

Dual Diagnosis An information guide

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Introduction

This guide was developed for the families of people with developmental disabilities. It provides basic information about dual diagnosis and explains what we know about services and supports and how to best access them. It also suggests ways to take care of yourself while being a caregiver.

1 What is dual diagnosis?

The term *dual diagnosis* is used to describe a situation where someone has both a developmental disability and a mental health problem.

Developmental disabilities and mental health problems are sometimes very hard to tease apart. Family members and treatment professionals often find it difficult to determine whether the behaviour they are looking at is due to an underlying disability or a mental health problem—or both.

A NOTE ABOUT LANGUAGE

Dual diagnosis: In Ontario, and in most places in Canada, the term *dual diagnosis* refers to the combination of a developmental disability and mental health problem. In countries other than Canada, dual diagnosis might refer to a different problem: psychiatric disorder and alcohol or other substance use issue. In reading about dual diagnosis, it is important to know which diagnoses the authors are referring to.

Developmental disability: The term we have adopted in this guide is the term used in Ontario legislation, but you may be familiar with related terms, such as *intellectual disability*, *developmental handicap*, *developmental delay* or *mental retardation*. In the U.K., this group of individuals is sometimes referred to as people with a learning disability. Each term means something slightly different, and the same term may mean different things to different people, but each term generally refers to very similar types of disabilities.

Mental health problem: A person experiencing serious psychiatric symptoms or mental health problems may be diagnosed as having a psychiatric “disorder.” The reality is that people may have a whole spectrum of symptoms, including milder problems that are not officially a disorder. For the purpose of this guide, we will use the word *problem* in most cases, and *disorder* when we are talking about a specific diagnosis.

Developmental disability

In Ontario, the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act* outlines the legal definition of *developmental disability*. The term refers to significant limitations in cognitive functioning (intellectual capacity to reason, organize, plan, make judgments and identify consequences) and adaptive functioning (capacity to gain personal independence, based on the person’s ability to learn and apply conceptual, social and practical skills to everyday life). These limitations need to have

originated before the person reached 18 years of age; are likely lifelong in nature; and affect areas of major life activity, such as personal care, language skills or learning abilities.

Developmental disability is an umbrella term for different disabilities. Some are genetic in origin, such as Down syndrome or fragile X syndrome. They can be caused by illness or injury pre-natally or during childhood, as is the case with congenital rubella, fetal alcohol syndrome and meningitis. Sometimes the cause is unknown, for example, with autism spectrum disorders. Approximately one to three in 100 people in Canada are thought to have a developmental disability.

People with developmental disabilities are nearly always identified by the time they reach the elementary school years (and often much earlier). Most will have more difficulty solving problems than peers without developmental disabilities, and will need support to help them live independently. The intensity of this support depends on many factors, including the person's intellectual ability, the things they would like to do, the demands placed on them by society and their stage in life. Each person with a developmental disability has individual strengths and weaknesses, and supports need to be tailored to their specific needs. Interventions should help them live as independently as possible. A developmental disability is not a disease that requires a cure, but a set of difficulties that require added support.

How common is dual diagnosis?

People with developmental disabilities are at increased risk for developing mental health problems throughout their lives. Large-scale studies indicate that people with developmental disabilities

are three to six times more likely to develop a mental health disorder than other people. Estimated rates vary depending on the types of problems included as the “second” diagnosis, but it is clear that many people with developmental disabilities have serious mental health problems:

- Psychotic disorders have been suggested to occur three times more often in adults with developmental disabilities compared to the general population (Cooper et al., 2007; Turner, 1989). Rates of psychotic disorder may be inflated in some studies due to challenges in making the diagnosis, particularly by clinicians with less training in developmental disabilities (Lunsky et al., 2006; Robertson et al., 2000).
- One large study in the U.K. reported that mood disorders (e.g., major depression, bipolar disorder, dysthymia) were three times more common in those with developmental disabilities than in the general population (Richards et al., 2001). Comparative studies have reported higher rates in individuals with developmental disabilities than in the general population.
- Anxiety disorders (e.g., posttraumatic stress disorder, separation anxiety, social phobia, specific phobias, panic disorder, generalized anxiety disorder) are also common in people with developmental disabilities, particularly among those with specific genetic syndromes (Harris, 2006).
- Challenging behaviour, sometimes called “disruptive behaviour” or “problem behaviour,” refers to behaviour that limits the person’s use of ordinary community facilities, or behaviour that, because of its intensity, frequency or duration, puts the physical safety of the person or others at risk (Emerson & Emerson, 1987). The overall prevalence of disruptive behaviour in adults with developmental disabilities has been estimated at 22.5 per cent (Cooper et al., 2007). This behaviour may be due to an underlying psychiatric disorder, but it may also have other causes.

2 Recognizing dual diagnosis

The relationship between developmental disability and mental health problems

The relationship between developmental disabilities and mental health problems is complex. Mental health problems present in unique ways in people with developmental disabilities, and how they present can change over time.

- Various biological, psychological and social factors make it more likely that a person with a developmental disability will develop a mental health problem, compared with someone without a dual diagnosis.
- How mental health problems look can depend on the developmental disability. It can be difficult to understand the inner experience of a person with a developmental disability because they might have difficulty expressing their thoughts and feelings. This makes traditional ways of making a diagnosis challenging because they depend on a person being able to report their inner experience.

- It is also hard to make a diagnosis when the behaviour of concern has increased in intensity but is an “old” behaviour, meaning that the person has exhibited it for a long time. For example, if a man has always pulled his hair, mostly when he is left alone, but has begun to pull much harder and more often, and not just when he is alone, does this change mean that he has a new mental health problem, or is it just part of the same problem?
- Diagnosing mental health problems in someone with a developmental disability requires information from various sources and from different settings.

GENETIC DISORDERS

Some genetic disorders that cause developmental disability can predispose a person to having specific mental health problems. For example, someone who has fragile X syndrome is at increased risk for developing social anxiety, and someone with 22q11 deletion is at increased risk for developing schizophrenia. This is one reason why it is very important to know the cause of a person’s developmental disability. We did not have the technology 20 years ago to recognize many of the syndromes that we can now identify, so there may be people with dual diagnosis who have a genetic disorder that has not yet been diagnosed.

At least nine genetic conditions have been shown to overlap with mental health problems and challenging behaviours (Dykens et al., 2000), as the table on the next page shows.

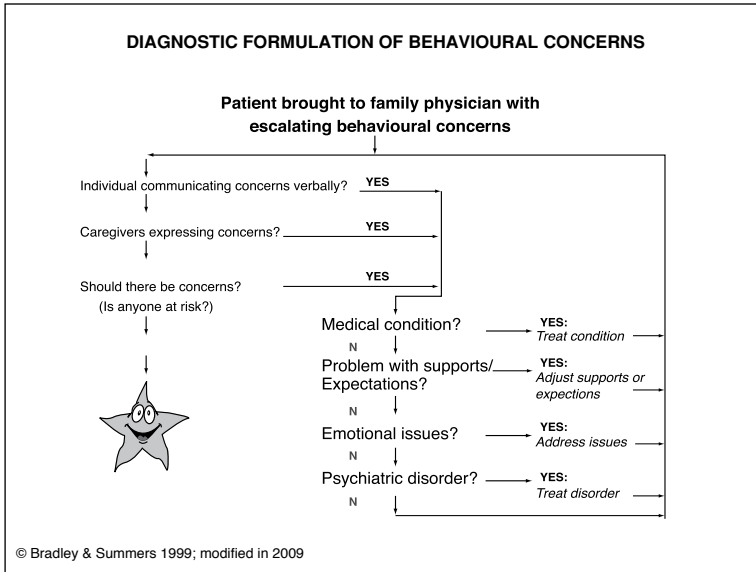
Genetic syndromes and dual diagnosis

SYNDROME	AGGRESSION	SELF-INJURY	ANXIETY DISORDER, PHOBIAS	ALZHEIMER'S DISEASE	DEPRESSION, MANIA, BIPOLAR DISORDER	SCHIZOPHRENIA
5p	X	X				
Prader-Willi	X	X	X		X	
William	X		X		X	
Smith-Magenis	X	X				
Lesch-Nyhan		X				
Turner			X			
Fragile X		X	X		X	
22q11 deletion (velocardiofacial)					X	X
Down			X	X	X	
Cornelia de Lange		X				

STEPS TO DETERMINE IF THERE IS A PSYCHIATRIC DISORDER

There are steps that clinicians can take to better understand how biological, psychological and social factors can affect a person's mental health. Health professionals often describe these steps as a "decision tree" (see p. 8). These steps include the following four questions (Bradley & Burke, 2002):

- Is there a medical problem?
- Is there a problem with supports and appropriate expectations?
- Is there an emotional problem?
- Is there a psychiatric disorder?



1. Is there a medical problem?

Many people with developmental disabilities have physical health concerns that can go unnoticed or undertreated. For example, a person who is constipated but unable to communicate the pain to others might become aggressive while in pain and lash out at others. Before considering whether this person has a psychiatric disorder, it would be important to relieve them of the constipation and resulting discomfort. Ask doctors to first perform a full physical exam, and get regular vision and hearing tests and dental checkups, if you are concerned that your family member might have mental health problems.

2. Is there a problem with supports and appropriate expectations?

After a doctor has checked for and treated physical conditions, it is important to examine how the support your family member is receiving—or not receiving—influences their behaviour. If they are

unable to do the things that are meaningful for them or expected of them, they may become anxious, angry or sad. For example, if a person with a developmental disability has a job packaging materials and needs help with structure and reminders in order to do well, they may become very upset if they cannot get that help. Alternatively, they may feel that they get too much help from others and are not given the independence they desire, which can also be frustrating. Ask yourself: Does my family member have needs that are not being met? Discuss with service providers how services can be optimized to meet your family member's needs.

3. Is there an emotional problem?

There is a difference between having an emotional problem and having a psychiatric disorder. We all experience times in our lives when we feel intense negative emotions, such as anger, sadness or anxiety. Sometimes, these feelings are caused by stressful things that are going on around us (e.g., moving, loss of a loved one, neglect or abuse). Other times, we have these feelings because of what is going on inside of us (e.g., low self-esteem, feeling inadequate). When we feel intense negative feelings, we are experiencing an emotional problem, and we seek ways to resolve it. For example, we can use our social supports or a coping strategy, and the negative feeling goes away. But when we try different strategies and nothing seems to help, then an emotional problem can turn into a psychiatric disorder.

4. Is there a psychiatric disorder?

There is no clear line that indicates when problems become severe enough to be described as a disorder in people with developmental disabilities. If emotional problems are not recognized and addressed, they can become more intense and severely affect the person and those around them. Many clinicians use diagnostic criteria from the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) to help screen and assess people for psychiatric disorders. Most people with

a psychiatric disorder will receive a specific diagnosis at some point during treatment. However, because the symptoms of many disorders are similar, the diagnosis may change several times during the course of treatment. Clinicians who work with people with developmental disabilities also use the *Diagnostic Manual—Intellectual Disability* (DM-ID) (Fletcher et al., 2007), which suggests adaptations to the DSM-IV for people with intellectual disabilities. They may also use the *Diagnostic Criteria in Learning Disability* (DC-LD) (Royal College of Psychiatrists, 2001).

Preparing for a specialist appointment

You can help clinicians with this systematic process by being prepared for your specialist appointment. The Primary Care Initiative at Surrey Place Centre in Toronto has developed a tool called *A Guide to Understanding Behavioural Problems and Emotional Concerns* that can help you prepare. You complete part of the form before the consultation, and the clinician completes the second part during the visit (see link to form at knowledgex.camh.net/dual_diagnosis).

Here are some helpful tips to make the most of your specialist appointments:

1. **Be prepared.** Take some time before an appointment to collect the information you need and write down your concerns. You may not have time during the appointment to discuss everything, so make a list in order of priority.
2. **Keep a clinical binder.** Always request a copy of reports that are prepared after a consultation and keep them in a clinical binder. Bring it with you to consultations. Clinicians can seek your permission to access the original reports after the fact, but it can take time to request and get the reports from the clinicians who prepared them.

Include in the binder a section on previous treatments, including a list of previous medication trials (you can get a printout from your pharmacy). Also include contact information for all members of the current clinical team and others involved in your family member's care.

3. **Be specific.** If you have a concern about a symptom or behaviour, offer concrete examples. Instead of saying that John doesn't sleep well, give examples of what not sleeping well looks like (e.g., taking 90 minutes to fall asleep, getting up six times a night). Instead of saying that John doesn't seem happy any more, give examples of activities that he used to enjoy but no longer does (e.g., dinners out with family, going bowling).

You can also bring photos or video recordings that show the behaviours you are concerned about. If Virginia trashed her room when she was agitated, take pictures of it or film it and share that with the clinicians. You can also show clinicians a recording of your family member when they were at their best, so the clinicians can see the contrast.

4. **Present multiple perspectives.** Whenever it is possible, bring other people who see your family member in other contexts, such as a teacher or work supervisor, to the appointment. If they cannot attend, get a report from them to bring with you.
5. **Get the most from the appointment.** Appointments with specialists can seem to pass quickly, and you might leave thinking, "Did I say everything I wanted to? I can't remember what we were supposed to do next or what they called the problem I described."

You might want to bring someone with you who understands your situation well and who also feels comfortable in clinical

situations. It might be a relative, a friend or a professional. They are there for you, to help you ask the right questions and understand what is being explained.

Another option is to make an audio recording of the feedback you receive. Sometimes you think you understand what is being explained, but it is so stressful that you may miss parts. Your family member may also like being able to listen to the conversation again.

3 Treatment

Treatment principles

When care for developmental disabilities and mental health problems is co-ordinated and integrated, people do better. Dual diagnosis treatment focuses on improved screening and assessment, specialized programming, and co-ordination (by one person or a treatment team) of developmental disability and mental health treatment. Five principles guide how to care for people with dual diagnosis:

1. People with dual diagnosis are people first, before their disabilities. They have strengths in addition to having problems.
2. Mental health problems in developmental disability are under-identified but common.
3. Mental health problems in developmental disability are complex but understandable.
4. Mental health problems in developmental disability are challenging but respond to care.

5. Mental health problems in developmental disability require responses that go beyond separate disability and mental health treatment.

People who have mental health problems and developmental disabilities are some of the most vulnerable people in society and in our health care system. Evidence suggests that if we address their problems in more co-ordinated and collaborative ways, they are more likely to get better. This means that instead of getting separate services for each type of difficulty, we take an approach that integrates the services. For many people, this is a long, complex process. Often, family members are the most constant companions in the journey to recovery. At points in the journey, the family may be called on to advocate, support and act as a case manager.

Where do people get treatment?

DEVELOPMENTAL DISABILITY AGENCIES

Many developmental disability agencies accept self-referrals or referrals from families. After an intake assessment, the person will be referred to the most appropriate service for their needs. This may include behavioural therapy or counselling, as well as speech and language or psychological assessments in order to better understand the disability. Some agencies provide only one or two types of these services. If the problems seem particularly complex, these agencies may make a referral to a specialized dual diagnosis service provider.

In Ontario, the Ministry of Community and Social Services and the Ministry of Children and Youth Services fund services in the community, often called “the developmental sector.” This sector can

include in-home and out-of-home respite, employment programs and other day activities and residential services.

In July 2011, Ontario introduced centralized access to developmental disability services for people age 16 and older through Developmental Services Ontario (DSO). In the past, families would need to call many different providers to get all the services they needed. Each of the nine DSO regional offices serves as the single door to services in that region. Someone at the DSO can usually give you information on eligibility for services, what services are available and the process to obtain services. Visit the DSO website (see link at knowledgex.camh.net/dual_diagnosis) for more information, including where your local DSO is located.

COMMUNITY MENTAL HEALTH AGENCIES

Every region of Ontario has community mental health agencies. You can find information about them in the ConnexOntario Mental Health Helpline online directory (see link at knowledgex.camh.net/dual_diagnosis). These agencies provide case management and counselling, as well as some group therapy and nursing and psychiatric services. They may also offer recreational and vocational programs for people with mental health problems. These services are not typically designed for people with dual diagnosis, but some individuals, particularly those with more mild disabilities, can benefit. Services and supports may also be helpful to other family members. In some regions, community mental health agencies offer specialized dual diagnosis supports.

DUAL DIAGNOSIS PROGRAMS

There are several specialized programs with clinicians who have expertise in both developmental disabilities and mental health

problems. Typically, these programs are interdisciplinary, meaning that clinicians, such as psychiatrists, psychologists, behaviour therapists, nurses, occupational therapists and social workers, work together to figure out what the problem is and how to best treat it. These programs can have long waiting lists, but they are appropriate when other more general services cannot provide the required care.

To learn more about specialized services in your area, contact your local DSO. You can also contact Community Networks of Specialized Care (CNSC) (see link at knowledgex.camh.net/dual_diagnosis). CNSC is a province-wide network that specializes in dual diagnosis. CNSC co-ordinators and health care facilitators may be able to help you to access specialized services in your region.

PRIMARY CARE

Family doctors, or general practitioners (GPs), are often the first professionals that people talk to about a mental health problem. A doctor can examine your family member's physical health and rule out problems that could be adding to or affecting changes in their mood, thinking or behaviour. Sometimes doctors can do a full psychiatric assessment, particularly for more common conditions, such as depression or anxiety. The doctor may suggest that your family member see a psychiatrist.

Treatment planning

There is no single correct intervention or program for people who have dual diagnosis. The treatment plan needs to be customized to address each client's particular needs. Treatment plans should:

- identify problems
- outline short-term and long-term goals
- establish approaches and interventions to meet the goals.

In many cases, treatment includes helping your family member with employment, housing, finances, leisure activities and basic daily self-care. The person conducting the assessment may recommend that your family member see a therapist or start taking medication. Sometimes treatment may include helping you to adjust your supports and expectations of your family member. It is often the case that we do not recognize how much support a person really requires and when we adjust our approach, there are noticeable improvements in behaviour.

CAPACITY TO CONSENT TO TREATMENT

In Ontario, everyone has the right to make decisions about their treatment if they are mentally capable to do so. This includes refusing treatment.

To be considered capable, a person must:

- be competent to give consent
- have the intellectual capacity to make the decision
- give the consent voluntarily
- have enough information to make an informed decision, including information on potential risks or side-effects of treatment.

If the person is not able to give informed consent, they must be declared incompetent. Someone is appointed to make decisions on the person's behalf. In some provinces, the decision-maker is a family member, while others use people appointed by the state. (In Ontario it is the Office of the Public Guardian and Trustee (see link at knowledgex.camh.net/dual_diagnosis).

Just because your family member has a dual diagnosis, it does not automatically give other family members the right to make decisions for them. Whether a person can make their own decision depends on the decision to be made and how the person is doing at the time. Some decisions are more complicated than others. For example, agreeing to follow a high-risk medication regimen is a more complicated decision than agreeing to participate in a counselling session. Some adults with dual diagnosis, when they feel well, are able to make informed decisions, but when they do not feel well, they lose that capacity.

If you have concerns about whether your family member can make their own decisions around mental health treatment, particularly in emergency situations, it can be worthwhile to talk about this with your care team before an emergency arises.

Types of treatment

Treatment for dual diagnosis can include psychosocial treatments and medication.

PSYCHOSOCIAL TREATMENTS

Psychoeducation

Psychoeducation is education about mental health problems. People who know about their problems are better prepared to make informed choices. Knowledge can help clients and their families deal with their problems and make plans to prevent future problems.

Psychoeducation sessions include discussions about:

- what causes mental health problems

- how the problems might be treated
- how to self-manage the problems (if possible)
- how to prevent future episodes.

Psychotherapy

Psychotherapy is sometimes called “talk therapy.” It helps people deal with their problems by looking at how they think, act and interact with others.

There are many types of psychotherapy. Some types are better for certain problems. Psychotherapy can be either short-term or long-term.

Short-term therapy has a specific focus and structure. The therapist is active and directs the process. This type of treatment usually lasts no longer than 10 to 20 sessions.

In *long-term therapy*, the therapist is generally less active, and the process is less structured. The treatment usually lasts at least one year. The aim is to help the client work through deep psychological issues.

Successful therapy depends on a supportive, comfortable relationship with a trusted therapist. The therapist can be a doctor, social worker, psychologist or other professional. Therapists are trained in different types of psychotherapy. They may work in hospitals, clinics or private practice.

BEHAVIOURAL THERAPY

Behavioural therapy focuses on changing a person’s behaviours. It teaches people how to be aware of why they behave in specific ways and teaches new behaviours that can replace their problematic ones. It involves looking at what purpose a behaviour serves and

the types of reinforcement that are instrumental in learning. There is a substantial amount of research showing that behaviour therapy can be helpful for people with dual diagnosis.

COGNITIVE-BEHAVIOURAL THERAPY

Cognitive-behavioural therapy (CBT) is based on the theory that thoughts have an important influence on how people behave. Therapists help people to identify unhelpful thoughts and behaviours and learn healthier skills and habits. The client and therapist identify goals and strategies. There is an emphasis on practising the skills between sessions (homework). There is a growing body of research demonstrating that CBT can be helpful for people with dual diagnosis who have the language skills necessary to participate in talk therapy.

SOCIAL SKILLS TRAINING

Social skills training uses techniques such as role playing, modelling, coaching, homework and feedback to help people learn (or re-learn) interpersonal skills and competencies. Social skills training can be helpful in teaching people with dual diagnosis more helpful ways of relating to other people.

DIALECTICAL BEHAVIOUR THERAPY

Dialectical behaviour therapy (DBT) is a type of cognitive-behavioural therapy. It is used to treat a range of behaviour problems. In DBT, people look at how their background and life experiences affect how they control their emotions. DBT draws on Western cognitive-behavioural techniques and eastern Zen philosophies. It teaches clients how to:

- become more aware of their thoughts and actions (“mindfulness”)
- tolerate distress
- manage their emotions

- get better at communicating with others
- improve their relationships with others.

PSYCHODYNAMIC (INSIGHT-ORIENTED) THERAPY

Psychodynamic psychotherapy, also referred to as insight-oriented therapy, is based on the theory that unconscious processes (issues that a person may not be aware of) influence behaviour. This approach helps people examine unresolved issues that have resulted from relationship problems in their past. There is not much evidence for the effectiveness of psychodynamic therapy for people with dual diagnosis, although in some specific cases it may be a part of treatment.

OTHER LESS LANGUAGE-BASED THERAPIES

Other forms of therapy that rely less on language are also used with people with developmental disabilities. They include play therapy, sand therapy, music therapy and art therapy. Therapies can focus on the person's sensory experience and provide new ways to increase distress tolerance. They also offer creative opportunities to express emotions and have a reciprocal exchange with another person. These therapies can build self-esteem and help the person to develop better ways of coping with stress.

Peer support groups

A peer support group is a group of people who have similar problems. Group members can share their struggles in a safe, supportive environment. They usually develop strong bonds.

There are peer support groups for clients with very mild developmental disabilities and mental health problems, and there are also groups specifically for families. Although these groups are often called *self-help*, peer support actually offers a type of help called *mutual aid*.

MEDICATION

Medications for psychiatric disorders

When a person is diagnosed with a psychiatric disorder (e.g., a mood disorder, an anxiety disorder, schizophrenia, attention-deficit/hyperactivity disorder), medication is often one component of the overall treatment plan.

Most psychiatric medications are used to help restore chemical balance in the brain. This can help to reduce the frequency and severity of symptoms. Medications are divided into four main groups based on the problems that they were developed to treat:

- antidepressants
- mood stabilizers
- anti-anxiety medications/sedatives
- antipsychotics.

Medications for behaviour management

It is not always possible to match the symptoms or behaviours of someone with dual diagnosis to a specific psychiatric disorder. Medication may be part of a treatment plan for “challenging behaviour” when the underlying psychiatric disorder is uncertain or unknown. In these situations, it is very important to know what the medication is targeting, what the behaviour looks like before intervention and how it changes with medication (see section on monitoring medication, p. 24).

Sometimes, as families or as professionals, we want a quick fix, a medication that can instantly solve a complex problem. We hope the medication can help because it is so difficult to manage the current situation. It is important to understand that there is no medication that can offer a quick fix that does not have its own problems. Medications, particularly antipsychotics, have histori-

cally been used to sedate people exhibiting challenging behaviour. However, there is limited research to suggest that medication for this purpose works in the long term. Sometimes the side-effects of these medications can lead to further distress and agitation.

MEDICATION MANAGEMENT

Medication management for people with developmental disabilities is particularly complex. It should be part of a broader approach. Careful monitoring is essential, particularly when the person cannot articulate their experience with the medication and report side-effects. *Primary Care of Adults with Developmental Disabilities: Canadian Consensus Guidelines* recommends that medications be reviewed every three months, and that comprehensive reviews of complex medication regimens occur annually (Sullivan et al., 2011).

Full remission can happen on medication for some people, but the amount of symptom relief varies from person to person. There is still a great deal of trial and error involved in finding the best medication for each person. You and your family member should be involved in the decision-making process and be given information about the benefits and risks, including side-effects of medications. It is important to be aware that medications can interact with one another; ask the doctor about this to prevent problems.

Identifying and minimizing side-effects

It is very difficult for people with developmental disabilities to self-report medication side-effects. Family members should work with the treatment team to identify potential side-effects of each medication and figure out ways to monitor them objectively, focusing on observable behaviour. Side-effects may increase or decrease over time and can range from mild discomfort to problems that are

severe enough to make it impossible to cope with day-to-day life. People often stop taking medication because of unpleasant side-effects without reporting them to anyone. It is dangerous to stop or change medication without consulting the treatment team.

The treatment team can suggest ways to minimize side-effects. Strategies include:

- taking the medication in smaller doses spread over the day
- taking medication with appropriate food
- taking an additional medication to treat specific side-effects
- changing the medication.

It is sometimes surprising how much of a difference even a very small dosage adjustment can make in how someone responds to treatment or is affected by side-effects. While a higher dose may be needed to control an acute episode, a person can generally be kept on a lower dose. The dose may also need to be changed over time.

Monitoring medication: The family's role

Make sure you and your family member know the name and dose of each drug and why it has been prescribed. The easiest way to do this is to get a printout from your local pharmacy that lists current and past prescriptions. Store this information in an accessible place in case there is an emergency or a visit to a doctor who does not have a current medication list on file.

Remember that doctors can use medications to treat all types of problems and that a medication for a physical problem might interact with a medication for a psychiatric issue. Everyone who prescribes medications needs to know the complete list.

You can also help to monitor medication by:

- ranking symptoms of the illnesses on a scale of one to 10 and reporting any improvement
- tracking behaviours in a journal to determine whether or not medication is working (e.g., what happened when a certain dosage was changed?)
- noting side-effects and discussing them with the treatment team
- checking with a doctor and/or pharmacist for drug interactions before your family member takes any new medication (prescription or over-the-counter).

Your input is important when making medication modifications. You can report on how the adjustment is going: Are symptoms worse? Are side-effects better?

You may also be the only person who can help the doctor decide if this is a good time to make changes to a medication regimen. If there are significant changes in your family member's routine or living situation, it might not be the best time to monitor medication changes because it is impossible to know how much of the change is due to the life situation and how much is due to the medication. For example, changing medications just before a family vacation, at the end of the school year or when your family member moves out of the house might not be a good idea. It is also important to review medications, so ask for a review if it is not happening.

Co-ordinating treatment

CASE MANAGEMENT

People with dual diagnosis may go to a community mental health centre for case management. These case managers have expertise in mental health but not in developmental disability. People with dual diagnosis may also go to a developmental disability agency, where case managers have expertise in developmental disability but not in mental health. The amount of support provided by the case manager can vary from one or two hours a week to more intensive contact, depending on the type of case manager and the situation.

Some case managers have expertise in dual diagnosis. In Ontario, if your family member needs case management and you are trying to decide how to pursue this, think about the kinds of services you want and how familiar you want the case manager to be with developmental disabilities. If your family member has significant mental health and developmental problems and you want help to co-ordinate care that goes beyond standard developmental disability or mental health case management, a good way to start is to contact your local DSO (see link at knowledgex.camh.net/dual_diagnosis). If you are having difficulties navigating between mental health and developmental disability services, you can also try contacting the co-ordinator for your region of the Community Networks of Specialized Care (see link at knowledgex.camh.net/dual_diagnosis).

ASSERTIVE COMMUNITY TREATMENT TEAMS

Some individuals with severe mental health problems can access more intensive community supports, known as assertive commu-

nity treatment (ACT) teams. These teams support people with dual diagnosis if they have a psychiatric disorder like schizophrenia, another psychotic disorder or bipolar disorder. You can find more details about the criteria in the Ontario Program Standards for ACT Teams (see link at knowledgex.camh.net/dual_diagnosis).

The ACT model was developed to meet the needs of clients with severe mental illness who often experienced relapse and rehospitalization, often due to their inability or unwillingness to go to local mental health centres. The ACT team provides around-the-clock support and services, such as case management, assessment, psychiatric care, employment and housing assistance, family support and education, and other services that help a person to live in the community.

Hospitalization

Sometimes a time-limited inpatient admission is warranted. The decision to admit someone to a hospital for a behavioural or psychiatric problem is usually made by a psychiatrist. Typically, this decision is made at the hospital emergency department, following a psychiatric assessment.

A hospital admission may be planned for someone who has been an outpatient. This happens for various reasons:

- The person may require very close observation.
- It might be important to see the person outside of their current environment.
- There may be complex medical problems that need to be addressed in a hospital setting.
- There may be a need to adjust medications in a very safe, controlled setting.

There are several advantages to a planned admission:

- It can help the individual and their family prepare for the admission.
- There is a shared understanding of why the person is being admitted.
- The hospital can prepare the space for the individual's unique needs.

Hospitalization can be very stressful for someone with a developmental disability, so it is not a decision that is made lightly. The team considers the risks and benefits of hospitalization. If hospitalization is the safest way to conduct an assessment or initiate treatment, it may happen, despite the stress it can cause the individual.

PLANNING A HOSPITAL STAY

There are various ways that families can make hospitalization less stressful for their family member.

Orientation to hospital

It is helpful when possible for families to visit the unit before admission. There are many rules in hospitals, so it is good to learn them. You may want to ask:

- When can visits happen?
- What can families bring to the hospital?
- When can my family member leave the hospital?
- Who do I call if I have a question?
- Are any types of restraints used in hospital?
- What are the procedures in using restraints? Will I be contacted if they are used?

It can also be helpful for your family member to visit the hospital before they are admitted or to see pictures of it and the room in which they will stay. It is very important for them to learn who the staff will be and what their jobs are. Learning names can be hard, so when your family member is admitted, it may be a good idea to put names of staff, if possible, with their pictures and explanations about what they do, in the room. For example, “Joan is my nurse. I talk with her about taking medication, eating my meals, the activities I do during the day. Dr. Lee is my doctor. She will ask me questions about how I am feeling and try changing the medication that I take to a medication that will make me feel less tired.”

Introducing hospital staff to your family member

Going from the community to hospital is a major change in routine that can be very hard for people with developmental disabilities. Tell hospital staff about your family member’s routines, the times of day that certain things happen and the days of the week for certain activities. Knowing these routines, even if they cannot be kept, can prepare staff to provide better support. For example, Wednesdays may be a very exciting day for your family member because Wednesdays mean bowling or pizza day at work. Even if bowling is not an option in the hospital, knowing the importance of Wednesdays is important for staff. If your family member always puts on clothes in a particular order, or always dresses after breakfast, then this is good information to give to nursing staff.

Describe any unique language or phrases that your family member uses that staff may not understand or appreciate. Let staff know how your family member would relay that they are in pain, upset or agitated. Explain how you respond in those situations to prevent the agitation from increasing.

The hospital passport is a useful way to introduce your family member to hospital staff. You can see two examples of hospital

passports on the EasyHealth.org website and the website of the American Academy of Pediatrics—New Jersey chapter (see links at knowledgex.camh.net/dual_diagnosis). Copies of the hospital passport can be kept at the nursing station and by your family member's bed.

It is also a good idea to consider whether there are any community-based activities or programs that your family member can continue to be involved in while in hospital. It is stressful and disruptive to have to miss out on community involvement.

Bringing comforts from home to the hospital

Decide with your family member and hospital staff what would be safe to bring to the hospital and what would make your family member's stay feel more home-like or familiar. This may mean putting photos on the wall or bringing comfortable clothes, music, games, activities, or a favourite pillow or blanket from home. We all need ways to soothe ourselves. Your family member may have particular music or activities that they enjoy when they feel stressed. It might be a good idea to bring these items to the hospital, as long as your family member can manage without them if they get lost or destroyed.

Safety

Hospitals have well-documented policies and procedures to protect clients and staff from risk. For example, all new inpatients are assessed for their risk of falling. The treatment plan incorporates prevention and safety precautions if necessary.

Medication reconciliation also happens before admission. This means that medications prescribed outside of the hospital are reviewed by the inpatient service to make sure that important medications are not changed unintentionally.

In a planned admission, the behaviours of a person with a dual diagnosis can be assessed before admission, and strategies that have previously worked can be incorporated into the treatment plan.

FAMILY INVOLVEMENT DURING THE STAY

How much family involvement occurs in the hospital will vary by family and individual. This is a very important topic to discuss with the hospital team. Predictability is very important for your family member. It is good to discuss how often visits will take place and for how long. It is very important that once these decisions are made, they remain consistent. Write down a schedule for visits and phone calls for your family member to see. It can be particularly frustrating for your family member to call when you are not available and get no answer. But if staff members know that a phone call will happen at a certain time, they can help reduce your family member's anxiety around the phone call.

Families can also stay involved with their family member's care by attending meetings. Find out when the team will meet to review your family member's case and see if you can attend to give information.

Part of family involvement during a hospital stay is preparing for discharge. Family and community staff who will be involved with your family member after discharge should spend time on the unit, learning your family member's routines and the best ways to respond so that the approach to care can be consistent after your family member leaves the hospital.

4 Crisis and emergency

Even the best planning can't always prevent a crisis. A crisis may also occur with little or no warning.

A *crisis* is any serious deterioration of a person's ability to cope with everyday life. It can be a turning point—for better or worse. A crisis develops when people feel they cannot control their feelings and behaviour and have trouble coping with the demands of day-to-day life. The person may experience extreme despair, sorrow or anger. They may not be able to sleep. They may hear voices or believe that they have superhuman powers. A crisis does not necessarily involve a danger of serious physical harm, but in many crisis situations, outside help is needed. This may involve the person's doctor or therapist or a mobile crisis service or crisis line.

An *emergency* is a situation in which there is an immediate danger that the person will harm either themselves or someone else (Chan & Noone, 2000). Emergencies include:

- threats of suicide
- threats of physical violence
- extreme impaired judgment caused by problems such as psychosis or intoxication.

Being prepared can help to prevent a situation from developing into a crisis. It can also ease the pain and anxiety for the individual and their family if a crisis does occur. Have a safety team in place in case a crisis happens. This team can involve any services and individuals that you think would be helpful. Keep their phone numbers on hand, and make sure that they have agreed to be part of the team. There are other ways of preparing for a crisis, such as having a crisis plan or preparing crisis cards.

Crisis and emergency plans

It may help to sit down with your family and the treatment team to discuss what you will do in a crisis or emergency. Don't try to deal with your family member when they or other family members are extremely upset. You may say things under the stress of the situation that you don't mean, or take action that makes things worse.

When everyone is calm, you can focus on planning what to do if:

- the family notices that some symptoms of the mental health problem are re-occurring
- the situation has already become a crisis.

DEVELOPING A PLAN

Developing a plan together ensures that your family member is an active participant in their care. Planning this *before* a crisis happens can sometimes help to avoid a crisis altogether. However, there are times when a crisis may not be preventable.

The Surrey Place Centre website provides an example of a completed crisis prevention and management plan that can be helpful (see link at knowledgex.camh.net/dual_diagnosis).

The following guidelines will help you to create a crisis action plan that is tailored to the needs of your family member:

- Make sure that your family member is actively involved and participates in the discussion as much as possible. Also make sure that their preferences are heard and respected. For example, your family member may sometimes need to be restrained when they are very upset in hospital, and you know that they prefer to be physically restrained rather than be forced to take medication. This information should be captured in the crisis plan.
- Involve as many members of your family as deemed appropriate and develop an approach that everyone can agree on.
- Develop very specific steps for carrying out your plan. Decide what role each member will have in implementing the plan. For example, decide who is the best person to accompany your family member to the hospital, who should stay on at the hospital and who should make phone calls from home.
- Decide who will speak to the treatment team—or in extreme situations to the police—if your family member is unable to do so.
- Get your family member's permission to relate particular information to hospital staff or to the police.
- Get input on how to create a crisis plan from your treatment team. Behaviour therapists in particular may have experience with helping to develop a crisis plan that everyone can review and sign.
- Be sure to include the local hospital in your crisis planning, especially if your family member has visited an emergency department before. The hospital may have good ideas about how to make an emergency visit less stressful. If they see a crisis plan that included their input, they will be more likely to follow it and provide the support you need. Crisis plans that are created with-

out hospital input may place unrealistic expectations on staff. A good person to approach to help with planning might be a crisis nurse or social worker who was involved in the previous visit.

- Consider how the crisis plan can be shared with hospital staff if your family member is likely to go to hospital without informing or involving family. Sometimes the hospital can store information about your family member electronically, so that anyone at the hospital can see it. A crisis card is another way of doing this.

CRISIS CARDS

People with dual diagnosis and their family members have found it very helpful to write important information on a card or a piece of paper folded small enough that it can be carried with them wherever they go. The paper may be placed in a visible part of the person's wallet.

A crisis card usually contains information important for others (e.g., friends, health care workers, police, strangers) to have in case your family member experiences a mental health crisis while away from home. It contains information such as:

- important phone numbers—who to call in a crisis or emergency, including who to call first and who to call as a back-up
- the person's mental health doctor (e.g., psychiatrist), therapist or worker
- the person's family doctor
- the hospital or treatment centre with which the person is currently or has previously been an inpatient or outpatient
- a list of the person's current medications, the proper dosage for each and the times that they are to be taken. You may also wish to include the name and phone number of the pharmacy at which the prescriptions are usually filled

- a list of medications to which the person is allergic
- a list of any medications used in the past that did not work or that the person would not take due to side-effects. You can list such medications in one column and list the side-effects in a second column
- tips for talking to and working with the person when they are in crisis—neutral topics of interest to them for engagement or distraction, comforting foods and self-calming measures, such as music or video games.

Surrey Place has developed an “Essential Information for Emergency Department” one-page form that may help emergency department staff care for your family member (see link at knowledgex.camh.net/dual_diagnosis).

Getting treatment in an emergency

If your family member experiences a crisis:

- try to be calm and supportive
- offer to call the contacts on the safety team: the doctor, day program worker, case manager or anyone else identified in the crisis plan. If possible, ask if your family member wishes to talk with these contacts on the phone.

Following these suggestions might prevent a crisis from becoming an emergency. However, be aware that sometimes an emergency cannot be avoided. It is helpful to know what you can do in an emergency.

If your family member threatens to harm himself or herself or you or anyone else, or to seriously damage property, do whatever

is necessary to protect yourself and others, including your family member, from harm. You may need to leave and call for help. This is advisable only under extreme circumstances, and only for very short periods of time. If possible, remove objects with which your family member could harm himself or herself.

Going to the hospital

It is best if you can get your family member to go to the hospital voluntarily. If they won't listen to you, ask someone else your family member trusts to convince them to go. This should be part of your pre-arranged action plan (see "Developing a plan" on p. 33). Try to offer your family member a choice. This reduces their fear that they are being coerced.

Calling 911

If your family member appears likely to endanger himself or herself or someone else, and refuses to see a doctor, you can get a judge or justice of the peace (depending on the province or territory in which you live) to issue a document that authorizes the police to take your family member to a hospital for an assessment. But if the danger is immediate, call 911.

Icovino and Esralew (2009) provide suggestions for what to do in case of an emergency:

1. Do not attempt to transport your family member to the nearest emergency department by yourself if you don't feel safe doing so.
2. While waiting for the police to arrive, try to make your surroundings as safe as possible by removing dangerous objects.
3. Tell the 911 dispatcher that the person in crisis has a developmental disability. This will alert the police, who are usually the first responders, to avoid unnecessary force. This includes not

having weapons drawn when they arrive if they know the person is aggressive. If there are enough family members around, have someone meet the emergency personnel before they enter the home, and tell them again that the person in crisis has a developmental disability.

4. Other individuals who do not need to be present to support the person in crisis should leave or move to a safe area.
5. If the person in crisis needs to visit the hospital, emergency staff will arrange transportation. You can follow the ambulance or police to the hospital in your own vehicle. You can also ask about riding with your family member in the ambulance.
6. If you have a crisis plan or information folder, take it with you when you go to meet your family member at the hospital (see “Developing a plan” on p. 33).

The advocacy organization Autism Speaks has developed some excellent tools for police and other first responders to help them work with your family member (see link at knowledgex.camh.net/dual_diagnosis).

Working with hospital emergency staff

If possible, go to the emergency department with your family member or meet them there. Emergency department staff should interview you because you have information that they need to decide how to treat your family member. If they don't ask to talk to you, insist that you get a chance to talk to them.

Try to provide an organized account of the events leading up to the hospital visit. If you are worried about your safety if your family member is not admitted, let the staff know.

Many emergency department staff members comment that they don't have much experience working with people with developmental disabilities. You can help them to know your family member's needs by being prepared. You may want to bring:

- comfort items (e.g., security blanket, stuffed animal, favourite book, photos)
- favourite food or drink and snacks (the wait can be long and food choices may be limited)
- communication tools or strategies that help your family member to confidently talk about himself or herself
- ways to illustrate what your family member is usually like when not in their current state (e.g., photos or video)
- a simple explanation or social story (a simple story with pictures) about how hospitals work (what your family member can expect)
- entertainment/activities to stay occupied while waiting (e.g., games, books, portable DVD player)
- all medications for the next 12 hours, because emergency departments will not dispense regular medications.

What to expect in the emergency department

You may be asked to sign a consent form for emergency department treatment for your family member and to complete a general information form. You must provide your family member's OHIP card, as well as their address and birthdate.

You will be seen by a nurse who will ask you and/or your family member general questions about why you came. The nurse will decide how urgent your situation is and will direct you where to go next to see a doctor (emergency physician). You may again have to wait to see them.

The doctor may ask some of the same questions as the nurse. As part of this assessment, your family member may have a physical examination to rule out medical causes.

The doctor may decide that your family member is OK to go back home, may make care suggestions or may decide that your family member should be seen by a psychiatrist or mental health team. If the doctor thinks your family member should be seen by psychiatry, you will wait again.

The psychiatrist or a member of the crisis team will ask more detailed questions about the current situation and about your family member's history of problems, treatment, previous emergency visits or hospitalizations and medications. Some questions will be for you and some will be for your family member. If you think the clinicians should talk more to your family member, say so. If you want to say something to the clinicians in private, let them know.

Why does your family member need a medical evaluation?

The emergency physician may decide that your family member needs a medical evaluation. This is done to rule out any major (and sometimes minor) medical problems that might be affecting your family member's behaviour. This also fits within the systematic approach/decision tree described on p. 8.

Remember that your family member may be reacting to pain or physical discomfort related to a physical illness in a way that makes it seem as though they have psychiatric problems. For example, an individual with constipation, an abscessed tooth or a urinary tract or other painful infection may be quite agitated.

The medical evaluation will try to identify and get medical treatment for individuals whose major problem is physical. This exam is only intended as an overview. Other medical or dental problems that contribute to your family member's emergency may be missed and should be followed up with after the emergency assessment.

Why must you wait in the emergency department?

One of the hardest things about going to the emergency department is the waiting. Families might think they have to wait a long time because emergency staff don't understand developmental disabilities. It is important to remember that *everyone* waits in the emergency department, not just people with developmental disabilities.

The amount of time you wait can vary, depending on what else is going on in the emergency department at that time. Be prepared to wait between two and 12 hours from start to finish.

While you are waiting in the emergency department, contact your family member's doctors to inform them of the crisis if possible. It is important to follow up with them after the visit ends and to bring them documentation from the emergency department. Ask if something can be sent directly to the doctor on the crisis card or emergency visit form. If you do not ask for a report, it may not be sent.

Involuntary admissions

Your family member may not want to get treatment after a crisis, or even after having serious symptoms. In Canada, a person can't be forced to get treatment for a mental health disorder unless they are a threat to themselves or others. This approach acknowledges the rights of the individual, but it can create complex problems for families. If a person who doesn't want to be admitted to hospital is admitted, they are considered an involuntary patient. The specific criteria used to decide whether a person can be admitted to the hospital without their consent vary, depending on the province or territory. The basic principles are:

- The person is believed to be a danger to himself or herself (e.g., is suicidal or self-harming).

- The person is believed to be a danger to others (e.g., is violent).
- The person is unable to care for himself or herself and is at immediate risk as a result (e.g., is not eating or drinking).

If the person meets criteria for involuntary admission, a physician can issue a document that authorizes a short stay in the hospital (usually one to three days) for emergency treatment. In some provinces and territories, another document must be issued if longer-term treatment is needed. This gets a little more complicated if your family member does not have the capacity to consent to treatment. In that case, it is important to discuss this with the physician at the time of admission.

After the crisis is over

It is very important to debrief about what happened. Include your family doctor in the debriefing process, and consider following up with a contact from the hospital if you think there may need to be another visit in the future. The hospital's input is important to crisis planning. If there is a crisis plan, see how it worked and if any changes need to be made to it. Be sure that everyone, including the hospital, gets a copy of the revised plan.

If there is no crisis plan in place yet, now is the time to develop one with the team.

Family members coping together with crises

Icovino and Esralew (2009) suggest that a crisis affects the entire family. We tend to focus on the people in crisis without realizing that each episode can have an immediate, destabilizing effect on other family members. The family may initially experience a loss of control over the situation; individual members may also experience a range of emotions, including fear, anger and guilt. When possible, it is best to discuss and revisit crisis plans when things are calm before or following the crisis and before another develops.

Families can work together to build a solid foundation of trust and mutual understanding. Exploring new strategies together can empower families and strengthen their resolve to face problems together by taking care of each member.

All members of the family should be reassured that they are not alone in dealing with the crisis. Finding solutions will be a family effort, and families will become stronger as their coping skills improve.

5 How dual diagnosis affects families

A growing body of knowledge highlights what many families already know too well: that mental health problems or challenging behaviours contribute to family conflict, wear away social support, and can negatively affect the mental health and well-being of family members.

Family relationships

PARENTS

Parents of people with developmental disabilities (even without mental health problems) work very hard to co-ordinate services and care for their child. When this child also develops mental health problems or serious challenging behaviours, parents can struggle to cope. They often describe feeling frustrated, angry, hopeless, stressed, sad or overwhelmed. Others may feel empowered and secure. Just because children develop problems does not necessarily mean that their parents will also develop problems. Each parent (and family) reaction depends on the problem; coping skills, strate-

gies and resources; and other life events that surround that family. Parents feel a tremendous sense of responsibility and worry about their children's care and well-being. Over time, the chronic nature of the problems can take its toll.

In the book *More Than a Mom: Living a Full and Balanced Life When Your Child Has Special Needs*, Baskin and Fawcett (2006) suggest various strategies to help parents and their families remain healthy and cohesive:

- Keep the lines of communication open between partners.
- Rely on each other for support.
- Seek help from each other or from others outside the relationship.
- Make time for each other, such as going to a movie or doing another activity to nurture your relationship.
- Attend some of your child's appointments together.
- Give each other time to deal with stress in your own way.
- Try hands-on concrete activities instead of only talking.
- Learn about your child's difficulties together.
- Ask for information to share with each other.
- Increase your partner's involvement slowly, rather than expecting too much too soon.
- Connect with other families in the same situation as you.
- See yourself as a "parenting team."
- Celebrate your differences.
- Remember the big picture of what your common goals are for your child.
- Recognize that sometimes family members have uneven parenting responsibilities, and parents should communicate with each other about their expectations.

SIBLINGS

Siblings may worry about developing mental health problems. They may worry about the stress and strain that their parents are facing and may take on the burden of trying to help. At the same time, brothers and sisters sometimes resent the time that parents spend supporting their sibling. They may become angry to the point of acting out or distancing themselves from family and friends.

Parents and/or guardians sometimes believe that they should protect younger children by isolating them from severe behavioural episodes. Often, however, this is not realistic, and siblings can benefit if they understand what the family is facing during crisis situations. Family-centred problem solving is an invaluable skill that younger family members can use throughout their lives. However, if younger children are in danger of physical harm during a behavioural crisis, they should be kept isolated from the event.

By openly discussing the challenges your loved one and each family member is experiencing, you have an opportunity to lessen a sibling's confusion and fear with sensitive age-appropriate explanations.

CAREGIVER BURDEN AND COMPASSION FATIGUE: A NOTE ABOUT LANGUAGE

The term *caregiver burden* is used in the professional literature to describe the emotional, social and psychological toll on the family that comes from caring for someone with a mental health problem. Many caregivers want others to recognize how difficult it is to care for an ill family member with dual diagnosis, but they don't like the term caregiver burden. They feel that 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 them 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 dual diagnosis may be better described as *compassion fatigue*. We use compassion fatigue in this guide to describe the overwhelming physical, emotional, social and spiritual exhaustion that can strike family members affected by dual diagnosis. It is a much more user-friendly term for describing the results of coping on an ongoing basis with extreme adversity.

You can find strategies for dealing with compassion fatigue at mytherapynet.com (see link at knowledgex.camh.net/dual_diagnosis).

6 Self-care for family members

Never underestimate the benefits of taking care of yourself. Families that take care of themselves have more physical and emotional energy to deal with the challenges they face, which will benefit the ill family member. Family members will each find their own way to care for themselves. Being able to soothe, relax and calm yourself involves:

- knowing what kinds of thoughts and behaviours make you feel better or worse
- coming up with a self-care plan that helps you to prevent or overcome the negative feelings.

A self-care plan involves following a structured routine each day, engaging in a particular activity, spending time with a good friend or focusing on a way of thinking—anything that may comfort you and give you a sense of well-being and stability. We will develop a self-care plan later in this chapter.

Developing resilience

Resilience is frequently described as the capacity to thrive and fulfil one's potential despite (or perhaps because of) stressful circumstances. All of us are resilient in one way or another, but some people seem to be more so. They are inclined to see challenges as learning opportunities that lead to healthy emotional growth and development.

In their book *Building a Joyful Life with Your Child Who Has Special Needs*, Whiteman and Roan-Yager (2007) describe resilience in terms of six distinct clusters of strength and qualities found in resilient parents when faced with stressful situations:

1. **Insight:** The ability to ask tough questions and give honest answers includes understanding, empathy and tolerance for ambiguity.
2. **Independence:** This quality refers to the ability to separate oneself emotionally and physically from the source of pain. It includes the ability to acknowledge the stressor, step back from it and develop alternative ways of viewing the situation.
3. **Relationships:** The ability to develop meaningful relationships is an important component of mental health. This includes the ability to find people who support, sustain and validate us.
4. **Initiative:** This ability to take charge of problems in a proactive way often includes problem-solving skills and sheer persistence.
5. **Creativity and humour:** Creativity involves using imagination to express our feelings. Many use some type of art form—painting, dancing or collage—to express their feelings through creativity.

Humour, described as finding the comic in the tragic, is an essential part of getting through daily challenges.

6. **Morality:** Morality means acting on the basis of an informed conscience, a sense of obligation to contribute to the well-being of others. Many resilient people have transformed their situations into conscious action in the world.

Self-care strategies

If you cannot take care of yourself, then you cannot take care of your family or your family member with dual diagnosis. You are one of the best caregivers for your family member, so staying healthy is critical.

Developing a self-care plan involves thinking about ways to care for yourself when you feel particularly stressed or worn down.

SHORT-TERM STRATEGIES

Short-term goals focus on the fast and relatively easy ways in which you can soothe yourself and replenish your energy. We call these strategies the “quick wins.” When we board an airplane, we are often reminded that if there is a drop in pressure, masks will drop from the ceiling and we are asked to put on our own masks first before helping a child with theirs. If you don’t care for yourself in the short term, you can’t care for those you love. Even if you feel that you don’t need these strategies, see them as an experiment. You won’t know what is helpful until you try.

Susan Senator (2010), in *The Autism Mom's Survival Guide (For Dads, Too!)*, notes simple activities that can be a “quick fix” for immediate help during a tough situation:

- Plunge into a hobby for a moment. Purchasing a small item that is for your hobby can help take you out of the stressful moment and into a better one.
- Go out to a nice dinner with a friend. If this isn't possible, even making yourself a cup of coffee at home and calling a friend to drink it “with” will provide a nice break.
- Challenge yourself physically. Go for a bike ride or a run.
- Do something that stimulates your intellect. Work on a crossword puzzle—exercise your mind.
- Join a club or interest group. You can go to www.meetup.com to find others in your area who enjoy similar things.
- Do something small and quick that makes you feel good about your appearance.
- Indulge in a treat, for example, a piece of chocolate.
- Take a moment to enjoy the beauty of nature. Buy yourself flowers at the supermarket or take a walk in a beautiful spot.
- Enjoy some music, for example, listen to a favourite song, or if you play an instrument, take it out, even if you think you aren't in the mood.

LONGER-TERM STRATEGIES

Recognize and address challenges

Try to identify and prioritize challenges. Sometimes you can change the problem, and sometimes you need to change the way you think about it. You may not be able to “fix” the problem, but you can find different ways of coping.

Build social support

Families often give up their own activities and can become isolated from their friends and colleagues when caring for a family member with dual diagnosis. Social support is crucial to help you achieve and maintain emotional and physical health. Participating in a group activity you enjoy, such as a walking club, sports team, reading club or church group, can help you retain your social network. Old friends and colleagues from whom you've grown apart may appreciate hearing from you.

There is no shame in seeking help from people outside your family. Sometimes neighbours, fellow congregants at your place of worship or friends can help by providing another perspective or actual support to you and your family member. Being open about your situation will often bring support from the least likely places and people. Joining a support group can help to remind you that you are not alone in your daily struggles.

RESOURCES FOR SOCIAL SUPPORT

You can find helpful information about local support groups in your area through:

- Developmental Services Ontario (for information about groups in your region)
- Community Living Ontario
- Extend-a-Family
- Family Alliance.

Some groups are focused on specific disabilities or specific cultural groups:

- Autism Ontario
- Fetal Alcohol Spectrum Disorder Ontario Network of Expertise support groups

- Heep Chi Association
- South Asian Autism Awareness Centre.

These regional support groups and family resources may also be helpful:

- Ensemble: (southwestern Ontario)
- United Families of Eastern Ontario (eastern Ontario)
- Youthlink Parent Group (Toronto)
- Concerned Parents of Toronto Inc.: Call 416 492-1468 for Jim or Elgi Johnston.

Links to these organizations are available at knowledgex.camh.net/dual_diagnosis.

Become informed

Many families seek formal and informal opportunities to learn about dual diagnosis. They find it helpful to learn as much as they can about their loved one's particular problems, including the causes, signs, symptoms and possible treatments.

Believe in yourself and your rights

You have a right to:

- your own support from health care professionals
- education about developmental disabilities and mental health problems
- information about the latest research and most effective treatment options
- respect and validation.

Building a self-care plan

Developing a self-care plan will help you to think about the small steps you can take in your life to build resilience and reduce your vulnerability to compassion fatigue.

Imagine what your self-care plan might look like. This plan should address all of your needs:

- biological self-care (caring for your own physical health)
- psychological self-care (taking care of your emotional health)
- social self-care (taking care of your social needs and networks)
- spiritual self-care (drawing on sources of spiritual help that might comfort and guide you).

This plan is called the biopsychosocial-spiritual self-care plan. Just remember to be very specific in your plan. For example, you may choose to include something like the following:

- I will work out at the local gym three times a week for 30 minutes each time.
- I will walk reasonable distances instead of taking my car.
- I will go to Pilates classes with my friend Sheila once every week.
- I will eat three fruits a day and take a B6 multivitamin.
- I will prepare two meatless dinners a week.

References

Baskin, A. & Fawcett, H. (2006). *More Than a Mom: Living a Full and Balanced Life When Your Child Has Special Needs*. Bethesda, MD: Woodbine House.

Bradley, E. & Burke, L. (2002). The mental health needs of persons with developmental disabilities. In D.M. Griffiths, C. Stavrakaki & J. Summers (Eds.), *Dual Diagnosis: An Introduction to the Mental Health Needs of Persons with Developmental Disabilities* (pp. 45-79). Sudbury, ON: Habilitative Mental Health Resource Network.

Chan, A. & Noone, J.A. (2000). *Emergency Mental Health Education Manual*. Vancouver: Mental Health Evaluation & Community Consultation Unit, University of British Columbia.

Cooper, S., Smiley, E., Morrison, J., Williamson, A. & Allan, L. (2007). Mental ill-health in adults with intellectual disabilities: Prevalence and associated factors. *British Journal of Psychiatry*, 190(1), 27-35.

Dykens, E.M., Hodapp, R.M. & Finucane, B.M. (2000). *Genetics and Mental Retardation Syndromes: A New Look at Behavior and Interventions*. Baltimore, MD: Paul H. Brookes.

Emerson, E. & Emerson, C. (1987). Barriers to the effective implementation of habilitative behavioral programs in an institutional setting. *Mental Retardation*, 25(2), 101-106.

Fletcher, R., Loschen, E., Stavrakaki, C. & First, M. (Eds.). (2007). *Diagnostic Manual—Intellectual Disability (DM-ID): A Clinical Guide for Diagnosis of Mental Disorders in Persons with Intellectual Disability*. Kingston, NY: NADD Press.

Harris, J.C. (2006). *Intellectual Disability: Understanding Its Development, Causes, Classification, Evaluation, and Treatment*. New York: Oxford University Press.

Icovino, D. & Esralew, L. (2009). *Family Crisis Handbook: How to Cope When an Adult Loved One with a Developmental Disability Experiences Mental Health or Behavioural Issues*. New Jersey: New Jersey Department of Human Services Dual Diagnosis Task Force.

Lunsky, Y., Bradley, E., Durbin, J., Koegl, C., Canrinus, M. & Goering, P. (2006). The clinical profile and service needs of hospitalized adults with mental retardation and a psychiatric diagnosis. *Psychiatric Services*, 57(1), 77–83.

Richards, M., Maughan, B., Hardy, R., Hall, I., Strydom, A. & Wadsworth, M. (2001). Long-term affective disorder in people with mild learning disability. *British Journal of Psychiatry*, 179, 523–527.

Robertson, J., Emerson, E., Gregory, N., Hatton, C., Kessissoglou, S. & Hallam, A. (2000). Receipt of psychotropic medication by people with intellectual disability in residential settings. *Journal of Intellectual Disability Research*, 44(6), 666–676.

Royal College of Psychiatrists. (2001). *Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation (DC-LD)*. London, U.K.: RCPsych Publications.

Senator, S. (2010). *The Autism Mom's Survival Guide (For Dads, Too!): Creating a Balanced and Happy Life While Raising a Child with Autism*. Boston, MA: Trumpeter Books.

Sullivan, W.F., Berg, J.M., Bradley, E., Cheetham, T., Denton, R., Heng J., Hennen, B., Joyce, D., Kelly, M., Korossy, M., Lunskey, Y., & McMillan, S. (2011). Primary care of adults with developmental disabilities: Canadian consensus guidelines. *Canadian Family Physician*, 57, 541–553.

Turner, T.H. (1989). Schizophrenia and mental handicap: An historical review, with implications for further research. *Psychological Medicine*, 19(2), 301–314.

Whiteman, N. & Roan-Yager, L. (2007). *Building a Joyful Life with Your Child Who Has Special Needs*. London, U.K.: Jessica Kingsley.

Resources

WEBSITES

Links to these websites are also available at knowledgex.camh.net/dual_diagnosis.

Autism Ontario

<http://autismcanada.org>

Canadian Association for Research and Education in Intellectual Disabilities (CARE-ID)

<http://care-id.com>

Centre for Addiction and Mental Health (CAMH)

www.camh.ca

Community Living Ontario

www.communitylivingontario.ca

Community Networks of Specialized Care

www.community-networks.ca

ConnexOntario Mental Health Helpline

www.mentalhealthhelpline.ca

Developmental Services Ontario

www.dsontario.ca

**FASD One: Fetal Alcohol Spectrum Disorder Ontario
Network of Expertise**

www.fasdontario.ca

**National Association for Persons with Developmental Disabilities
and Mental Health Needs (NADD)**

www.thenadd.org

NADD Ontario

www.dualdiagnosisontario.net

Surrey Place Primary Care

www.surreyplace.on.ca/Clinical-Programs/Medical-Services/Pages/PrimaryCare.aspx

BOOKS

Baskin, A. & Fawcett, H. (2006). *More Than a Mom: Living a Full and Balanced Life When Your Child Has Special Needs*. Bethesda, MD: Woodbine House.

Senator, S. (2010). *The Autism Mom's Survival Guide (For Dads, Too!): Creating a Balanced and Happy Life While Raising a Child with Autism*. Boston, MA: Trumpeter Books.

Tilton, A. (2004). *The Everything Parents Guide to Children With Autism*. Avon, MA: Adams Media.

Whiteman, N. & Roan-Yager, L. (2007). *Building a Joyful Life with Your Child Who Has Special Needs*. London, U.K.: Jessica Kingsley.

In my experience, becoming the primary advocate for your son or daughter is the best approach to creating a long-term support system. Having had to tackle the situation on my own, it would have been extremely helpful to have had a primer to point me in the right direction instead of wasting time traveling down many blind alleys in search of a livable solution.

The experience of others who have pioneered support strategies on their own, or who have had some success with the systems, has been very helpful. Even so, we often have the same unanswered questions. A guide like this gives us very useful information and points us to sources that can answer our questions, or at least provide us with alternatives to consider.

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