

How concurrent disorders affect family life

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Outline

- Behaviour changes
- Relationship changes
- Increased responsibility
- Impact on caregivers

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When families learn that a relative has both a mental health disorder and a substance use disorder, they often feel shocked and scared. Mental health disorders on their own can overwhelm families. Families who once had a safe and comfortable daily routine may find themselves on an emotional roller coaster.

There are many studies that document the stress families experience when they have a relative with a mental illness. However, few studies have looked at the added impact when that family member with mental illness also has substance abuse problems. One study by researchers in the United States showed what many of these families already know too well: that substance abuse contributes to family conflict and wears away social support (Kashner et al., 1991).

Family members' lives often change dramatically after a family member develops concurrent disorders. Many of these changes create stress. This chapter discusses:

- behaviour changes in the person with concurrent disorders
- relationship changes between family members
- increased responsibility for caregiving
- the impact on the caregivers.

Before we discuss these experiences further, it's important to recognize that some positive changes can and do happen. While family members must acknowledge and cope with the challenges they face, these challenges represent only one aspect of the caregiver experience. Many family members describe a renewed sense of closeness with their loved one and an appreciation for the truly important things in life, such as connecting emotionally with another human being, having hope, overcoming extreme hardships and experiencing the journey of recovery along with their loved one. Many family members find a positive way to think about difficult circumstances—for example, seeing caregiving in terms of hope and personal growth, as an experience that has positively transformed them.

BEHAVIOUR CHANGES

Mental health problems can bring frightening changes in how people experience reality. These changes can affect their relationships and ability to function. Behaviour changes include paranoia and hallucinations, feelings of anger, drastic mood changes or overwhelming anxiety. People with mental health problems may:

- begin to lose trust in close family members
- find it hard to make even simple decisions, to complete plans or to set goals
- stop participating in activities that they once enjoyed
- cut themselves off from the outside world
- find it hard to express their feelings and thoughts
- retreat into their own inner world
- become hostile, even with their families.

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You have lots of your own feelings about it, and then lots of feelings for your loved one. How is this going to affect their life? What's going to happen to them? There are so many things that just come pouring in. And you have concerns for their siblings, for your other children . . . it can affect so many people.

Substance use problems can interfere with a person's ability to follow family routines and meet their responsibilities. They may:

- spend more time getting and using substances, and less time or no time in their usual activities
- have financial problems (the cost of using substances can become quite high; in some cases, substance use can lead to job loss, which can create further money problems)
- act out physically.

RELATIONSHIP CHANGES

The family member with concurrent disorders

The person with concurrent disorders will often feel that family members are invading his or her personal life. Resentment about being overprotected may lead to anger, rebellion and acting out. These behaviours may increase the risk that the mental health problems will worsen or that the person will end up in unsafe situations. The cycle of the family's preoccupation and the loved one's reaction then repeats itself. This costs everyone in terms of time, physical and emotional energy, and quality of life.

Parents

Parents of children with mental health disorders often feel a great sense of loss and sadness when they see the changes in their child. Family members may have to change their expectations for their loved one regarding education, career paths, marriage and children. This can involve emotional pain, a sense of loss, grief, sadness and anger. The grieving process is similar to the one experienced by those who have had a loved one die, or who must adjust to a serious chronic physical illness in a loved one.

The whole family—we had so many other problems to face, you know? I remember feeling grief and frustration and a sense of tremendous loss, for my daughter and for her potential.

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Siblings

Siblings may worry about developing mental health problems, substance problems or both. They may worry about the stress and strain that their parents are enduring, and may take on the burden of trying to make up for what their parents have lost in their other child. At the same time, brothers or sisters sometimes resent the time that parents spend with their sibling. They may become angry to the point of acting out or distancing themselves from family and friends.

I remember being teased as a child because I was so serious, so sombre—and people told me that I acted like a middle-aged woman, a lot older than I actually was. It was impossible to explain to other people—like, you go to school after not sleeping all night, and after the police were at your house because of your sister’s psychotic episode, and no one thought of dinner or anything like that because she overdosed and your parents had to go to the emergency room with her, and then you go to school the next day and it’s like, all the expectations are still on you. But you don’t tell anybody anything, you just carry on as usual. You can’t talk to anybody about it. Nobody will understand . . .

Siblings may also experience anger, hostility or verbal or physical aggression from their brother or sister. These behaviours can evoke shock, dismay, fear and a sense of abandonment and rejection. Sometimes, children may feel like they have lost their best friend. They may feel guilty that they have a better life than their brother or sister.

HELPING CHILDREN COPE

Parents can help their other children by:

- assuring children that behaviours such as aggression are symptoms of the illness and shouldn’t be taken personally
- sharing feelings and encouraging children to talk about how they feel and how their brother’s or sister’s problems are affecting them
- explaining that family members often feel uncomfortable, embarrassed or ashamed of their relative’s behaviours, symptoms and diagnosis
- if appropriate, discussing the issue of stigma and why it happens, as well as effective ways to deal with it (see Chapter 6 for more information about stigma)
- helping siblings learn about substance use and mental health problems and how these interact with and affect each other
- spending time alone with siblings, talking and doing enjoyable activities
- helping children build a new relationship with their brother or sister and creating unique ways of being with their sibling.

INCREASED RESPONSIBILITY

Caring for basic needs

Family members may begin to take on much more responsibility for their relative. In more severe cases, the relative may be unable to care for basic needs such as keeping up with personal hygiene, eating meals or even getting out of bed. If the caregiver is also the family's only source of income, being unable to leave the family member alone can lead to huge financial consequences for the family and more emotional strain for the caregiver.

Our son not only has schizophrenia, but he uses drugs, he's been involved with gangs—and with the police. Half the time we're not sure if he's taking his medication—he gets mad if we keep after him to do simple things, like have a shower . . . we're so stressed as it is. We're trying to find out things, how we can resolve some of these problems. Sometimes I think I can't deal with it all.

People with concurrent disorders often have trouble maintaining stable and decent housing. They may:

- spend their money on substances rather than rent, which can lead to eviction
- become involved in criminal activity such as robbing, property theft, prostitution or the sale of drugs to raise the large amounts of cash needed to buy the substances they use, which can result in loss of supportive housing and sometimes homelessness
- open their home to others involved in problem substance use, then be unable to maintain that home, forget to feed and bathe themselves, pay heat and light bills, and face eviction.

These consequences create even more challenges for the families.

Co-ordinating treatment

Some mental health programs refuse to treat people with concurrent disorders, or only treat the mental health problem. Similarly, some addiction treatment programs and facilities may not address the mental health problem. Families may have to take responsibility for co-ordinating treatment between two or more service providers, as well as caring for their relative.

Having a loved one who is suffering from both a mental illness and a substance use disorder can represent a significant disruption in the lives of families and can have an enormous impact on overall family functioning and sense of well-being.

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People need to be able to call somebody when their loved one is in the hospital because of a mental illness or a drug problem. They need to be able to touch base and get information from someone. It's hard for people who don't know the system—like, what channels have to be manoeuvred—or who to call when you have specific questions. There are so many roadblocks.

Some suggestions for navigating the substance use and mental health system are discussed in Chapter 7.

IMPACT ON CAREGIVERS

Family members may be concerned about leaving their relative alone because they are worried that he or she will take harmful drugs, forget to take medications, take part in dangerous or criminal behaviour to get illegal drugs, or harm him- or herself during a serious episode of illness. If family members are constantly watching for symptoms and dealing with the impact of the illness, they may feel overwhelmed.

You become extremely protective of [family members who are ill]. It takes incredible emotional energy.

Some family members may find it almost impossible to soothe their own anxieties, and distract themselves from the strain of coping with their relative. They may feel unable or even guilty to take time for themselves, to relax, care for their own emotional and physical health, and rebuild their own coping resources. Sometimes, family members even feel guilty if they experience resentment or anger. They should admit if they are extremely tired, worn out, angry or bitter. Denying these emotions can lead to exhaustion, depression, isolation and hopelessness.

They may feel isolated from others who were once very good friends. They might feel that they don't have the time to maintain friendships, or they may be embarrassed or ashamed about the concurrent disorders.

Think about your own situation and how your life has been affected. Remember that all family members experience difficult circumstances and negative feelings. It is very common for family members to feel guilty when they are asked to think about how this has affected their own lives. However, before you can begin to take care of yourself and play a positive role in your loved one's recovery, you need to think honestly about the different ways that your life has been changed.

Caregiver burden and compassion fatigue: A note about language

The term **caregiver burden** is used in professional literature to describe the emotional, social and psychological toll on the family that comes from caring for someone with a substance use and/or mental health problem. Many caregivers, while they like others to recognize how difficult it is to care for a family member with concurrent disorders, don't like the term "caregiver burden." They feel it ignores the positive side of looking after the needs of someone important to them and negates the fact that, in spite of the stress, they love the person and would go to the ends of the earth to help and protect them. It also dehumanizes their loved one, and reduces him or her to a "burden," which the caregiver hopes will not always be the case.

The stress and feelings of powerlessness that are such a large part of caring for a family member with concurrent disorders may be better described as **compassion fatigue**. We use compassion fatigue here to describe the overwhelming physical, emotional, social and spiritual exhaustion that can strike family members affected by concurrent disorders. It is a much more user-friendly term for describing the results of ongoing coping with extreme adversity.

You can find some strategies for dealing with compassion fatigue at:

www.mytherapynet.com/Public/ShowText.asp?EUID=&articleid=134&articletype=25

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Activity 4-1: Personal impact log

This log will help you think about the effects of your loved one's mental illness and substance use problems on your own physical, emotional, social and spiritual health. It will help you break the overall impact on your life into smaller, more manageable areas of concern.

Below is an example of a personal impact log.

PERSONAL IMPACT LOG	
Physical health	Emotional health
<ul style="list-style-type: none"> • chest pain has returned—too worried about my son • no time to go to my own doctor anymore • no longer exercising • always tired • can't sleep without taking sleeping medication (never used to need anything to sleep) • joint stiffness & neck pain • eat high-sugar foods, don't care about my diet anymore 	<ul style="list-style-type: none"> • constant worrying about Kevin • worrying about everything now • bad anxiety and sadness • I'm always angry or frustrated or depressed these days • I snap at my other children and then feel guilty • I'm angry with my husband—he gets to leave for work all day and leaves me to deal with all of our problems
Social life	Spiritual life
<ul style="list-style-type: none"> • never go out with husband or close friends anymore • never have guests over for dinner or Friday euchre nights • can't concentrate on reading • spend all of our time in emergency rooms or visiting Kevin on psychiatric wards 	<ul style="list-style-type: none"> • do not know what this is anymore! • don't go to church • no time for my daily meditation readings • don't feel like doing my yoga sessions anymore • bitter and resentful about my son's illness—why our family? • angry with God

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On the blank personal impact log, write down the ways your life has been affected in the areas that apply to you. You may find that you fill in only some of the areas.

You will use this information again as you work through the self-care plan in the next chapter.

PERSONAL IMPACT LOG	
Physical health	Emotional health
Social life	Spiritual life

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Activity 4-2: Preoccupation and impact

It can be difficult to take even the smallest steps forward if you don't know the source of your worry, preoccupation and distress.

This is an early version of a tool we are calling the family concurrent disorders **Preoccupation and Impact Scale (PAIS)**. It'll help you think about how much having a family member with concurrent disorders is affecting your life; specifically, how absorbed you are with thoughts, fears and worries about your family member with these disorders. This scale still needs to be formally tested, so at this point the intention (rather than interpreting your score) is simply to encourage you to consider how much the preoccupation effect has infiltrated which aspects of your life. Completing this quiz may help you realize that you have moved beyond a constant state of preoccupation to an emotionally healthier, calmer, more balanced lifestyle. Indicate how strongly you agree or disagree with each statement. Circle 1 if you strongly agree, 2 if you agree, 3 if you disagree and 4 if you strongly disagree.

How strongly do you agree or disagree with these statements?	Strongly Agree	Agree	Disagree	Strongly Disagree	Don't Know
I can't stop worrying about my family member's illness.	1	2	3	4	9
I am able to maintain a healthy balance in my life.	1	2	3	4	9
I have trouble thinking about anything other than my family member's mental illness and substance use problems.	1	2	3	4	9
I feel that I'm completely preoccupied with my family member's mental illness and substance use problems.	1	2	3	4	9
My daily routine completely centres on my family member's illness.	1	2	3	4	9
I find myself a lot more anxious these days.	1	2	3	4	9
I make sure that I find time to do things for myself and to have fun.	1	2	3	4	9
I never feel that I am doing enough for my ill family member.	1	2	3	4	9

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Sometimes I feel that I am drowning in my family member's illness.	1	2	3	4	9
I focus so much on my ill relative's problems that I have difficulty finding time to spend on other members of my family.	1	2	3	4	9
I have very little time and energy to socialize with my friends.	1	2	3	4	9
My physical health (e.g., nutrition, sleep and rest) has been negatively affected since I've been dealing with my family member's mental health and substance use problems.	1	2	3	4	9
I have had a hard time gaining a sense of emotional well-being since my family member developed mental illness and substance use problems.	1	2	3	4	9
I am able to cope with my loved one's mental illness and substance use problems.	1	2	3	4	9
I think it is OK for family members to feel angry with, or resentful of, their ill loved one.	1	2	3	4	9

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Activity 4-3: The family concurrent disorders index of concerns quiz

The items included in this quiz may also help you pinpoint your areas of concern. Once you've listed them, you can think about how to resolve them. Think in terms of small steps you can make gradually.

Completing this quiz may also help you to:

- identify personal areas of concern over which you have little control
- consider how you might learn to accept what you cannot change.

For each item, circle the number that best corresponds with *how you are feeling right now*. Once you have completed all of the questions, add them up. The higher your total score, the more uneasy, worried or alarmed you are overall about your situation and the more you need to focus on your own emotional, social and physical health and well-being.

How concerned am I about...

the immediate overall health and well-being of my ill family member?	0	1	2	3	4	5	6	7	8	9	10
the immediate overall health and well-being of the other members of my family?	0	1	2	3	4	5	6	7	8	9	10
my own immediate overall health and well-being?	0	1	2	3	4	5	6	7	8	9	10
the long-term overall health and well-being of my ill family member?	0	1	2	3	4	5	6	7	8	9	10
the long-term overall health and well-being of the other members of my family?	0	1	2	3	4	5	6	7	8	9	10
my own long-term overall health and well-being?	0	1	2	3	4	5	6	7	8	9	10

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	← <i>Not concerned</i>									<i>Very concerned</i> →	
how much my ill family member is suffering?	0	1	2	3	4	5	6	7	8	9	10
how much the other members of my family are suffering?	0	1	2	3	4	5	6	7	8	9	10
how much I am suffering?	0	1	2	3	4	5	6	7	8	9	10
my ill family member's ability to get through this?	0	1	2	3	4	5	6	7	8	9	10
the ability of my other family members to get through this?	0	1	2	3	4	5	6	7	8	9	10
my own ability to get through this?	0	1	2	3	4	5	6	7	8	9	10
the emotional health of my ill family member?	0	1	2	3	4	5	6	7	8	9	10
the emotional health of the other members of my family?	0	1	2	3	4	5	6	7	8	9	10
my own emotional health?	0	1	2	3	4	5	6	7	8	9	10
whether my ill family member is getting enough social support?	0	1	2	3	4	5	6	7	8	9	10
whether the other members of my family are getting enough social support?	0	1	2	3	4	5	6	7	8	9	10
whether I am getting enough social support?	0	1	2	3	4	5	6	7	8	9	10
my ill family member's physical health?	0	1	2	3	4	5	6	7	8	9	10
the physical health of the other members of my family?	0	1	2	3	4	5	6	7	8	9	10

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	<i>Not</i> ←————→ <i>Very</i> <i>concerned</i> <i>concerned</i>										
	0	1	2	3	4	5	6	7	8	9	10
my own physical health?	0	1	2	3	4	5	6	7	8	9	10
the spiritual health of my ill family member?	0	1	2	3	4	5	6	7	8	9	10
the spiritual health of the other members of my family?	0	1	2	3	4	5	6	7	8	9	10
my own spiritual health?	0	1	2	3	4	5	6	7	8	9	10
my ill family member's financial situation?	0	1	2	3	4	5	6	7	8	9	10
the financial situation of the other members of my family?	0	1	2	3	4	5	6	7	8	9	10
my own financial situation?	0	1	2	3	4	5	6	7	8	9	10
my ill family member's journey of recovery?	0	1	2	3	4	5	6	7	8	9	10
the recovery journey of the other members of my family?	0	1	2	3	4	5	6	7	8	9	10
my own journey of recovery?	0	1	2	3	4	5	6	7	8	9	10

REFERENCES

Kashner, T.M. et al. (1991, February). Family characteristics, substance abuse and hospitalization. *Hospital and Community*, 195–197.