved one's illness
- encourage families to 'vent,' to share, to support and to learn from each other

The first Cantonese Psychoeducation and Mutual Sharing Family Support Group, begun in 1993, started with a humble beginning of six families. Over the course of several years, both the attendance and responses have been overwhelmingly positive. In total, the group has more than 100 participants, with average attendance of between 40 to 50 members. Over 50% of the participants are parents of a loved one with a major mental illness. A small percentage of participants are siblings or spouses. Cantonese is the group's preferred language.

Many participants openly state that they have benefited from the group as they no longer feel alone. Also, ►

A Family Story | *continued from previous page*

illness to get to the doors of recovery from alcoholism. I ran on alcohol, lived for alcohol, and was dying of a seemingly hopeless malady. I remember the insanity near the end of my drinking career thinking, "If this stuff makes me feel better after work, it must do the same if I drink in the morning before the workday begins!" And on it went, until June 10, 1990, when I hit the wall and admitted defeat. The fear of drinking overtook the fear of not drinking, but it was another three years before I got the help I needed for my reason for drinking in

the first place: social anxiety disorder and depression.

The illness known as alcoholism is a mystery to most, but not to the alcoholic. In our minds, it is the only way to deal with and stay in the game of life. It is an allergy of the body coupled with an obsession of the mind. The body says, "I can't drink," yet the mind says, "I must!" – a more perplexing and terrifying dilemma is difficult to imagine. It is even more troublesome when the alternative to being intoxicated is being clinically depressed and anxious.

And it was, and probably still is, a mystery to my family as to what was happening to me.

Public education on mental illness and addiction, then and now, is sorely needed, yet remains inadequate.

Since coming into the field of mental health, and learning in recovery what alcoholism is (and isn't), I have often wondered about the different life I may have lived had my parents known the signs and symptoms of mental illness and where to go for help. Along with cutting into the profits of Labatt's, Mol-

son and the makers of Jack Daniels, this knowledge might have saved me more than 20 years of not knowing about the life-threatening illnesses I was dealing with. That is why this work is so important to me.

Information needs to be delivered in the classrooms, doctors' offices, hospital waiting rooms and other public places so that years of suffering by our children can be avoided. It is truly the difference between many of them living a full and happy life or dying a slow and painful death. ■

the education is appreciated by the group members, some saying they feel better equipped to observe early relapse symptoms and deal with crises. They become proactively involved with the treatment of their loved ones, for example, by forwarding pertinent information to the treating professionals. They also feel less stigmatized and are more receptive to discussing mental health issues. It is a far cry from the early days when groups had to be held away from and out of sight of the Chinese community or any mental health settings. Nowadays, members are comfortable sitting in a circle in a mental health office. A few members are even comfortable enough to talk about their experience in a video which is used by the World Health Organization in Beijing for educational purposes.

The original group has expanded and become an umbrella group. Three other Chinese family subgroups have emerged: the Cantonese Satellite Mutual Support Group (1996), the Mandarin Psychoeducation Group (1998), and the Cantonese Early Psychosis Intervention Family Group (2000). While the original Cantonese Psychoeducation and Mutual Sharing Group continues to provide basic education and information, the smaller spin-off groups have evolved to become more self-directed and task-oriented in areas like problem-solving, communication, coping and/or advocacy. The Cantonese Satellite support group gives families a forum for sharing their personal experiences, which reduces feelings of isolation and stress. The Early Psychosis group helps Cantonese families with younger members in their teens to early 30s, who are experiencing a first psychotic episode, to understand mental illness and to develop coping mechanisms for dealing with developmental challenges, schooling and vocational needs.

Over the past decade of working with these groups, we are witnessing a progressive improvement in the willingness of Chinese families to seek out mental health professionals. The percentage of Chinese clients in mental health treatment teams in Vancouver is getting comparable to the general population (e.g., 23% Chinese clientele at the Northeast Team vs. 30% Chinese citizens in the area). In the past decade, over 1500 Chinese clients and/or families have accessed mental health treatment through the Chinese Mental Health Liaison program.

Other things would be even more beneficial to the Chinese community, such as organizing conferences and seminars in ethnic communities, liaising with the ethnic media to produce objective mental health programs, and providing culturally sensitive, appropriate and accessible approaches and information.

As facilitators of these family support groups, we feel privileged to be involved with so many courageous and insightful individuals and families. We are touched by their determination and their strength to ward off adversity, while remaining focused on striving for mental and physical well-being for themselves and their loved ones. ■

Peer Support for Parents of Psychosis Sufferers

Nicole Chovil

In 2002, a group of parents in the South Fraser health area (south of Vancouver) formed a support group so they could share information and provide support to other families dealing with mental illness. This group of families all have loved ones who suffer psychosis and who are involved in the Fraser South Early Psychosis Intervention (EPI) Program.

The first thing families learn when they enter the program is that recovery is expected. They then learn that, as parents, they are viewed as an essential part of the recovery team. The Fraser South EPI team strongly believes that parents are equal partners in their children's treatment – after all, they are the 'experts' on their children.

The group recognizes that while all cases are individual, there are experiences, thoughts and emotions common to families dealing with early psychosis. Peer Support for Parents of Psychosis Sufferers (PSPOPS) is committed to providing support in the form of information and encouragement to parents who have discovered that their child is suffering from early psychosis.

What we don't do is offer a diagnosis or medical advice; we leave that up to the experts. What we do offer is expert guidance from real people intimately involved with this illness.

Meetings have both an educational and support component. The 'caring and sharing' is often a favourite part of the meeting for many people and is the main reason they attend. It gives each person an opportunity to discuss and receive feedback on their particular situation. With each meeting, there are new people who come to share and learn, people who have success stories that instill hope and people who just need to know that what they are experiencing is not unique and that there is love and support available.

The support group has been so successful that a second group has just started. The group has also created a website to support as much as possible all those parents who are not as lucky as the families who have connected through the EPI program. The website offers information, personal stories, reviews of books, minutes of meetings, frequently-asked questions about psychosis, how to educate others (and why it's important), and helpful hints and resource material. We encourage people to visit the site at www.psychosissupport.com. ■

Anyone interested in starting a similar group in their community can contact the support group by emailing pspops@psychosissupport.com

The Art of Involving Families at CAPE

Deb Kinvig

Deb is a full-time registered nurse working in the Child and Adolescent Emergency Unit (CAPE) unit at BC Children's Hospital. She is a former police officer specializing in juvenile crime, and is a coach specializing in personal and organizational change

Jamie is an engaging 11-year-old boy with a wide grin who greets the staff of the CAPE Unit shouting "I'm back!" Well known to everyone on CAPE, he is one of the several children for whom the CAPE Unit has become a place of refuge when his out-of-control rages threaten the safety of his foster mother and the other children in the home.

This time, when asked once too often to clean up his room, Jamie had taken a knife from the drawer in the kitchen and threatened to kill himself. His foster mother, fearing for her safety, called the police. Jamie was then taken to the Emergency Department at BC Children's Hospital for psychiatric assessment. A child for whom a loving, stable home is just something that happens for other kids, Jamie is on his 20th Ministry placement – a life of chaos, upheaval and instability.

It is not surprising that Jamie considers the nurses and doctors of the Child and Adolescent Emergency Unit to be his friends. They are a series of adults who have appeared in his short life that have attempted to bring understanding and a sense of order to the bewilderment and the anger he feels at his plight.

In a hospital examination room waits 14-year-old Angie. Having taken an overdose of over-the-counter medications, Angie rang a friend and told her what she had done. A long series of stressors – including increased tension between her and her parents, trouble with a boyfriend and an inability to cope with her schoolwork – had led Angie to consider the only 'painless' way she could think of to end her life. Now here she sits, embarrassed, sullen and waiting to be transferred to the CAPE Unit, after being admitted under the Mental Health Act.

The CAPE Unit is a three-bed Psychiatric Emergency Unit for children aged between six and 17 years, staffed by registered nurses, psychiatrists, residents and a social worker. The Unit serves the entire province of British Columbia. The focus is on family involvement, assessment and referral to the appropriate community agencies to ensure the children receive the follow up that is necessary.

Jamie and Angie are some of the over 2000 children and young persons admitted to the CAPE Unit every year, typically in a crisis situation. In an effort to rebuild their lives, they

benefit from individualized, innovative plans of care.

Mental illness remains one of the subjects that our society would rather not discuss openly and frankly until, perhaps, it affects those close to us. Involving families is crucial, particularly in early psychosis education and treatment. Research has shown that when done in conjunction with medication, teaching the family and the young person about the illness (psychoeducation) can be a significant contributor to the therapeutic outcome.

Early intervention, drug therapies, psychoeducation, and a multidisciplinary approach to psychiatry now bring hope to a diagnosis that was once a tragedy preventing young lives from reaching their full potential.

Within this approach, the young person's family or caregivers are empowered to work in conjunction with the CAPE Team to determine the best avenues of treatment for the individual child or young person.

Families are supported and are an integral part of the decision-making process because, after all, they know their own child best. Discharge planning is an important focus, and care is taken to ensure that agency supports, such as Mental Health Teams in the community, are in place before the young person comes home.

The work for families continues when they leave the CAPE Unit. In their homes, living day to day is where the real work begins and continues. Crucial to the outcome of an admission is the need for family dynamics to be taken into consideration, as they have a direct impact on how the child or young person integrates this experience.

Across all social classes, anxious parents, concerned friends and families alike face the devastating prospect of their child being admitted to the CAPE Unit, entrusted to the care of people for whom this work is so important – and whose job it is to alleviate distress and offer hope and support.

It is in our communities that these troubled teens and children live: kids that push buttons, close minds and harden hearts; the bully at school terrorizing other kids, angry, hurt, striking out, of whom others are afraid; children for whom life is a struggle, who need respite and understanding, not judgment.

The work is difficult, demanding, and the rewards can be few for a team who work with the vision of providing the best possible care under often trying circumstances. The work continues, kids come and go and all are remembered by the 'CAPERS.' None are forgotten. †

our job it is to alleviate distress
and offer hope and support

Donnie Darko

Youth mental illness on film



Equal parts science-fiction fantasy, psychological drama and wry satire of suburban life circa 1988, the film *Donnie Darko* tells the story of a moody and perceptive high-school student who happens to receive visitations from a demonic giant rabbit named Frank telling him that the world is about to end. Is he an individual experiencing symptoms of schizophrenia or is he, in the words of director Richard Kelley, experiencing “a break in the space-time continuum, exposed to cosmic forces that are clearly going to screw with his head?” Donnie’s parents worry about his erratic behaviour, unaware that he is also receiving messages from Frank to commit increasingly destructive, violent acts. We learn in an early scene that he is seeing a psychiatrist and hasn’t been taking his medications.

Up-and-coming Jake Gyllenhaal plays the lead, and some of the inspired casting includes Maggie Gyllenhaal, Drew Barrymore, Noah Wyle, Mary McDonnell and Patrick Swayze. *Donnie Darko* wasn’t released in Canada when it came out in October 2001, but has become a huge cult hit on video/DVD among the 15-30 crowd.

The film’s original and irreverent take on the theme of teen alienation is a big part of its appeal, as well as its blistering satirical portraits of the straight-laced, high-school characters that surround Donnie. Director Kelley never does answer the question of whether Donnie really is the only character who sees the truth of what’s happening around him or whether his perspective is based on an elaborate web of hallucinations and delusions. Well worth seeing for all sorts of reasons, perhaps the most moving moment of the film is the following exchange between Donnie and his mother: Donnie (in a tone of self-contempt) – “How does it feel to have a wacko for a son?” Mother – “It feels wonderful.”

Unfortunately, a disturbing aspect of the film is the nature of its violence. Frank’s messages ultimately lead Donnie to flood his school and burn his nemesis’s home. Although dramatically effective, in the world of psychiatry, it would be hard not to interpret the events as Donnie’s response to ‘command hallucinations,’ an extremely worrisome scenario when encountered in the real world of mental illness. Donnie’s acts also fuel the media’s exaggerated link of violence and mental illness. This association is now well-recognized and was one reason *Donnie Darko* was screened recently at a workshop for high school students during the Frames of Mind mental health film festival, held May 13-16, 2004 at the Pacific Cinémathèque theatre in Vancouver.

After the film, a panel discussion (Analee Weinberger, Sarah Hamid-Balma (CMAA), Dr. Derryck Smith (BC

Children’s Hospital), Dr. Harry Karlinsky) explored the relationship between the media’s depiction of people with mental illness as unpredictable, violent and dangerous, and youth perceptions of mental illness. The audience also talked with the panel about the consequences of media-driven stereotypes and stigmatization. Following upon the very positive audience reception of the topic, an in-class workshop on movies, mental illness and stigma is now being developed for high-school students.

Schools and programs interested in the ‘Movies, Mental illness and Stigma’ workshop should contact Analee Weinberger at (604) 688-8202 or analee.weinberger@cinematheque.bc.ca. The Education Department at Pacific Cinémathèque also offers other film and media literacy and video production programs for youth, educators and community groups in BC, as well as classroom-ready teachers’ guides on various aspects of film and media literacy. ❖

Analee Weinberger and Harry Karlinsky

Analee is the Education Director at Pacific Cinémathèque. For more information about programs of Pacific Cinémathèque’s Education Department, visit www.cinematheque.bc.ca/education.html

Dr. Karlinsky, is the Director of Continuing Medical Education and Professional Development, Department of Psychiatry, University of British Columbia

the frames of mind series

www.psychiatry.ubc.ca/cme/film

With the recognition that films can be engaging and accessible instructional tools, the UBC Department of Psychiatry and Pacific Cinémathèque will continue to use thought-provoking films to promote professional and community education of issues pertaining to mental health and illness. The nationally-award-winning Frames of Mind film series consists of ongoing, once-a-month evening film screenings and post-screening presentations and discussion featuring a range of speakers and panelists from the clinical, advocacy, consumer and family, and cinematic fields.

Other aspects of the series include its rotating co-sponsorship by relevant community organizations and its accredited continuing education status. To date, topics ranging from addiction to schizophrenia to Alzheimer’s disease have now been successfully presented to over 2000 attendees. September 16th, join us for Mary Harron’s *I Shot Andy Warhol*: a rare depiction of how unreasonable beliefs of persecution can crystallize into full-blown delusions with tragic consequences.

All Frames of Mind film screenings are held at the Pacific Cinémathèque theatre, 1131 Howe St., Vancouver (doors open at 7pm). For more information about the mental health film series, visit our website (see above) or contact Dr. Karlinsky at harryk@telus.net

New Resource for Families



The BC Partners for Mental Health and Addictions Information is pleased to announce the upcoming *How You Can Help: A Resource for Families*. The toolkit is comprised of five modules for families who have a family member with one (or more) of the following disorders: anxiety disorders, eating disorders, mood disorders (bipolar disorder and depression), schizophrenia, or alcohol or other drug addiction.

The modules cover topics such as mental and substance use disorders, supporting recovery (illness management and relapse prevention), communication and problem-solving skills, caring for yourself and the rest of the family, and supporting children and youth with mental or substance use problems in the school system.

You may benefit from reading this toolkit if:

- ⦿ You're seeing your family member engage in behaviours that you instinctively know are not quite right
- ⦿ You've noticed that quirks or behaviours haven't improved despite your child getting older
- ⦿ Your adolescent or teenager is showing unusual behaviours that are interfering with their school, social life or relationship with the rest of the family
- ⦿ Your family member (child, youth or adult) has been recently diagnosed
- ⦿ Your family member is struggling with their mental health problem and you would like to know how you can help them to have a better quality of life
- ⦿ You are seeking general information about how you can support a family member who has an ongoing mental illness.

Look for *How You Can Help: A Resource for Families* coming in the early fall to www.heretohelp.bc.ca; you will also be able to request your own paper copy by calling the Mental Health Information Line at 1-800-661-2121

resources

- **The Sibling Voice.** Thorning, H & Lukens, EP. (1999). *New York City Voices: A Consumer Journal for Mental Health Advocacy*. www.newyorkcityvoices.org/jul99j.html
- "Commitment: In Sickness and in Health." Bayes, KA. (1998). In **The Experience of Spouses**. *The Journal of the California Alliance for the Mentally Ill*, 9, 2. www.healthieryou.com/j92.html
- "We All Make Accommodations." Frese, P. (1998). In **The Experience of Spouses**. *The Journal of the California Alliance for the Mentally Ill*, 9, 2. www.healthieryou.com/j92.html

Awareness and Networking Around Disordered Eating
(604) 739-2070 or 1-877-288-0877 | www.anad.bc.ca

BC Schizophrenia Society
(604) 270 7841 or 1-888-888-0029 | www.bcscs.org

Canadian Mental Health Association, BC Division
(604) 688-3234 or 1-800-555-8222 | www.cmha-bc.org

FORCE Society for Kids' Mental Health Care
(604) 878-3400 | www.bckidsmentalhealth.org

Mood Disorders Association of BC
(604) 873-0103 | www.mdabc.net

From Grief to Action (addictions)
(604) 454-1484 | www.fromgriefftoaction.org

Organizations Providing Information and Support to Families

Anxiety Disorders Association of BC
(604) 681-3400 | www.anxietybc.com



**BC Partners for
Mental Health and
Addictions Information**
EMPOWERMENT THROUGH INFORMATION

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