



FAMILY CAREGIVER SUPPORT

**STRATEGIES AND TOOLS TO PROMOTE CARE-
GIVERS MENTAL AND EMOTIONAL HEALTH**

GUIDE





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Lead partner: Department for Psychiatry and Psychological Medicine, Medical University Rijeka

With contributions from:

School of Allied Health Technologies, Instituto Politécnico do Porto

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INTRODUCTION

Family caregivers play a central role in the care of persons with severe mental illness. This is an important fact and the result is that the majority of caregivers live with the illness of their affected relative 24 hours of the day, each day of the year.

Research shows that family members who provide care to individuals with chronic or disabling mental conditions are themselves at risk. Emotional, mental, and physical health problems arise from complex caregiving situations and the strains of caring for frail or disabled relatives.

As a response to this situation, our project intends to empower family members as caregivers and to give them access not only to relevant medical information, but also to psychological support for their own needs.

This Guide provides the complement to the Resource Pack which is available in the Internet (<https://www.family-caregiver-support.eu>). On the online platform, interested readers will find modules with information for the following nine mental disorders:

- Dementia
- Substance abuse
- Schizophrenia
- Common mood disorders
- Intellectual disability
- Attention deficit hyperactivity disorder (ADHD)
- Autism
- Eating disorders
- Post-traumatic stress disorder (PTSD)

Each module contains various units which cover caregiving aspects about understanding the respective disorder, the concerns of the caregiver, the role of nutrition, activities to support and empower the caregiver and activities for the person receiving the care.

This Guide gives background information about each disorder, explains which behaviour of the patient can be expected, focuses on concerns which the caregiver may have, and presents strategies what can be done and how to deal with this disorder.

We hope that this Guide and the Resource Pack will help and empower family caregivers in their demanding tasks.

Würnitz, April 2020

Wolfgang Eisenreich, project coordinator





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DEMENTIA





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1. DEMENTIA

Compiled by School of Allied Health Technologies, Instituto Politécnico do Porto

1.1 WHAT IS DEMENTIA?

Dementia is the clinical expression of several pathological entities. It is defined as a complex process involving an interaction between specific molecular pathways that affect cell functions, leading to loss of synaptic bonds, cell death, inflammation, and disruption of functional networks underlying cognitive, personality, behaviour and sensorimotor functions, thus resulting in the loss of individual autonomy. Aging is the most robust risk factor for dementia. Its incidence and prevalence increase exponentially with age, where more than 90% of dementias appear after age 65. However, there are other genetic and environmental factors (e.g. low educational level or the performance of low stimulating work / occupational activities), which may increase the predisposition for the development of the syndrome.

According to the World Health Organization (WHO), Alzheimer's disease (AD) was considered the 5th most frequent cause of death. In 2015. The World Alzheimer's Report, a comprehensive meta-analysis of population studies, estimated that 46.8 million people worldwide live with dementia, and that figure is expected to reach 131.5 million by 2050.

Dementias are classified based on their underlying pathologies, which are broadly defined by the accumulation of abnormal protein aggregates in neurons, as well as in the extracellular compartment, in vulnerable brain regions. In addition, dementias can be difficult to clinically diagnosed due to its multifactorial causes, overlapping symptoms and variety of degenerative pathologies, resulting in inconsistent clinical presentation and diagnostic challenges. It is estimated that degenerative dementias correspond to 80% of the most common clinical conditions, Lewy Body Dementia and Frontotemporal Dementia are the most common subtypes.

Dementia is not a single disease; it's an overall term — like heart disease — that covers a wide range of specific medical conditions, including Alzheimer's disease. Disorders grouped under the general term "dementia" are caused by abnormal brain changes. These changes trigger a decline in thinking skills, also known as cognitive abilities, severe enough to impair daily life and independent function. They also affect behaviour, feelings and relationships.

Alzheimer's disease accounts for 60 to 80 percent of cases. Vascular dementia, which occurs because of microscopic bleeding and blood vessel blockage in the brain, is the second most common cause of dementia. But there are many other conditions that can cause symptoms of dementia, including some that are reversible, such as thyroid problems and vitamin deficiencies.

Dementia is often incorrectly referred to as "senility" or "senile dementia," which reflects the formerly widespread but incorrect belief that serious mental decline is a normal part of ageing.





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Symptoms of dementia can vary greatly. Examples include:

- Problems with short-term memory;
- Keeping track of a purse or wallet;
- Paying bills;
- Planning and preparing meals;
- Remembering appointments;
- Travelling out of the neighbourhood.

Many dementias are progressive, meaning symptoms start out slowly and gradually get worse. If you or someone you know is experiencing memory difficulties or other changes in thinking skills, don't ignore them. See a doctor soon to determine the cause. Professional evaluation may detect a treatable condition.

1.1.1 STAGES OF DEMENTIA

Dementia affects each person in a different way, depending upon the impact of the disease and the person's personality before becoming ill. The signs and symptoms linked to dementia can be understood in three stages.

Early stage: The early stage of dementia is often overlooked, because the onset is gradual. Common symptoms include:

- Forgetfulness;
- Losing track of the time ;
- Becoming lost in familiar places.

Middle stage: As dementia progresses to the middle stage, the signs and symptoms become clearer and more restricting. These include:

- Becoming forgetful of recent events and people's names;
- Becoming lost at home;
- Having increasing difficulty with communication;
- Needing help with personal care;
- Experiencing behaviour changes, including wandering and repeated questioning.





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Late stage: The late stage of dementia is one of near total dependence and inactivity. Memory disturbances are serious and the physical signs and symptoms become more obvious. Symptoms include:

- Becoming unaware of the time and place;
- Having difficulty recognizing relatives and friends;
- Having an increasing need for assisted self-care;
- Having difficulty walking;
- Experiencing behaviour changes that may escalate and include aggression.

1.2 EARLY SIGNS AND SYMPTOMS: IS IT ALZHEIMER'S OR AGE-RELATED SIGNS?

Memory loss that disrupts daily life may be a symptom of Alzheimer's or another dementia. Alzheimer's is a brain disease that causes a slow decline in memory, thinking and reasoning skills. There are warning signs and symptoms. If you notice any of them, don't ignore them. Schedule an appointment with your doctor. But don't panic! Maybe they are just minor age-related changes!

<i>Memory loss that disrupts daily life</i>	<i>Age-related changes:</i>
One of the most common signs of Alzheimer's disease, especially in the early stage, is forgetting recently learned information. Others include forgetting important dates or events, asking for the same questions over and over, and increasingly needing to rely on memory aids (e.g., reminder notes or electronic devices) or family members for things they used to handle on their own.	Sometimes forgetting names or appointments but remembering them later.
<i>Challenges in planning or solving problems</i>	<i>Age-related changes:</i>
Some people living with dementia may experience changes in their ability to develop and follow a plan or work with numbers. They may have trouble following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things than they did before.	Making occasional errors when managing finances or household bills.
<i>Difficulty completing familiar tasks</i>	<i>Age-related changes:</i>
People with Alzheimer's often find it hard to complete daily tasks. Sometimes they may have trouble driving to a familiar location, organizing a grocery list or remembering the rules of a favourite game.	Occasionally needing help to use microwave settings or to record a TV show.
<i>Vision problems</i>	<i>Age-related changes:</i>
For some people, having vision problems is a sign of Alzheimer's. This may lead to difficulty with balance or trouble reading. They may also have problems judging distance and determining colour or contrast, causing issues with driving.	Vision changes related to cataracts.





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<i>Confusion with time or place</i>	<i>Age-related changes:</i>
People living with Alzheimer's can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there.	Getting confused about the day of the week but figuring it out later.
<i>New problems with words in speaking or writing</i>	<i>Age-related changes:</i>
People living with Alzheimer's may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary, have trouble naming a familiar object or use the wrong name.	Sometimes having trouble finding the right word.
<i>Misplacing things and losing the ability to retrace steps</i>	<i>Age-related changes:</i>
A person living with Alzheimer's disease may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. He or she may accuse others of stealing, especially as the disease progresses.	Making a bad decision or mistake once in a while, like neglecting to change the oil in the car.
<i>Withdrawal from work or social activities</i>	<i>Age-related changes:</i>
A person living with Alzheimer's disease may experience changes in the ability to hold or follow a conversation. As a result, he or she may withdraw from hobbies, social activities or other engagements. They may have trouble keeping up with a favourite team or activity.	Sometimes feeling uninterested in family or social obligations.
<i>Changes in mood and personality</i>	<i>Age-related changes:</i>
Individuals living with Alzheimer's may experience mood and personality changes. They can become confused, suspicious, depressed, fearful or anxious. They may be easily upset at home, with friends or when out of their comfort zone.	Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

1.3 BEHAVIOURS TO EXPECT

In Alzheimer Dementia, memory decline is considered the major symptom. In an early stage of illness, recent episodic memories are most affected, while memories of the distant past are generally preserved. Person can recall all the memories from the childhood but is not able to tell what happened yesterday. In contrast to episodic memory, working memory and semantic memory are preserved until later in life disease. Language deficits, especially difficulties in finding words, are a common early symptom in Alzheimer disease. The subtle decline in visuospatial skills occurs equally in the mild stages of dementia and progresses over the course of dementia. Impairment of executive functions, on the other hand, begins even earlier and like all other cognitive domains, worsens with over time. Individuals with Alzheimer disease have a variety of psychiatric symptoms. The first





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symptoms are apathy, anxiety and irritability. Mild to moderate depressive symptoms are also often present from the onset. Appetite and sleep disorders, disinhibition, and changes in perception (hallucinations) or thoughts (delusions) like paranoid ideas that somebody is stealing things, usually occur in later stages of dementia.

In general, and regardless of the etiological subtype and primary clinical manifestations, dementias result on deterioration of capabilities:

- Cognitive;
- Behavioural;
- Functional.

Many people find the changes in behaviour caused by Alzheimer's to be the most challenging and distressing effect of the disease. The chief cause of behavioural symptoms is the progressive deterioration of brain cells. However, medication, environmental influences and some medical conditions also can cause symptoms or make them worse.

In early stages, people may experience behaviour and personality changes such as:

- Irritability;
- Anxiety;
- Depression.

In later stages, other symptoms may occur including:

- Aggression and anger;
- Anxiety and agitation;
- General emotional distress;
- Physical or verbal outbursts;
- Restlessness, pacing, shredding paper or tissues;
- Hallucinations (seeing, hearing or feeling things that are not really there);
- Delusions (firmly held belief in things that are not true);
- Sleep issues and sun downing.

1.4 TREATMENT POSSIBILITIES

While there is no cure for Alzheimer's disease or a way to stop or slow its progression, there are drug and non-drug options that may help treat symptoms. Understanding available options can help individuals living with the disease and their caregivers to cope with symptoms and improve quality of life.





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Medication for memory

As Alzheimer's progresses, brain cells die and connections among cells are lost, causing cognitive symptoms to worsen. While current medications cannot stop the damage, Alzheimer's causes to brain cells, they may help lessen or stabilize symptoms for a limited time by affecting certain chemicals involved in carrying messages among the brain's nerve cells. Doctors sometimes prescribe both types of medications together.

Alternative treatments

A growing number of herbal remedies, dietary supplements and "medical foods" are promoted as memory enhancers or treatments to delay or prevent Alzheimer's disease and other dementias. Claims about the safety and effectiveness of these products, however, are based largely on testimonials, tradition and a rather small body of scientific research.

1.5 CONCERNS ABOUT DEMENTIA

1.5.1 ROLE OF THE FAMILY IN CARE

Family caregivers play an important role in early recognition of signs of dementia as they contact patients daily and know them well. However, the family often has difficulty making the decision to consult a doctor; feeling guilty about suggesting that something is not right or betraying trust. In any case, after being able to take the family's patient to the doctor, the doctor usually orders a series of exams that allow a timely and safe diagnosis.

Often family members do not recognise the first signs of dementia because the ill person can be able to maintain a lot of his/her functions for some period of time (can still cook, from time to time putting a bit much salt etc.). Person with early stages of dementia can overbridge his/her lack of memory with experience or routine. But if we put them in a position to solve a bit more complicated and new problems, they will not be able to complete. There is a simple test that can be performed to see if there are some difficulties in synthesis: tell the person to draw the watch with 10 minutes past 11. The organisation of the drawing will show the possible difficulties in time and place organisation that could be signs of dementia development.

Sometimes the family members feel that the person is changing, often they describe that person becomes more prone to quarrel or is not trusting anyone.

Often ill persons start to think that somebody is stealing things (in fact they cannot find things anymore).





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1.5.2 STIGMA

Stigma is a collective phenomenon manifested, for example, in the fear and shame that relatives of individuals with dementia may feel concerning the negative social connotation of disease, which in many cases lead to the "concealment" of dementia symptoms as well as to the search late of relevant health services. Stigma is also expressed when older people with dementia and their support networks are aware of stigma directed at the disease. This, in turn, is associated with decreased self-esteem, self-efficacy and quality of life, increased anxious and depressive symptoms, social exclusion and disability. Dementia is correlated with processes of social exclusion, leading to an unwanted situation in which people are prevented from engaging in society at large, with detrimental consequences for the individual and even society.

1.5.3 RISK PRACTICES

Several studies have consistently shown that dementias are multifactorial in nature, with numerous genetic, environmental and behavioural factors conferring protection or risk to them. Given the large number of modifiable risk factors, including physical inactivity, poor diet, smoking, poor education, middle-aged hypertension, middle-aged obesity, diabetes, depression and occupational performance, prevention through increased cognitive reserve and reduction of modifiable risk factors offer potential non-pharmacological alternatives to reduce the increasing number of individuals who develop dementia. Non-pharmacological multi-domain interventions like taking care of smoking, diet, regular medication for other somatic diseases, provide an opportunity to address the multiple risk factors present simultaneously among older people at risk for dementia.

1.6 WHAT CAN BE DONE?

As Alzheimer's and other dementias progress, behaviours change—as does your role as caregiver.

Non-drug approaches to managing behaviour symptoms promote physical and emotional comfort. Many of these strategies aim to identify and address needs that the person with Alzheimer's may have difficulty expressing as the disease progresses. Non-drug approaches should always be tried first.





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Steps to developing successful non-drug treatments include:

- Recognizing that the person is not just "acting mean or ornery," but is having symptoms of the disease;
- Identifying the cause and how the symptom may relate to the experience of the person with Alzheimer's;
- Changing the environment to resolve challenges and obstacles to comfort, security and ease of mind.

If the family option is to keep the elderly person with dementia in their own home or in the home of a family member, some safety measures need to be implemented to prevent accidents. As the disease progresses, the elderly become less and less able to take care of themselves and safely. Some general safety principles may be helpful to the caregiver family:

- Family caregivers should leave emergency numbers (to which the elderly person with dementia can call in case of need) and the address of their home next to all phones of the person's home with dementia;
- Installing a fire alarm at home can be a very useful strategy for prevention and immediate action by the family;
- The caregiver family should eliminate the existence and use of flammable products indoors;
- Installing safety locks on all exterior doors and windows is essential for the safety of the elderly person with dementia as well as the caring family;
- The family should keep a spare key outside the house in a safe place, as the elderly person with dementia can lock the door and leave caregivers outside;
- Eliminating path wires and carpets are good strategies for the family to adopt;
- Put specific protectors in the sockets;
- If the house has stairs, they must have a single handrail that goes from the first to the last step;
- The family should lock all medicines in a safe place, as well as plastic bags (the elderly with dementia may choke himself accidentally);
- Eliminating shadows, glare, and patterns that may confuse or frighten the elderly with dementia is a good strategy for the caring family to adopt.

1.6.1 STRATEGIES FOR CAREGIVERS TO ADOPT

An elderly person with dementia cannot express his emotions to those around him and may resort to strange behaviours. Family caregivers should understand that these reactions are not intentional but characteristics of their condition.





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Case Story

Alice is 65 years old, lives in her daughter's house with her son-in-law and grandchildren. Alice's daughter is very worried that her children often see her grandmother pacing around her room or around the dining room table and get scared. Alice's daughter also mentions that she always asks the same questions, even when she has just answered him. "I get angry and yell at her." confesses Alice's daughter.

Response:

- While it can be very annoying and uncomfortable for the caregiver family, the behaviour of walking non-stop in and of itself does not cause harm or endanger the person or family.
- The family caregiver should let her walk and explain to distant children or relatives that this behaviour is natural due to their health condition and only reveals some agitation on the part of the elderly with dementia.
- Family caregivers should reorganize the environment to allow older people with dementia to have room to walk without going against furniture or other obstacles.
- If behaviour is constant, family caregivers should arrange outdoor walks, preferably in the afternoon, in low-traffic places.
- Regarding repetitive questions there has no point in being irritated or trying to argue; just answer and understand that this is the maximum elaboration that the elderly with dementia can reach.
- Saying, for example, "I've answered more than twenty times" or yelling at the elderly with dementia will only increase their insecurity.
- The family should let the elderly person with dementia ask and must seek to answer the question clearly, precisely, slowly and articulate, and ask to the elderly person to repeat what has been said.
- If the repetitive question refers to the time ("What time is it?"), The caring family should try to relate the answer to some activity ("It's lunch time", "dinner time", "taking shower" etc.). The activity may still serve as a mention of time, while the value of the hour has probably lost its concrete meaning.
- When ill person forgets the name of their own child or relatives, it is not because they do not or did not love them, but because of pathological processes in the brain.

1.6.2 TIPS FOR CAREGIVERS REGARDING THE FAMILY MEMBER WITH DEMENTIA

A person living with dementia will eventually need assistance with daily living. By using creativity and caregiving skills, you can adapt routines and activities as needs change.

- Monitor personal comfort. Check for pain, hunger, thirst, constipation, full bladder, fatigue, infections and skin irritation. Maintain a comfortable room temperature.
- Avoid being confrontational or arguing about facts. For example, if a person expresses a wish to go visit a parent who died years ago, don't point out that the parent is dead. Instead, say, "Your mother is a wonderful person. I would like to see her too."





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- Redirect the person's attention. Try to remain flexible, patient and supportive by responding to the emotion, not the behaviour.
- Create a calm environment. Avoid noise, glare, insecure space and too much background distraction, including television.
- Allow adequate rest between stimulating events.
- Provide a security object.
- Acknowledge requests, and respond to them.
- Look for reasons behind each behaviour. Consult a physician to identify any causes related to medications or illness.
- Explore various solutions.
- Don't take the behaviour personally, and share your experiences with others.





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SUBSTANCE ABUSE





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2. SUBSTANCE ABUSE

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2.1 WHAT IS SUBSTANCE ABUSE?

Substance abuse may be defined as “the recurrent use of the substance resulting in the inability to fulfil professional or personal obligations, in important physical damage or in recurring social and legal problems. It may occur in relation to alcohol and illicit drugs, even if there is still no dependence” (*National Institute on Drug Abuse*).

Over 275 million people experienced drugs during 2016, some 31 million people who use drugs suffer from drug use disorders and need treatment.

Psychoactive substances can be divided in three main categories:

- **Depressants**, that slow down the activity of the central nervous system, decreasing alertness, breathing and heart rate (examples are alcohol, heroin, cannabis and prescription tranquilisers, such as benzodiazepines);
- **Stimulants**, which increase central nervous system activity, making the person more alert and aroused (examples are nicotine, caffeine, cocaine, ecstasy and the methamphetamines, “speed”);
- **Hallucinogens**, responsible for making a person see, hear, smell or feel things that does not exist (examples are LSD, magic mushrooms, ecstasy and cannabis).

Among psychoactive substances, **alcohol** is the most used by young people, showing higher values when compared to tobacco and illicit substances. However, it is noteworthy to make the distinction between abusing drugs and alcohol and being dependant on them. It is not so difficult to cross the line separating them, being extremely important that the progression into dependency is arrested before serious problems appear. Among alcohol users, 16.9% show an excessive consumption, 0.9% consumption of risk and 2.1% an alcohol dependency. Thus, contrarily to some drugs like cocaine or heroin, alcohol is not particularly addictive; however, alcohol abuse occurs in part of the population with significant consequences for themselves, their families and society as a whole. In this line of evidence, data show that the consumption of alcohol is responsible for 3.3 million deaths per year (5.9% of all deaths), as a result of road accidents, cardiovascular and gastrointestinal diseases, diabetes, cancer, traumas, foetal death, cirrhosis, etc.

After alcohol, **cannabis and amphetamines** are the most commonly used drugs. The tendency to adopt risky behaviours increases until adolescence, reaching its maximum exponent at this stage of life. Adolescence is a critical period associated with the beginning of substance experimentation/use and it is also a period with a high incidence of users. Although prevention programmes at school, substance abuse is still a reality.





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Concerning drug use, roughly 450.000 people died as a result of drug use in 2015, according to WHO. In the same year, at about 16.500 drug-related deaths were reported in Europe, where overdose deaths are attributable in most cases to cannabis and opioids.

The brain is one of the main targets of the action of alcohol and other psychoactive drugs. Research has been demonstrating that those drugs are neurotoxic, with direct effects on nerve cells. This aspect is particularly relevant for adolescents and young people where the development of the brain only reaches complete maturation around 25 years. The immaturity of the biological system enables it to degrading and/or eliminating alcohol and illicit drugs from the body, enhancing brain damage and neurocognitive deficits which impacts learning and reasoning, attention, decision making and memory.

Scientific evidence shows that the age of starting the use of drugs is a strong predictor of dependence and occurrence of problems associated to abuse through life. The average time to alcohol dependency is usually bigger than for illicit drugs like heroin and cocaine, and the drinker often cannot foresee it.

Unlike alcohol abuse and limits of safe drinking, it is unclear what constitutes drug abuse as opposed to drug addiction or dependency. The inconsistency in the drugs purity as well as the unknown formulae of the new drugs and combinations available, make unpredictable both the individual's tolerance as well as the effects of the consumption, with a high probability of dependency, and death.

2.2 BEHAVIOUR TO EXPECT

In **all dependencies** usually we can observe:

- Damage to relationships;
- Poor work performance;
- Bad health performance.

Those are a few of the signs of addictive behaviours. Besides the aggressive and violent behaviour expected from an alcoholic individual, one important problem related to alcohol abuse is the

- Sleep disorder.

Alcohol can disrupt the sequence and duration of sleep states. The consumer awakes from dreams and the returning to sleep is very difficult. Particularly related to this problem, the elderly are at increased risk because they achieve higher levels of alcohol in the blood and brain than do younger persons consuming an equivalent dose.





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Concerning drug abuse, frequent behaviour symptoms are:

- Increased aggression and irritability;
- Changes in attitude/personality;
- Sadness, lethargy, depression;
- Great changes in habits/priorities and even;
- Engagement in criminal acts.

When trying to discuss his/her dependencies one can expect several common explanations. An alcoholic individual would **“defend” his or her consumption** with. The first one would be negation. Usually one would state... “I am not dependent, I can be without alcohol and I can stop in any minute, alcohol is not a problem...”. Then, once accepting own alcoholism, there is frequently the “transfer of guilt”, where one could state... “Well, yes I am alcoholic, but it is because my wife does not understand me, my friends are not supportive, my boss does not value me...”, trying to avoid his/her own role in alcoholism.

Moreover, a dependent person could also try to “find a reason” for the consumption or relapse. It is frequent to hear about that “It happened because my wife has left me..., because my friend died..., because I cannot earn enough money...”. These are common pointed facts for the consumption of alcohol. For a caregiver, the most difficult defence to cope with is refusing of any help with an attitude like “I know I am alcoholic, but I like drinking and that is my life and I will drink...I do not care for the consequences...”. To cope properly with this attitude, the caregiver of the alcoholic or drug abuser needs to be really empowered. Thus, it is vital to search for help and support from professionals or self-help groups.

Special concern should be given to the fact that individuals should be very well informed about the **impact of stopping alcohol and other psychoactive substances use**. Some effects occur such as

- Increased levels of anxiety;
- Sleep disturbance.

It is important to know adaptive strategies – sleep habits, relaxation, and management of anxiety, to minimize the risk of developing dependence on other substances.

2.3 CONCERNS OF THE CAREGIVER ABOUT SUBSTANCE ABUSE

2.3.1 ROLE OF THE FAMILY IN CAREGIVING

Nowadays, health professionals have turned their eyes not only for patient, but also for the family as the central focus of care, since the family has a significant role in establishing and maintaining health. In this line of evidence, there is an inversion in the practice of care, where the family frequently assumes the main importance. In fact, family enrolment has a great influence in the effectiveness of





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treatment, where adherence or rejection to treatment, and consequently the recovery or worsening of the patient, will depend on their support.

Many programs exist where support is given to the individuals and/or their families. Some of these programs include community resources such as legal assistance, work, day care and parenting classes. Thus, it is believed that care directed to the family member is one of the possibilities for intervention, aiming at not only the well-being of the patient as well as the well-being of the family.

2.3.2 STIGMA

Alcohol abuse entails physical and psychic disorders, changing the behaviour and causing individual and social damages to the consumers. This is a condition with a high stigma (both personal and perceived) rate, when comparing with other health problems. For this reason, a special concern about this condition is the stereotype of dangerous and unpredictability, which creates greater social distancing. Family caregivers should be aware of this problem and try to deal with. But the stigma can be connected to maintenance of abstinence (*“what will my friends say when I am not drinking at least a bit...”*). That is additional reason for strong family support.

2.3.3 RELAPSE

In the context of relapse, it is still vital to help the individual identify prior relapse experiences and reflect on how they handle the situation, explore the individual's beliefs about their dependence on alcohol, beliefs about their ability to avoid relapses and to deal with lapses, strategies for dealing with high-risk situations, mood swings, and the presence of social and family support. Relapses occur due to several factors, namely:

- **Emotional states:** mood swings, stress, conflicts, social pressure, lack of motivation, excessive self-confidence in the ability to control alcohol consumption.
- **Social isolation and family factors:** interpersonal conflicts with friends, family, colleagues or bosses. Unemployment or job dissatisfaction.
- **Environment:** avoid attending consumption environments or places where the individual habitually consumed; avoid places where there is alcohol or substances of abuse;
- **Social context:** situations of social interaction that promote the consumption of alcohol (e.g. dinners, parties, etc.).

2.3.4 IMPLICATIONS OF SUBSTANCE/ALCOHOL ABUSE IN FAMILY DYNAMICS

- Family dynamics changes when one of the member is alcoholic. Usually the other adult need to take care for everyday life decisions. It is a burden but that can cause lot of disbalances when the member stop drinking and try to take over his/her previous family roles.





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- It is well known that substance abuse, essentially alcohol, is associated to behavioural disinhibition, impulsivity, lack of attention, aggression and conduct problems.
- Descendants of alcoholics presents a high risk of interpersonal and behavioural problems as well as psychiatric disorders. Moreover, it is well established that the children of alcoholics are at an increased risk of developing alcohol dependence (which can reach the quadruple risk).

2.3.5 ALCOHOL AND SUBSTANCE ABUSE BY CAREGIVERS

Among the 44 million family caregivers, almost half of them take more medication than they did before the caregiving role. Moreover, about 10% of family caregivers are thought to be substance abusers.

The main causes could be:

- Fear and anxiety about how well they are managing caregiving duties;
- Stress from too much responsibilities;
- Sadness and even clinical depression as a result of watching a person decline, who is taken care for (if this is the case);
- Pain caused by the physical demands of caregiving (i.e. back pain, neck pain);
- Isolation (care recipient who isn't safe staying alone);
- Resentment (towards siblings or other family members who don't help with caregiving);
- Anger at being placed in such a difficult position;
- Unhealthy (and long-standing) family dynamics.

2.4 WHAT CAN BE DONE

This section of the manual lists some recommendations to take into consideration in the care of consumers. However, prior to any approach, it should be ensured that each intervention is done according to the needs of the individual, and in a comprehensive manner; that is, to consider that the problem is multifactorial, with various forms of presentation that depend on the type of consumption, the characteristics of the subject and the social, motivational and behavioural factors.

2.4.1 FIND OUT WHAT'S CAUSING THE ABUSE

The individual is unlikely to tell you why he drinks, but you may be able to pick up clues by observing what he says and does. It could be that he is depressed, anxious, lonely, grieving... If you suspect an emotional issue, ask for help of a psychiatrist or experienced therapist to figure out how to help and support him.





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2.4.2 SEEK FOR PROFESSIONAL HELP

Here are some important recommendations when dealing with a problem of substance abuse:

- Ask doctors for advice;
- Call addiction organizations to undergo a program available;
- Get answers from experts and experienced caregivers.

2.4.3 HELP THE INDIVIDUAL INTEGRATE INTO SELF-HELP GROUPS

Self-help programs have existed for several years and may consist of a source of help on their own, or a form of support complementary to medical and / or psychological treatment.

For some people it may be important to be in a context where they can hear testimonials and indications from people who, like them, are experiencing difficulties associated with abusive substance use. One of the most well-known self-help programs worldwide is the **12 Step Program**. Individuals who attend this type of program have a better result compared to their consumption when compared with individuals who do not attend the program. Aspects that seem to contribute to this improvement are the literature readings of the 12 steps, working the steps and having a sponsor and/or becoming a godfather who guides the recovery process.

2.4.4 INCREASE THE INDIVIDUAL'S MOTIVATION FOR BEHAVIOUR CHANGE

This could be done by identifying/remembering the risks associated with consumption, the cost-benefit weighting associated with consumption (work area, family, social, etc.) and helping to manage ambivalence.

2.4.5 HELP REDUCE OR STOP CONSUMPTION

Through the integration of strengthening techniques; self-control training; help with goal setting and the organization of free times.

2.4.6 HELP THE INDIVIDUAL LOOK FOR OTHER SOURCES OF PLEASURE

Behavioural coping is thought to strongly help those individuals to look for other sources of pleasure. This strategy aims to focus on distracting activities and / or sources of pleasure, whether physical (e.g. physical exercise, leisure activities, walking) or mental (e.g. reading, writing), as well as on the consumption of non-alcoholic beverages, avoidance, and relaxation exercises, strengthen family ties...).





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2.4.7 PREVENTING DISCRIMINATION AND STIGMATIZATION

This could be done in the work of various professionals or sensitizing the community. Due to the stigmatization of the condition, is extremely important to encourage the search for help. Moreover, evidence reveal that the intention to seek help by these individuals is very low.

2.4.8 FACILITATE ACCESS TO OBJECTIVE INFORMATION

Information on the consequences of substances/alcohol consumption in their own lives; one important strategy is the cognitive coping, where individuals are encouraged to think about the benefits of not drinking in their health and other areas of life; use of thought to delay consumption or distract oneself.

2.4.9 HELPING THE INDIVIDUAL IN SOCIAL REINTEGRATION

Try to establish satisfactory relationships with others and with himself.

2.4.10 ADOPTION OF STRATEGIES THAT HELP THE INDIVIDUAL TO AVOID RELAPSES

It is extremely important to recognize that relapse is possible in unexpected situations.

- The possibility of relapse must be anticipated with the individual, as well as the strategies to be used in different situations.
- Remove all alcohol (or other substances) from the environment. Other substances containing alcohol like including cough syrup and other “innocent” sources should also be cleared out.
- Make sure all family and friends know not to buy or bring any alcohol (or other substances)
- Notify stores not to deliver alcohol. If necessary, restrict access to money that can be used to buy alcohol or other substances
- Substitute wine or beer by non-alcoholic drinks





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2.4.11 TAKE SAFETY MEASURES AND PROTECT YOURSELF

Due to aggressive/violent and unpredictable behaviour of the individual, it is vital to assure the security for both. Here are some tips:

- Prevent individual from driving by removing car keys, disabling the car, or moving the car away;
- Remove or lock away sharp objects and weapons to prevent injury;
- Secure doors or add door alarms to prevent accidents;
- Lock away cleaning supplies and other toxic liquids – they could be used as alternatives;
- Try to know your limits and make sure that the situation is safe. If the individual becomes overly aggressive or violent, it's time to seek professional help
- Identify support systems for yourself as the caregiver – therapy, counselling, or support groups for people who are close to an alcoholic or drug abuser.

Case Story

Paul is 41 years old and this is the fourth incident where Paul has been involved in the last two months. He was a very calm person, but he has been aggressive and reacts with anger for “small things”. Her wife has already caught him drinking whiskey during the morning.

Response:

- Try to identify the main cause of the situation (unemployment, problems at work, familiar issues, or other);
- Improve the motivation of Paul to solve the problem underlying the alcohol consumption;
- Maybe Paul does not like to feel he is being controlled – try to quietly perceive the behaviour of Paul concerning drinks, i.e., try to quantify the amount and frequency of alcohol intake;
- In a calm conversation, ask Paul if he realizes he has a drinking problem – he really needs to make a “self-evaluation” and confess/surrender the problem. This is essential for a commitment to recovery;
- Help Paul engaging healthy activities or pleasure activities based on his preferences (nature sports, table games, cycling, cinema, theatre, ... with children or best friends);
- Remove all alcoholic beverages from your home and/or replace them by non-alcoholic drinks;
- Inform family and friends about your strategy – they should be aware to help you dealing with the problem;
- Ask for professional help if you cannot counteract the situation or if you feel you are not able to deal properly with it;
- If the aggressive episodes persist, remove dangerous and or sharp objects.





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SCHIZOPHRENIA AND PSYCHOTIC DISORDERS





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3. SCHIZOPHRENIA AND OTHER PSYCHOTIC DISORDERS

Compiled by Department for Psychiatry and Psychological Medicine, Medical University Rijeka

3.1 WHAT ARE SCHIZOPHRENIA AND OTHER PSYCHOSES?

Psychoses are mental disorders characterised by difficulties in distinguish reality from unreal. Person can have sensations, feelings or thoughts that distort the view on what is going on around or within him/her. This can cause difficulties in management of emotions, relation to other people and normal functioning.

Some of psychotic disorders can be lifelong disabling disorders (schizophrenia, paranoid disorder, schizoaffective disorder) or can be an acute state from which person recovers without significant consequences (acute psychotic disorder).

We still do not know the exact cause of psychosis but we do know what has a role in occurrence of the illness – like having particular genes, traumatic experience especially in the earliest period of life, and damage of the brain that could happen any time during the life span. Probably, psychosis is caused by an interplay of various biological, psychological and societal factors. This results in impaired function of neurotransmitters, substances that carry impulses within the brain. One of them, dopamine, plays a special role in patients with schizophrenia. Number of studies have shown that an impairment of the function and the structure of brain tissue is responsible for the onset of psychosis.

3.1.1 SYMPTOMS OF PSYCHOTIC DISORDER:

<i>Hallucinations</i>	Hearing voices, seeing people or feeling strange sensations that are not real. Hallucinations are sensations that emerge without real external stimulus. Depending of sensory system there could be visual, auditory, aromatic, tasteful, and bodily. Usually, hallucinations are unpleasant experience.
<i>Delusions</i>	Having strange beliefs which cannot be remedied by arguments. This could be paranoid/persecutory ideas (somebody has something against the person), ideas of guilt or worthlessness, religious ideas, pathological jealousy, ideas of having some disease, ideas of grandiosity, etc.
<i>Unusual thinking or speech</i>	Way of thinking could be without logical structure for a bystander, speech sound confused and unclear, sometimes with new word constructs or saying the same words/sentences repeatedly. Often speech is monotone, and communication is usually short.





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<i>Problems in decision making</i>	Usually there is an ambivalence that makes all decisions difficult and that could happen with little everyday demands as well as with important life decisions. This can block most of the person's activities.
<i>Trouble interpreting other emotions or motives</i>	Schizophrenia patients have difficulty recognizing emotional states in other people or can misinterpret them under the influence of delusions.
<i>Suicidal thoughts</i>	Suicidal ideation and thoughts should be taken very seriously. Up to 15% of people with schizophrenia commit suicide.
<i>Loss of interest and enjoyment in things or activities</i>	They have a problem with motivation for the activities even such as everyday hygiene or daily routine.
<i>Problems with emotions</i>	There is a lack of expressiveness, lack of eye contacts. Expressed emotions could be paradoxical (laugh when situation is sad)
<i>Withdrawal from other people</i>	Persons seem not interested in the world and people around.
<i>Motor changes</i>	This could be numbness or agitation, strange mimics or postures.

Some authors divide psychotic symptoms in “positive” and “negative” ones. **Positive** are hallucinations and delusions, while withdrawal, ambivalence, loss of interest and emotional problems are **negative** symptoms.

Characteristics of particular psychotic disorder is the combination of symptoms. The most well-known, **schizophrenia**, is characterized by the presence of most of the negative symptoms and very frequent presence of the positive ones. Negative symptoms often remain unchanged even when other symptoms are withdrawn during treatment and recovery. **Paranoid psychosis** is characterized mainly by the presence of persecutory delusions that can be very "organized " and persistent to treatment.

Schizoaffective psychosis has, together with positive or negative symptoms, a more pronounced mood variations.

Acute psychotic conditions can have any of the combinations of symptoms that last a relatively short period of time, usually one month.

As schizophrenia is the most common and well-known psychotic disorder, we will focus on it further in the text.





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3.1.2 EARLY WARNING SIGNS OF SCHIZOPHRENIA

Schizophrenia can develop suddenly but more often the disease occurs gradually. The person begins to change in his/her behaviour which often becomes bizarre, begins to isolate him/herself, fails to perform daily or work responsibilities, can start to talk in a strange way or the content of speech can be strange. The environment often recognizes that something unusual is going on with the person. This condition can last for a long time before any positive symptoms occur. The most common **early signs** are:

- Deterioration of personal hygiene;
- Social withdrawal;
- Often depressed mood;
- Face without emotional expression;
- Irrational statements;
- Sleep disturbances;
- Inappropriate emotional expressions.

Schizophrenia most commonly occurs between the ages of 15 and 25, and both sexes are affected equally. It occurs in about 1% of the population everywhere in the world. Risk factors include lower socioeconomic status, lower education, family history of schizophrenia, stressful situations such as the loss of a loved one, violence in the family or the environment. Consumption of psychoactive agents can trigger a psychotic episode as well.

3.2 TREATMENT POSSIBILITIES

It is extremely important to start the treatment as soon as possible because any prolongation and repetition of psychotic episodes lead to additional gradual damage of brain tissue. Treatment of schizophrenia is a long-term process, often lifelong, but with the adequate treatment, people with schizophrenia can be fully functional and lead a rich life of a good quality.

As the causes of schizophrenia are biological and psychosocial, treatment that encompasses both biological and psychosocial methods is the best choice.

Most commonly, the biological method involves medication with antipsychotics which are mostly taken over a long period of time. Usually these are tablets, but the person with schizophrenia may also receive depot preparations, i.e. long-acting antipsychotics which are given once every two weeks, monthly or even every three months. Medicaments usually work on positive symptoms and are relatively ineffective with negative ones. In addition, antipsychotics can have serious side effects like involuntary movements, sedation, and weight gain and this sometimes is the reason behind patients' refusal to take them.





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The length of recommended medication intake for the first episode is at least two years. In the case of second episode the medication period is up to five years. Repeated psychotic episodes, three or more, need the lifelong medication and treatment.

Electroconvulsive therapy nowadays could be a treatment of choice in rare cases when symptoms are extremely severe, and the usual treatment is ineffective.

The results are better when combining medication with social support within psychosocial group treatments that offer social skills training, family therapy, individual therapy, vocational rehabilitation, and self-help groups.

Studies show that significant percentage of people with schizophrenia successfully recover when treated adequately.

3.3 CONCERNS ABOUT SCHIZOPHRENIA

3.3.1 STIGMATISATION OF SCHIZOPHRENIA

Schizophrenia is the mental disorder with the strongest stigmatizing potential. The stigma of schizophrenia is not only related to the patient but to his/her family as well. Stigma can make it much more difficult for the affected one to maintain social relationships and workplace and he/she remains constantly under the magnifier even when there are no significant symptoms.

There are numerous prejudices about schizophrenia that can be the cause of delaying or refusing treatment:

1. **Schizophrenia is a rare condition.** In fact, this is not true as even 1% of population suffers from schizophrenia.
2. **Schizophrenic patient is irresponsible, like a child.** This attitude is at the root of the view that somebody else should take care of everything instead of the ill individual. In fact, there is always a part of the activity that the affected person can take care of, even when a psychotic episode is in progress.
3. **People with schizophrenia are dangerous.** The fact is that sometimes delusions and hallucinations can lead to violent behaviour, but most of those with schizophrenia are not more violent than the common, unaffected people. In contrary, they are at risk for being the victim of violence or maltreatment.
4. **People with schizophrenia cannot be helped.** In fact, with adequate treatment up to 60% schizophrenic patients can live productive lives and have good quality of life.

3.3.2 IMPACT OF SCHIZOPHRENIA ON THE INDIVIDUAL

The onset of schizophrenia brings change in about every segment of the person's life. The disease significantly impairs his or her ability to participate in family and social life, daily activities, and





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diminishes work capacity. But we need to bear in mind that severity, scope of symptoms and expression of illness differ widely between people.

When the symptoms recede, the environment continues to look at him/her through the illness, which adds an additional burden to the already diminished social capacity. In addition, there is ongoing medication for which the affected one often sees no reason, and which may have unpleasant side effects.

Therefore, it requires a lot of additional strength from the one with schizophrenia to function normally.

A person with schizophrenia can have other mental health problems like depression, anxiety, substance abuse, and addiction, smoking in particular. The physical health is often compromised in those with schizophrenia as well.

3.3.3 IMPACT OF SCHIZOPHRENIA ON THE FAMILY

When a family member becomes ill with schizophrenia, it has a significant impact on the whole family. Ill member needs constant help, sometimes even with everyday things, often becomes ineffective at work and is not able to contribute to the family. He/she is often very sensitive to family relationships, but on the other hand, often withdraws from everyday family life. Family members have to find new ways of how to relate and communicate. Often, the inactivity of schizophrenic patients is taken as laziness, which can be an additional burden in communication.

Family members can have feeling of guilt for various reasons such as the feeling of not being a good enough parent/partner or not being able to tolerate symptoms.

The constant care, such as making sure the person who is taken care for, is taking the medication regularly and is going to group therapy, often becomes a daily routine for the caregiver who often takes responsibilities and makes all decisions for her/him.

In the case of reoccurrence of symptoms, sometimes it is the caretaker who has to persuade the individual to go to the psychiatrist or hospital and even needs to decide to take some difficult additional measures like contacting services, GPs or police without the permission of the affected family member.

3.4 BEHAVIOUR TO EXPECT

Persons with schizophrenia are likely to live occasionally or even most of their time in their own world without having the need to communicate with others. **Social isolation** is one of the main characteristics of the disease.





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It is often **difficult to motivate them** for simple activities such as maintaining hygiene habits. Some **are not inclined to take medication** or to report to a psychiatrist. In fact, they often feel that they do not need medication.

They are often very **stingy in verbal expression** and emotional expression can be the opposite of expected in the circumstances or inappropriate. They may **have unusual eating habits**.

It is of the utmost importance to recognize the **early signs of a recurrent psychotic episode** such as strong withdrawal, unusual speech or the expression of strange thoughts. It can be recognized if someone is **listening to voices or has visual hallucinations**.

The **sleep cycle** is usually the first to be disrupted in relapse of psychotic episode. Sometimes person can show the **signs of suicidality**, whether a person expresses suicidal thoughts (the life is not worth living, I have to break this life) or self-harm. People affected with schizophrenia in 15% of cases do commit suicide.

Many individuals with schizophrenia **rely on the emotional and practical help from family members** to overcome disorder and continue with their life.

Case Story

Martha was always withdrawn and had only two girlfriends during her school age. Upon graduation, she took a job as accountant. She was 26 years old when she first heard voices accusing her and she began to feel that people around her were starting to look weird to her and the police was preparing to arrest her. She was hospitalized for a month, after which she continued to take medication for some time.

But when she stopped taking the medication after a few months because she was feeling well, the symptoms recurred.

This time she was involved in socio-therapeutic groups and her parents were involved in family therapy during the hospitalization and afterwards in the outpatient setting.

Gradually the symptoms subsided and Martha began to take an active part in the group. She regularly and often talked about medication. She recovered and returned to work and continued to come to the group. At the workplace, colleagues were understanding of her occasional absences when she felt tired.

After a year and half, she went out on a date for the first time and once a month she met her friends for a coffee. During the family therapy, her parents learned not to control every minute of her life.

After medication taken orally, she continued with monthly injections, which no longer presented her a major problem.





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Response:

- In the early stages of illness it is difficult to recognise the “soft” symptoms of change in the behaviour. Withdrawal from peers could be the first sign but could be just a sign of an adolescent difficulties or temperament as well.
- So called positive symptoms like hallucinations or delusions are usually the signs that mobilise family members or friends. They can develop gradually or suddenly and usually call for hospitalisation and taking medication. In this period it is crucial to give support to the person in relaying to medication and outpatient programs.
- It is especially important to find a proper measure in support. Overprotection is always contra-productive.
- Combining medicaments and psychosocial programs are the treatment of choice for psychotic patients.
- Persons with schizophrenia can live a productive and fruitfully life when cured properly and with adequate support of caregivers, friends and colleagues.

3.5 WHAT CAN BE DONE?

The main thing a caretaker can provide is a **supportive environment**.

It is particularly important for both, the caregiver and the affected person, to **learn about the illness** and to understand what schizophrenia is.

Some of behavioural patterns, such as **keeping daily routine** in meals, going to sleep, and other routine activities, can be helpful. Predictability gives a sense of security for people with schizophrenia. **Supporting the person who is taken care of** should be without patronizing, it is important not to act as if he/she were a small child.

In communication it is important to be **clear and simple** and not to express negative emotions, criticism, angry reaction, disappointment, etc. Arguments with other family members need not be in front of the affected member. Their **need for peace** should be respected.

3.5.1 TIPS FOR CAREGIVERS REGARDING THE FAMILY MEMBER WITH SCHIZOPHRENIA

We can help our ill family member by:

- Empowering him/her through emphasizing things in which they are successful;
- Learning about the disease;
- Learning how to identify early signs of illness;
- Helping with regular visits to the doctor and engaging in psychosocial therapy programs;
- Helping in choosing a trusted person;
- Motivating to engage in activities he/she enjoys, especially one-on-one activities;





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- Providing additional support, especially after psychotic relapses and hospital treatment;
- Engaging in physical activities such as exercise or walking, taking care of regular sleep, eating healthy, and avoiding taking psychoactive agents, including nicotine and alcohol.

What does not help is constantly reminding him/her to take the medicine! It is better to turn what can be experienced as nagging into a daily routine.

In the case of reoccurring symptoms of psychosis, it is important

- Do not try to convince the person who is taken care for, that his or her delusions are not realistic,
- Do not shout or express anger,
- Do not touch them or seek eye contact. It should be remembered that your family member can be very upset and frightened by what they are going through. It can help to calmly invite the person to sit and rest.
- Reduce the noise and light in a room with as few people as possible nearby because this has a calming effect.
- In a **case of suicidal thoughts or self-harm** it is important to refer to the psychiatrist or emergency services as soon as possible .

3.5.2 TIPS FOR CAREGIVER REGARDING HER/HIMSELF

1. Take care of your basic needs.
2. Learning about schizophrenia will allow understanding of illness and make the care for the ill person easier.
3. Ask other family members and friends for assistance so you can take a break.
4. Give some responsibilities even to the ill member of family.
5. Set boundaries and be realistic about what you're capable of giving.
6. Manage your own stress.
7. Accept (and expect) mixed feelings.
8. Be aware that sometimes family cannot provide the adequate help, and if the person who is taken care for cannot take care of him/herself or the family relations are so damaged, **foster home** would become the best solution for both, the affected member and the family.

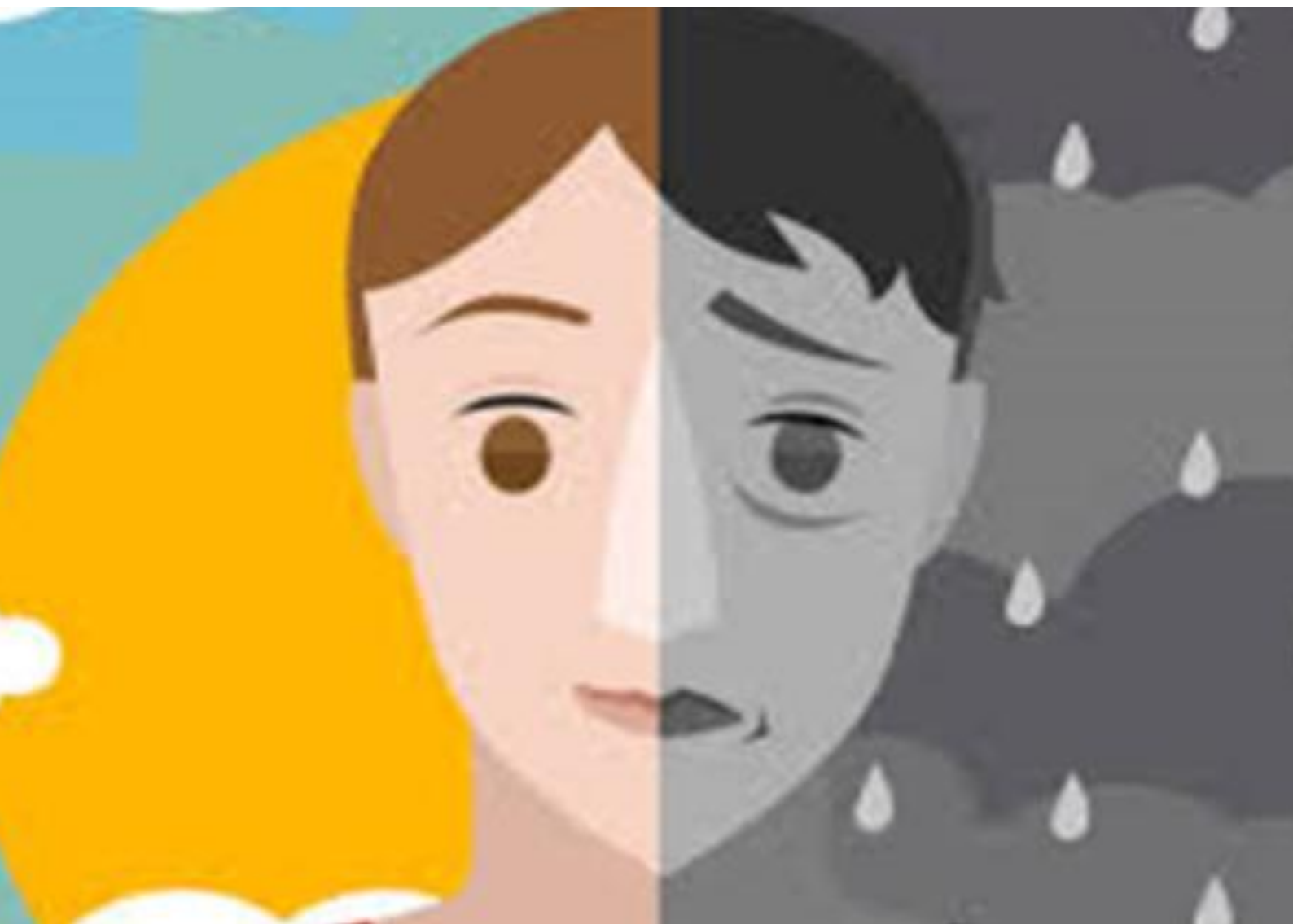




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COMMON MOOD DISORDER





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4. COMMON MOOD DISORDER

Compiled by Department for Psychiatry and Psychological Medicine, Medical University Rijeka

4.1 WHAT ARE MOOD DISORDERS?

4.1.1 DEPRESSION

The total number of people living with depression in the world is 322 million and the proportion of the global population with depression in 2015 was estimated to be 4.4%. Depression is the most common mental illness and according to the World Health Organization, will be one of the biggest health problems worldwide by the year 2020. Globally, depressive disorders are ranked as the single largest contributor to non-fatal health loss. It is more common among females (5.1%) than males (3.6%). Rates vary by age, peaking in older adulthood (above 7.5% among females aged 55-74 years, and above 5.5% among males). Depression also occurs in children and adolescents below the age of 15 years, but at a lower level than older age groups.

Depression results from a complex interaction of social, psychological and biological factors. People who have gone through adverse life events (unemployment, bereavement, psychological trauma) are more likely to develop depression. Depression can, in turn, lead to more stress and dysfunction and worsen the affected person's life situation and depression itself. There are interrelationships between depression and physical health. For example, cardiovascular disease can lead to depression and vice versa.

Everyone could experience feelings of sadness, grief, hopelessness or being in low spirits at times, usually as a response to a perceived loss. Mental illness is present when these feelings become so disturbing and overwhelming that people have great difficulty coping with day-to-day activities, such as work, enjoying leisure time, and maintaining relationships. Depressive disorders are characterized by sadness, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, feelings of tiredness, and poor concentration. Depression can be long-lasting or recurrent, substantially impairing an individual's ability to function at work or school or cope with daily life. At its most severe, depression can lead to suicide. Close to 800 000 people die due to suicide every year. Suicide is the second leading cause of death in 15-29-year-olds.

Depressive disorders include two main sub-categories:

Major depressive disorder / depressive episode, which involves symptoms such as depressed mood, loss of interest and enjoyment, and decreased energy; depending on the number and severity of symptoms, a depressive episode can be categorized as mild, moderate, or severe; and





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Dysthymia, a persistent or chronic form of mild depression; the symptoms of dysthymia are similar to depressive episode, but tend to be less intense and last longer.

A further important distinction concerns depression in people with or without a history of manic episodes.

Prevention programs have been shown to reduce depression. Effective community approaches to prevent depression include school-based programs to enhance a pattern of positive thinking in children and adolescents. Interventions for parents of children with behavioural problems may reduce parental depressive symptoms and improve outcomes for their children. Exercise programs for the elderly can also be effective in depression prevention.

There are effective treatments for depression. Health-care providers may offer psychological treatments and medication. Psychosocial treatments are effective for mild depression. Antidepressants can be an effective form of treatment for moderate depression but are not the first line of treatment for cases of mild depression. Medications are indicated in severe depression and bipolar affective disorder. Health-care providers should keep in mind the possible adverse effects associated with medication.

4.1.2 BIPOLAR AFFECTIVE DISORDER

Engendering both manic and depressive episodes, and featuring moments of “normal” or stabilized mood, bipolar affective disorder this illness impacts approximately 60 million people worldwide.

Manic episodes can involve elevated or irritable mood, hyperactivity, inflated self-esteem and a lack of desire to sleep. Hypomania is a less severe form of mania. Depressive episodes are often characterized by feelings of extreme sadness, hopelessness, little energy, and trouble sleeping.

A mixture of genetic, neurochemical, and environmental factors can play a role in the cause and progression of the illness, which can be treated through medications which are absolutely indicated and psychosocial support. The Bipolar spectrum includes the following sub-categories:

Bipolar I: The individual has had at least one manic episode that lasted 7 days or longer or was severe enough to result in hospitalization. The manic episode may precede or follow a major depressive episode.

Bipolar II: The person has less severe symptoms of mania, called hypomania, that last at least 4 days and are present most of the day, nearly every day. The hypomanic episode may precede or follow a major depressive episode.

Cyclothymic disorder: This form of the disorder involves periods of hypomania with shifts to periods of depression, none of which are severe enough to meet the diagnostic criteria for a hypomanic episode or a major depressive episode.





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Mood disorders cause a great deal of suffering not only to those experiencing them, but also to their families and friends.

4.2 BEHAVIOUR TO EXPECT

4.2.1 BEHAVIOUR TO EXPECT WHEN PERSON IS DEPRESSED

<i>Symptoms</i>	<i>Behaviour</i>
Depressed mood	<ul style="list-style-type: none"> • Static, non-expressive face, downcast eyes; • Head usually pointed downwards; • Shoulders probably not stretched backwards; • Curved back most of the time; • Bad posture; • Legs usually banded, might not stand on two legs in the same time; • Closed body language: Crossed arms and legs. <p>Notice: A person could also look like anyone else or even look “happy” in “smiling depression” – appearing happy to others while internally suffering depressive symptoms.</p>
Markedly diminished interest of pleasure in all	<ul style="list-style-type: none"> • Giving up on taking care of hygiene and grooming: stop putting makeup on and wearing good clothes, unwashed hair, unkempt clothes; • Not having sex and sexual activities, neglecting the sexual partner; • Diminished interest for work and achievements (sick leave or quitting job); • Missing and omitting leisure activities, family gatherings, birthdays, wellness activities;
Fatigue or loss of energy	<ul style="list-style-type: none"> • Lying in bed instead of sitting and tending to lie in bed more often; • Speaking without energy, slowly, pausing a lot while talking; • Spending more time in sedentary, solitary activities; • Frequent breaks while performing activities or inability to finish activities because of the fatigue.
Significant change in appetite or weight (weight gain or loss)	<ul style="list-style-type: none"> • Not engaging in joint meals with family or friends; • Skipping the meals; • Lack of clothing due to weight loss or gain; • Lack of energy.





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Sleep problems (sleeping too much or too little)	<ul style="list-style-type: none"> • Insomnia: habitual sleeplessness; inability to fall asleep or stay asleep at night, resulting in unrefreshing or non-restorative sleep; • Drinking coffee, smoking, eating, drinking during nights; • Excessive daytime sleepiness; • Hypersomnia: prolonged sleep periods that are not restorative or refreshing.
Slowing down or restlessness/agitation	<ul style="list-style-type: none"> • Moving less frequently; • Slowing overall movement of the body and feet, walking as dragging the feet; • Unable to rest or relax, i.e. not being able to sit still with constant moving or fidgeting.
Problems with concentration, beliefs of worthlessness, excessive guilt and indecisiveness	<ul style="list-style-type: none"> • Not paying attention during talk; • Difficulties during reading or inability to read; • Seeming absent during activities ("blanking" or "zoning out", "brain fog"); • Avoiding deciding and struggling between choices; • Being on "automatic pilot"; • Forgetting appointments or tasks; • Excessive worrying.
Suicidal thoughts and acts	<ul style="list-style-type: none"> • Sudden calmness after a period of depression or moodiness; • Choosing to be alone and avoiding friends or social activities; • Dangerous or self-harmful behaviour: reckless driving, engaging in unsafe sex, and increased use of drugs and/or alcohol; • Recent major life crisis such as death of a loved one or pet, divorce or break-up of a relationship, diagnosis of a major illness, loss of a job, or serious financial problems might trigger a suicide attempt; • Making preparations: visiting friends and family members, giving away personal possessions, making a will, and cleaning up his or her room or home, writing a note before committing suicide; • Threatening suicide should be taken seriously.
Multiple persistent physical symptoms with no clear cause	<ul style="list-style-type: none"> • Complain of recurring aches and pains, hence the popular saying 'depression hurts'; • E.g. gastrointestinal upset such as nausea, abdominal pain, or even diarrhoea.





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4.2.2 BEHAVIOUR TO EXPECT WHEN PERSON IS MANIC

<i>Symptoms</i>	<i>Behaviour</i>
Euphoric, elevated, expansive mood Irritable mood Anger	<ul style="list-style-type: none"> • Mania can look like happiness or rage; • Excessively friendly behaviour; • Individuals believing themselves to be in a "creative cycle"; • Behaviour seems exaggerated and extreme; • Exaggerated sense of importance may result in a sudden, angry outburst; • Disinhibited or recklessly impulsive behaviour; • Interpersonal confrontations.
Increased interest or pleasure	<ul style="list-style-type: none"> • Exaggerated grooming: dressing outlandishly or standing out in a way that is inappropriate; • Engaging in multiple tasks at one time; • Excessive involvement in activities that have a high potential for painful consequences i.e. engaging in unrestrained buying sprees, sexual indiscretions, foolish business investments etc.
Problems with concentration, beliefs, sense of self	<ul style="list-style-type: none"> • Inflated self-esteem or grandiosity; • More talkative than usual or pressure to keep talking; • Flight of ideas or subjective experience that thoughts are racing; • attention too easily drawn to unimportant or irrelevant external stimuli.
Significant change in appetite and sleep habits	<ul style="list-style-type: none"> • Decreased need for sleep (e.g., feels rested after only three hours of sleep); • poor appetite and weight loss or increased or inappropriate appetite.
Restlessness / agitation	<ul style="list-style-type: none"> • Excessive involvement in pleasurable activities; • Moving more frequently; • Speeding overall movement of the body and feet; • Unable to rest or relax i.e. not being able to sit still with constant moving or fidgeting.

4.3 CONCERNS OF THE FAMILY CAREGIVER

4.3.1 HOW DOES FAMILY AFFECT DEPRESSION?

Family caregivers are integral to the health and wellbeing of their families. Medical professionals often remark on how helpful family members and friends can be in reporting changes in patients'





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symptoms and ensuring that patients consistently follow their treatment plan. A family caregiver support and empower depressed family members, often times helping them manage the day-to-day struggles they may face as a result of their mood disorder, and ultimately helping them to find the treatment they need to get well. It is important to learn as much as it is possible about the mood disorder. By doing it, family caregiver will be able to help them access resources and the support they need.

A person with a relative who suffers from depression is almost five times as likely to develop it. Research has explored the possibility of a connection between genes and depression. The other family factors are even more important. A person who grows up with someone with depression may be more susceptible to the disease. A child who watches a depressed parent or sibling may learn to mimic that person's behaviour under certain conditions. A child who sees a parent spend days in bed may not think it unusual. There are types of families that increase a risk for depression. A perfectionist family for example, is characterized by demanding the most out of everyone. These families don't accept that failure is an inevitable part of life. There's a big difference between a family that causes depression, and demanding parents who want a good future for their children and care most about how hard they try. Depression in this kind of family results because of the immense stress of believing that if the family member is not perfect the world will come crumbling down on him. Those families are sabotaging their family members. The negative message they receive is they're not good for anything. Violent families are united by a strong bond. When you look more closely, you'll realize that there's not just one victim. They all act as though they're in a battlefield.

The person who is depressed may feel guilty about the demands his or her illness makes on the family.

4.3.2 HOW DOES FAMILY AFFECT BIPOLAR DISORDER?

Many studies of bipolar patients and their relatives have shown that bipolar disorder sometimes runs in families. Perhaps the most convincing data come from twin studies. In studies of identical twins, scientists report that if one identical twin has bipolar disorder, the other twin has about 40% to 70% chance of developing bipolar disorder. The lifetime risk in first-degree relatives is 5–10%; around seven times higher than the general population risk. Along with a genetic link to bipolar disorder, research shows that children of bipolar parents are often surrounded by significant environmental stressors such as childhood maltreatment, substance misuse, living with a parent who has a tendency toward mood swings, alcohol or substance abuse, financial and sexual indiscretions, and hospitalizations.

4.3.3 HOW DOES DEPRESSION AFFECT THE FAMILY?

How a family responds to depression varies based on the age and developmental stage of the ill individual, the strength and coping mechanisms of the family, and the family life-cycle stage. There





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are many different ways that depression can affect a family. When one person becomes emotionally fragile those around him/her learn the “rules” to keep things “normal.” Whenever certain subjects or activities become “off limits” they become life rules people must follow to stay in good relationship. Children can become caregivers or emotional supporters, spouses can become parents, and friendships can become one-way relationships when depression dominates our life. Allowing these role reversals to become long-term is what accounts for the “special rules”. Family members become less able to prepare for future events and implement reliable patterns for managing basic life tasks and interests since the state of depressed family member become the top priority and final arbiter of schedules and decisions. The quickest way to control and make sense of something emotional is to take responsibility for it (whether it is accurate or healthy or not). The family members may experience sorrow and guilt and it can be awkward or guilt-provoking when depression has this kind of influence on others. Unfortunately, there is still a social stigma associated with depression. It can make other’s knowledge of what you’re experiencing feel like a secret. Secrets create a sense of separation and, with that separation, shame. Depression generates many God-questions and may generate spiritual crisis in the family.

4.3.4 HOW DOES BIPOLAR AFFECTIVE DISORDER AFFECT THE FAMILY?

Where mood swings are mild, the family will experience many forms of distress but, over time, may adapt well enough to the demands of the illness. If episodes are more severe, the symptoms can be related to an individual's aggression or inability to fulfil responsibilities. The family members may experience anger if they see the individual as malingering or manipulative. Anger can also be directed at the "helping" professionals who are unsuccessful in curing the illness "once and for all". Anger may be directed at other family members, friends or God. Family members often feel exhausted because of the time and energy spent on issues related to the illness. Siblings may experience jealousy if too much attention is devoted to the ill member and not enough to themselves. In general, the emotional welfare of all family members is at risk because of the ongoing stress.

In severe cases of manic-depressive illness, families typically find that their social network starts shrinking. The family is often embarrassed by the varied symptoms of an ill relative whether these symptoms have to do with poor self-care skills or belligerent behaviour. Visitors may feel awkward about what to say or how to help the family. Whether the shrinking of social outlets happens from within or without, the family still needs a social network. Support groups made up of others whose family member is similarly affected can help tremendously.

Regardless of which family member is ill, role relationships often shift in response to the illness. Taking care of the family member with bipolar disorder may mean that there is little time, money or energy left to spend on outside relationships and activities. This can put everyone on edge. Marital stresses may increase, sibling rivalries may become more of an issue and even shifting of roles among members may take place. The rest of the family will need to become educated about the disorder to keep expectations reality-based.





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4.3.5 DOES DEPRESSION INCREASES THE RISK FOR SUICIDE?

The majority of suicide cases are linked with mental disorders, and most of them are triggered by severe depression. Warning signs that someone with depression may be considering suicide include: making final arrangements, such as giving away possessions, making a will or saying goodbye to friends, talking about death or suicide – this may be a direct statement, such as "I wish I was dead", but often depressed people will talk about the subject indirectly, using phrases like "I think dead people must be happier than us" or "Wouldn't it be nice to go to sleep and never wake up", self-harm, such as cutting their arms or legs, or burning themselves with cigarettes, a sudden lifting of mood, which could mean that a person has decided to attempt suicide and feels better because of this decision.

4.3.6 DOES BIPOLAR AFFECTIVE DISORDER INCREASE THE RISK FOR SUICIDE?

People with bipolar disorder are at great risk for suicide if they are not getting treatment and it is a leading cause of death in patients with bipolar disorder. Risk factors for suicide include younger age of onset of the illness, history of past suicidal behaviour, family history of suicide acts, comorbid borderline personality disorder and substance use disorders, and hopelessness. The warning signs calling for immediate action include the patients threatening to harm themselves, or looking for ways to kill themselves (seeking access to pills or weapons), or the patient talking or writing about death and all already mentioned warning signs in the previous paragraph.

4.3.7 SHOULD DEPRESSED PERSON SEEK PROFESSIONAL HELP?

Untreated depression can be extremely debilitating to an individual, interfering with every part of life. In addition, severe depression can potentially lead to suicide if it does not receive immediate attention. Current evidence suggests that someone who has had one episode of depression has increased risk for another and with each additional episode, this risk is higher. The family should encourage depressed member to seek treatment. If family member is facing treatment challenges, the person needs support and patience more than ever. Education can help both find out all the options that are available and decide whether a second opinion is needed. Depressed member should be supported to take medication as prescribed, and not to assume the person isn't following the treatment plan just because they aren't feeling 100% better. Treatments such as psychotherapy and support groups help people deal with major changes in life. Several short-term (12-20 weeks) "talk" therapies have proven useful. One method helps patients recognize and change negative thinking patterns that led to the depression. Another approach focuses on improving a patient's relationships with people as a way to reduce depression and feelings of despair. Antidepressant drugs can also help. These medications can improve mood, sleep, appetite and concentration. There are several types of antidepressant drugs available. Drug therapies often take time before there are real signs of progress. It is important to keep taking medication until it has a chance to work. After feeling better, it is important to continue the medication for at least four to nine months to prevent a





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recurrence of the depression and never stop taking an antidepressant without consulting the doctor. Antidepressant drugs can have side effects, but they are usually temporary. If side effects persist and are troublesome the doctor should be contacted.

4.3.8 SHOULD PERSON WITH BIPOLAR AFFECTIVE DISORDER SEEK PROFESSIONAL HELP?

Bipolar affective disorder is a chronic mental health condition. The changing moods associated with bipolar disorder can become very disruptive and debilitating and usually requires a long-term treatment plan involving medication as well as psychological treatment and lifestyle approaches. Treatment includes mood stabilizer medications, i.e. so-called second-generation antipsychotics, medication to alleviate anxiety and insomnia, as well as with antidepressants during depressive episodes. It may take time to find the right medication for bipolar affective disorder but, at its best, the medication effectively prevents or alleviates depressive or manic episodes. Sometimes the best medication is a combination of several drugs. In order for the treatment to be successful, it is imperative to take the medication according to the instructions. Many people who have bipolar disorder have been able to seek help and live active, fulfilling lives.

Case Story

Vedrana was married to an engineer and had a new-born child. She could not take care about the baby and was overwhelmed by guilt weeping all day long. She had no energy and everything was in slow motion. She almost completely stopped taking food and slept irregularly. Her husband found it hard to believe that someone like her who has such great life and family has problems with depression. He was full of disbelief, fear, and even anger when she resisted to snap out of it.

Response:

- Vedrana's husband decided to learn about depression and realized it is difficult to find material which is user-friendly, easy-to-read and focused to the needs of the family member and caregiver.
- He decided to listen to Vedrana to understand how she feels avoiding critics, blame and judgments. He understood the importance of communication with Vedrana as communication is a key of support.
- He caught the message it is important to get professional help, to understand there is no quick solution and decided to go along with Vedrana to the psychiatrist.
- He informed other family members about the situation and asked them to help his wife practically and support them all during the difficult times.





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4.4 RECOMMENDATIONS FOR CAREGIVERS

4.4.1 TIPS FOR CAREGIVERS REGARDING FAMILY MEMBER WITH MOOD DISORDER

- Educate yourself about mood disorder.
- **Try to keep in touch.** Try to talk not necessarily about how she or he feels. Just talking about everyday things without pressure can make a big difference to how someone feels.
- **Be willing to listen** to the family member will make her/him to feel less alone and isolated. Try to understand how she or he feels. Just listening and being understanding can be a powerful healing tool.
- **Don't be critical.** When the person wants to talk, listen carefully, but avoid giving advice or opinions or making judgments. Try not to blame them or put too much pressure on them to get better straight away. Give positive reinforcement. People with mood disorder may judge themselves harshly and find fault with everything they do.
- **Be understanding** Let your friend or family member know that you're there if they need a sympathetic ear, encouragement, or assistance with treatment. People with mood disorder are often reluctant to seek help because they don't want to feel like a burden to others, so remind the person that you care and that you'll do whatever you can to help.
- **Help create a low-stress environment.** Creating a regular routine may help a person with depression feel more in control. Offer to make a schedule for meals, medication, physical activity and sleep, and help organize household chores. Give suggestions about specific tasks you'd be willing to do, or ask if there is a particular task that you could take on.
- **Support them to get help.** Explain that treatment is not personality-altering and can greatly help to relieve symptoms. It's important to reassure your depressed family member that it's OK to ask for help, and that there is help out there.
- **Help them to adhere to treatment.** Help them prepare for mental health care provider appointments by putting together a list of questions. Offer to go along to health care appointments and to attend family therapy sessions. Help them stick with the prescribed treatment plan. Help them keep records of symptoms, treatment, progress, and setbacks.
- **Show patience.** Getting better takes time, even when a person is committed to treatment. Don't expect a quick recovery or a permanent cure. Be patient with the pace of recovery and prepare for setbacks and challenges. Managing mood disorder can be a lifelong process.
- **Stay alert for warning signs of suicide.** If your family member is severely ill, prepare yourself for the possibility that at some point he or she may feel suicidal. Take all signs of suicidal behaviour seriously and act immediately. Contact a doctor, a hospital or emergency medical services for help. Let other family members or close friends know what's going on. Remove all available means of attempting suicide (medication, sharp objects and poisonous household chemicals).





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4.4.2 TIPS FOR CAREGIVERS REGARDING THEMSELVES

- **Keep a balance.** Being afraid to upset someone because they might get depressed or angry will not reduce negative behaviour, and will enable them to act in ways that are unacceptable in society and will only cause them hardship later in life. Setting boundaries is necessary for the safety of the individual and the family. Thoughts and feelings of the caregiver are of equal importance;
- **Take care of yourself.** Mental health of the caregiver is important too, and looking after someone else could put a strain on caregiver's wellbeing. Follow a healthy life style to reduce stress and maintain wellbeing (e.g., regular meals, exercise, meditation...);
- **Avoid unhealthy lifestyle** that include malnutrition, unhealthy diet, smoking, alcohol consuming, drug abuse, stress and so on;
- **Ask for and accept help from friends and family.** Developing a strong network for social and emotional support (e.g., support group, spiritual group) Holding family meetings to discuss ongoing issues and plan changes. Confiding in people you trust, but being aware that some people will not be supportive because they are uncomfortable or ill-informed about mood disorders (e.g., they might say something like "just tell him to look at the good things in life);
- **Locate helpful organizations.** A number of organizations offer support groups, counselling and other resources for depression.





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INTELLECTUAL DISABILITY





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5 INTELLECTUAL DISABILITY

Compiled by Health Promotion Research Centre at the National University of Ireland

5.1 WHAT IS INTELLECTUAL DISABILITY

When a person has an intellectual disability, this means that they have a reduced capacity to learn and apply new skills. They may have difficulty understanding new or complex information and so may require extra help with learning new things. Young children with intellectual disability may experience delays in development- learning to sit-up, crawl or walk for example. Some people with intellectual disability may have problems with communication and developing and maintaining relationships with other people. People with intellectual disability may also have problems interacting with their environment- this is known as social or adaptive functioning.

Adaptive functioning usually encompasses three key skill sets:

Conceptual: affecting reading, problem solving and abstract reasoning. For example, using numbers, telling the time, using money and communicating with others.

Social skills: affect how a person understands and follows social norms and rules. For example, dressing appropriately for special occasions, sensing when someone might not be telling the truth and/or understanding and obeying laws.

Practical life skills: affect a person's ability to engage in basic self-care and hygiene. For example, to manage and clean oneself, to use transportation, to take medication and to complete housework.

Impaired adaptive functioning means people with intellectual disability may find it difficult to cope with some aspects of life, such as work and education, and caring for themselves. This may include, for instance, many of the day-to-day tasks that are necessary for most people- looking after one's personal hygiene, cooking, cleaning and doing the grocery shopping. With the right supports however, there is no reason why a person with an intellectual disability cannot actively be included and participate in society.

Intellectual disabilities are usually present from childhood and will likely last throughout a person's life. There are different types of intellectual disabilities and the severity of intellectual disability conditions can range from mild to profound. The difficulties that someone may face will depend on the type and severity of their condition and the level of support they receive.

5.2 WHAT BEHAVIOURS ARE TYPICAL OF PEOPLE WITH ID

Given that the term intellectual disability can refer to a broad range of conditions, behaviours may vary from individual to individual. However, given how intellectual disability often affects a person's





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adaptive functioning, there are some common behavioural traits that many people with intellectual disability exhibit. These include impulse control difficulties, challenges in controlling or regulating emotions, low tolerance for frustration, low self-esteem, and anti-social tendencies.

Thinking about the adaptive functioning skills mentioned earlier, it can be imagined how having limited capacity with those skills may impact on a person's behaviour. For example:

Given that children with intellectual disability often have difficulties with abstract reasoning, this can affect how they understand cause and effect processes. Whereas a child that does not have will quickly learn that touching a hot stove will burn them and thus will avoid doing this in future, a child with intellectual disability will may not make the connection between the burnt hand and the hot stove as easily. This can affect future impulse control.

A lowered capacity for understanding and following social rules might mean a child with intellectual disability would have problems with the concept of turn-taking whilst playing with other children or waiting in line at a bus-stop or in a queue.

Some people may exhibit what are known as 'challenging behaviours.' These can include aggressive or violent behaviours that can cause injury to themselves or others, and anti-social behaviours such as stealing. These behaviours can cause a good deal of distress to parents and caregivers and can create significant challenges for service providers.

It is difficult to say how many children with exhibit these behaviours, but studies suggest between 10% and 40% may engage in challenging behaviours. Children with severe intellectual disabilities are more likely to be affected. Children with additional psychosocial or sensory impairment conditions- such as ADHD, autism, or mood disorders- are also more likely to be affected by challenging behaviours. Additionally, the problem can be compounded by lower levels of support and access to services.

5.3 CONCERNS OF THE CAREGIVER

The majority of people with intellectual disability are cared for by a family member – usually a parent, but sometimes a sibling – at home. Caregivers are more likely to be a female relative than a male relative- although this is not always the case. Depending on the intensity of the care needs, and on whether there are other health issues (also known as co-morbidities), this can sometimes be a full-time, or almost full-time, job. In addition, many caregivers may be what is known as 'compound' caregivers. This means that in addition to the person with intellectual disability, they may have care duties towards others- other siblings for example, or an elderly parent.

Being a caregiver can be challenging and can sometimes result in a more stressful home environment for both parents and other siblings. It is natural for caregivers to worry for a person who is taken care for, particularly as they get older.





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Common concerns of caregivers may include:

The health and well-being of the person who is taken care for.

People with intellectual disability are often disproportionately affected by certain health conditions and may require a higher level of medical attention and care than other children. Managing things like medications and doctor, physiotherapist or occupational therapy appointments requires planning and organisation. Planning ahead and having a system to do this efficiently may help reduce caregiver stress. Being informed can be empowering- asking questions of the physician and other healthcare professionals, and seeking out information about the condition of a person who is taken care for, will also help with care-planning and dealing with the day-to-day concerns related to caring for the individual with intellectual disability. Keeping careful records and documenting the medical history of the person is also helpful.

The safety of the individual:

Caregivers may be concerned about the safety of the individual, particularly where there is a tendency towards challenging behaviours. Furthermore, people with intellectual disability – particularly those that live in residential care facilities or attend day services – may be vulnerable to violence and abuse by others. Being aware of safe-guarding procedures and protocols of any care facility is important for caregivers. Recognising the signs of abuse or violence is also important. If the person with intellectual disability has problems communicating verbally, caregivers should watch out for changes in behaviour, unexplained bruises or injuries and other indications of distress.

Social inclusion:

With the right supports, people with intellectual disability can live full and happy lives. Seeking out services and organisations that facilitate sporting, cultural and recreational activities for them can increase their participation in the community and improve their overall health and well-being. Getting involved with the Special Olympics, for example, may be an activity that the whole family can get involved with. In addition, this can provide an outlet for caregivers to meet with other caregivers, share experiences and increase their own social support network.

Self-care:

It is important for caregivers to look after their own physical and mental health. Taking time out to spend time with other family and friends or to exercise and relax is necessary to avoid burn-out and fatigue. Having a strong support network is essential so that care giving duties may occasionally be delegated to other family members or trusted friends. Research has shown that caregivers who have strong social supports are healthier, happier, and more resilient than those with lower social supports. Seeking out information about what supports and/or respite services may be available is also a good idea. Respite care refers to short term care services that give families a break from the day-to-day duties of caring for a loved one with disabilities.





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5.4 STRATEGIES FOR THE PATIENT/EXERCISES FOR THE CAREGIVER

As the needs of people with intellectual disability will vary from individual to individual and condition to condition, there is no one-size-fits-all approach to developing strategies to help the person. Nevertheless, there are certain steps that caregivers can take in assessing the needs of a person who is taken care for and deciding how best to care for and support them.

5.4.1 ADOPTING A PERSON-CENTRED APPROACH

A person centred approach means that those involved in caring for an individual take into account the specific needs, wants and preferences of the individual when developing a person centred care plan for them. The aim of a person centred approach is to empower the person to be involved in decisions that affect their lives. There is some evidence to suggest that person centred approaches can help improve relationships and social interactions, increase independence and improve overall quality of life for people with intellectual disability.

Caregivers can support the person who is taken care for to engage with healthcare practitioners to develop a person centred plan that is tailored to their individual needs, preferences and abilities. This plan should reflect what is important to them, set realistic goals and objectives and put in place a means of measuring progress. It should also involve input from the caregiver and other family members. Person centred care plans should further take into account what is achievable given the resources and services that are available to the individual.

Case Story

Michelle is 42 years old and living with a learning disability. Michelle wants to make friends and engage in social activities outside of her home. However the last few times Michelle has tried to talk to people she meets they have ignored her or spoken to her caregivers. This has caused Michelle to feel upset and lately she has been refusing to leave her home. Michelle's caregivers are concerned that she is becoming isolated and has little opportunity to use and develop her social skills.

Response:

- Familiarity at places in the local community can increase the likelihood of making friends. Encourage and support Michelle to go for a coffee at the local coffee shop or walk to the local park. Many people visit these places everyday so it is a great way to meet people;
- Support Michelle to become more independent and visit places without you her caregivers (if possible). Explore local bus routes with Michelle for a couple of occasions and then support Michelle to get the bus by herself. Having a charged mobile phone and a personal safety alarm can enable both caregivers and individuals to feel more confident while out in the community;
- Source clubs and groups in the local community relating to things Michelle is interested in for example: drama groups, basketball clubs or book clubs;





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- Support Michelle to find volunteer opportunities locally.
- The caregiver can network with other caregivers (online, at service providers etc) to arrange to meet and engage in activities together as a group;
- Explore employment opportunities for the person in your local community. Both mainstream and supported employment opportunities would provide Michelle with additional social opportunities.

5.4.2 ROUTINES

If possible, it is helpful to have consistent routines. Having a structured routine can help many people with intellectual disability know what to expect and when to expect it. This can help reduce anxiety and assist with reducing challenging behaviours. Additionally this can help increase a person's independence, as once they adapt to a routine they can begin to implement it for themselves. Having a schedule of the day's events and activities can be helpful. This may be visual rather than written if the person has trouble with literacy or with understanding numbers or the concept of time. Printable visual time-tables can often be found online, for example. Other strategies to help someone manage their time could include using clocks or egg-timers so that they know when it is time to move on to the next activity. Acknowledging completion of one task or activity will provide positive reinforcement and will encourage sticking to the schedule. Incorporating choices of activities within the schedule will help avoid monotony and will also increase the person's control over their day. For example, if there is recreation time scheduled after lunch, a caregiver could give the option of going to the park or play on the computer.

5.4.3 MINIMISING CHALLENGING BEHAVIOURS

Minimising challenging behaviours may involve several strategies. Identifying what triggers such behaviours will help to begin to address any problems. Caregivers can make changes to the environment of the individual to help reduce such behaviours. For example, for people with intellectual disability that have trouble with sensory processing, this might mean reducing noise levels in the home or changing the lighting in the house, if possible. Preventative strategies for challenging behaviours may involve identifying specific activities to divert and distract the individual when they start to become distressed. Similarly, caregivers could explore different relaxation techniques, such as meditation or deep breathing, to practice daily with the person under their care. It is important to seek advice about any interventions to manage challenging behaviours from a health care professional such as a psychologist, occupational therapist or physician. Medication for challenging behaviours is usually a last resort measure where there is a significant risk of injury to the self or others. Medication should be used in conjunction with other behavioural management strategies and should always be overseen by a health care professional.





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Case Story

Peter is 27 years old and is living with a learning disability. Peter is being cared for at home by his parents but has been displaying challenging behaviour recently. Peter has assaulted his caregiver on two occasions. Peter's caregivers are concerned that this behaviour may persist and they may be unable to continue caring for him at home.

Response:

- Stay calm in your response to the challenging behaviour. Keep your voice and body language as consistent as possible.
- Communicate. Ask Peter why he is upset and what you can do to help. Use pictures or sign language depending on Peter's needs.
- Change the environment: if the challenging behaviour occurs in the sitting room, take a walk outside or go to another room in the house.
- Distraction can redirect the challenging behaviour. Offer Peter a choice of what to do next, or an activity to engage in.
- Praise positive behaviour. It is really important to communicate to Peter that you notice and are happy that he is behaving positively.
- Make a note of each instance of challenging behaviour. What happened earlier in the day? What happened immediately before Peter's behaviour changed? Was there a change in routine? This may help to identify possible triggers and thus help to avoid them in future.
- Make a note of effective ways you have avoided the challenging behaviour, and use this to guide you with future experiences.
- Avail of respite care. Give yourself the opportunity to have a break and recharge your batteries.
- Prioritise your self-care. Speak to your doctor about the effects of challenging behaviour on your physical and mental health.





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ATTENTION DEFICIT HYPERACTIVITY DISORDER





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6 ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD)

Compiled by Health Promotion Research Centre at the National University of Ireland

6.1 WHAT IS ADHD?

Attention Deficit Hyperactivity disorder (ADHD or sometimes ADD) is a medical/neuro-biological condition which means it affects how the brain works and affects behaviour. ADHD affects the chemicals noradrenalin and dopamine in the brain causing them to not work as they should. This is a long-term condition that is usually diagnosed in childhood and can last into adulthood and across the life course. Individuals with ADHD may have difficulties relating to behaviour, learning and self-regulation. This means that the person may be unable to control their own behaviour and reactions in the way that other people do. Impulsivity, hyperactivity and inattentiveness are common with ADHD.

- **Impulsiveness** causes the person to react before thinking of what the outcome might be, for example crossing a busy road without checking how safe this is;
- **Hyperactivity** means that the individual may find sitting still very difficult and may feel the need to jump, run around or move constantly;
- **Inattentiveness** means that the person may have difficulty focusing on something for a long time, or staying focused for long enough to complete a task.

Individuals with ADHD are 60 to 80% more likely to also be affected by conditions such as: dyspraxia, oppositional defiant disorder, autistic spectrum disorders, anxiety and mood disorders.

6.2 BEHAVIOURS TO EXPECT

- Difficulty waiting in turn;
 - Poor social skills;
 - Hypersensitivity;
 - Short attention span.
- Impulsivity;
 - Self-injuring;
 - Physical violence;
 - Aggression;
 - Difficulty following instructions.
- Difficulty staying on task;
 - Difficulty keeping still / sitting for long periods.
- Emotional outbursts;
 - Damaging property;
 - Sleep difficulties.





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6.3 TREATMENT

Medication is considered the most effective treatment for ADHD. However, the decision to try medication is a personal one. Caregivers should take time to discuss medication with the person who is taken care for and health care professionals. Possible side effects and benefits should be carefully considered. Do your own research on the medication being recommended for the person who is taken care for, and when you have all the information you can make a decision.

6.3.1 SOCIAL OPPORTUNITIES

Create social opportunities and interactions for the person you care for. Make contact with other parents or caregivers and try to arrange meet ups and outings. Find out about all activities, groups, and events in your local community that the person you care for might like to attend. Try to support the individual when they are with other people and help them to remember taking turns and listening when other people are speaking. Talking about interactions after they happen and thinking about other ways the person could have acted or behaved may be helpful.

Contact the person's doctor to see if there are group therapy sessions available or groups to build social skills. Find camps available during the Summer in your local area for children and adults that may help the person you care for to meet other people and have fun. Support the person you care for to find social opportunities for themselves, maybe about something they enjoy like art, or cycling. Encourage the person to join a group or club about a topic they find interesting such as computer programming or science fiction. If the person is interested in the subject, they are more likely to stay involved.

6.3.2 LOW MOOD

Listening to and supporting the person with low mood can be helpful. Being available and open to listening to them is important. Encourage the person you are caring for to meet with friends and be active in the community. When their mood is low the person may feel like staying home and avoiding social events. This may cause further feelings of sadness or hopelessness. Try to motivate the person to leave the house and spend time doing things they love such as hobbies or sports. Physical activity increases the feel good chemicals in the body and is a very helpful way to respond to low mood. Talking therapies such as: counselling, cognitive behavioural therapy and family therapy may be useful in responding to low mood. Medication may be an option for individuals living with ADHD and suffering from low mood and can be discussed with a healthcare professional.

6.3.3 VIOLENCE AND AGGRESSION

The most important things a caregiver can do when responding to aggressive or violent outbursts is stay calm. Speak in low and calm tone of voice and remove any other children or vulnerable people





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from the situation. Ask the person why they are upset. Repeat what they have told you, so they know that you are listening, and you have heard them. Ask the person to come to a different room or outside to talk about how they are feeling. A change in environment can help to calm the situation.

Rewards for good behaviours may be helpful in reducing violent outbursts and aggression. If the person you care for has something they would like to buy, or an activity they would like to do such as going to the cinema, they can work towards this with good behaviour. Praise the person when they are calm and interacting well, as they may feel they get more attention for challenging behaviour.

Talking therapies may be helpful in responding to aggressive or violent outbursts. This may include: cognitive behavioural therapy, family therapy or counselling. Medication may be considered for the person living with ADHD as a response to violent and aggressive behaviours. Caregivers should discuss this with the person's doctor.

6.4 CONCERNS OF THE CAREGIVER

6.4.1 ACCEPTING THE DIAGNOSIS

Some caregivers may struggle to accept the diagnosis of ADHD for the person who is taken care for. Common reactions include denial, feelings of guilt, worry and anxiety about what will happen next and what the long-term outcome for the person will be. The stigma surrounding ADHD may lead caregivers to look for other causes or reasons for the behaviours of the person who is taken care for. Stigma is the negative reaction of other people about mental or physical health conditions. Caregivers may also worry that accepting the diagnosis of ADHD may cause more difficulties for the person they care for and they may refuse to accept the diagnosis.

6.4.2 SAFETY OF INDIVIDUAL

Accidental injury and intentional self-injury are more common in people living with ADHD. In adults with ADHD, road traffic accidents are more likely due to lapses in concentration and impulsivity. Children with ADHD are more likely to suffer cuts, burns and broken bones from falls and accidents.

6.4.3 EFFECTS ON PARENTS AND SIBLINGS

Living with an individual diagnosed with ADHD may result in a more stressful home environment for parents and siblings. Parents may face more conflict in their marriages or relationships as a result of the stress that caring for a person with ADHD may present. Exhaustion and feelings of being overwhelmed are common and parents or caregivers are more likely to suffer from stress, depression and anxiety.





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Siblings may feel they are living in a chaotic home environment where they feel anxious or worried about what may happen next. Siblings may feel threatened physically and may be the victim in violent outbursts. Siblings of children with ADHD may also feel the burden of providing care. They may have more responsibility in preventing outbursts or trying to help their parents with managing challenging behaviour. Siblings may feel that their parents do not have time for their needs and that the rules of behaviour for them are different compared to their sibling with ADHD.

6.4.4 SLEEP DISTURBANCE

ADHD may cause and increase the likelihood of insomnia and sleep disturbances. 66% of adults with ADHD report sleep disturbance. While in children some 70% report sleep disturbances. Some individuals may take hours to fall asleep and may wake frequently throughout the night. This poor sleep routine can result in lower concentration and increased emotional outbursts for the person as they cope with being tired the next day. For caregivers they may spend most of the night awake with the person they care for. Then the caregiver may suffer themselves from fatigue, exhaustion and burnout.

6.4.5 WHETHER OR NOT TO MEDICATE

Stimulant medications are often used to treat the symptoms of ADHD and help the person's mood. This medication increases dopamine in the brain and improves attention and impulse control. However, many caregivers worry when deciding whether or not to medicate the person who is taken care for. Some caregivers fear that medication may make problem solving more difficult for the person with ADHD. While side effects of medication such as loss of appetite, sleep disturbances and a "zombie like" state make the decision whether or not to try medication even more challenging. Caregivers may also feel pressure to medicate if the person who is taken care for is having difficulties in school, or because no other options for treatment are provided.

6.4.6 SOCIAL EXCLUSION

Individuals living with ADHD may face social exclusion as a result of their condition. Caregivers may feel concerned for the person who is taken care for if they are left out and do not get opportunities to meet with people their own age. The individual may struggle with turn-taking, may interrupt constantly or may be aggressive towards other people. This may mean that other people will not want to engage with them. Children with ADHD may not be invited to play with other children or to birthday parties and may struggle to make friends. While adults with ADHD may struggle to make and keep friends.





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6.4.7 Low Mood

Low mood and depression are more common for people living with ADHD. The person may feel sad, hopeless and have little or no energy. The person may feel no motivation, guilt and may have trouble sleeping.

6.4.8 AGGRESSIVE VIOLENT OUTBURSTS

Individuals with ADHD may have aggressive behaviours or violent outbursts. This can create challenges for the care giver in coping with and responding to these outbursts. Examples of violent and aggressive outbursts may be kicking, biting, hitting, destruction of property and threatening family members. Caregivers may need to protect themselves and other family members from being harmed. Behaviours such as these may also affect the emotional and mental well-being of the caregiver and other family members.

6.5 STRATEGIES FOR THE PATIENT AND CAREGIVER

- Accepting the diagnosis: When the person who is taken care for is diagnosed with ADHD, it can help to acknowledge to yourself that he/she is still the same person and their care needs are also still the same. You may also have more information about how to meet their specific care needs and how best to help the person to reach their full potential. Try to not let your struggle to accept the diagnosis delay any therapies or support the person who is taken care for may need. The sooner support is given the better in the long-term for person you care for.
- Allowing yourself the space to feel: upset, sad, or angry about the diagnosis of ADHD will allow you to work through your own feelings and emotions and accept the diagnosis. Attending a counsellor, talking to a healthcare professional or a close friend can be helpful. You may find it useful to attend a support group for caregivers locally or within an online forum and chat with other caregivers who understand exactly how you feel. Having a diagnosis means the person who is taken care for can get the correct care for their condition and people may be more understanding of their needs and behaviour.
- Safety: Safety planning can help caregivers to support the person with ADHD to cope when a dangerous situation occurs. Teaching the person who is taken care for to stop and think before they act will help to keep them safe yet may also be difficult for them. Continue to talk about this regularly to help the person to pause and check if they are safe before they act. For example, when crossing a road, the person must stop, look, listen, check etc. If they do not, they may run into oncoming traffic. Or if the person is near a swimming pool they need to be reminded to stop, and check that they are safe for examples:
 - How deep is the water?
 - Is there a lifeguard?
 - Do I have permission to get into the pool?
 - Which side of the pool should I enter?





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- Reminding the individual how to behave when they are near a road or water, will help to keep them safe. You may need to repeat these lessons as the person you care for may forget or act without thinking.

6.5.1 PRACTICAL TIPS FOR CAREGIVERS

To make your home a safer place include: locks on windows and doors (e.g. the bathroom), the use of a safety gate for stairs, the use of plastic cutlery and plates and cups. Keep sharp or dangerous objects such as medications safely locked away and remove any other item that the person you care for may use to hurt themselves or anyone else in the home with. Medication can be useful for helping people with ADHD to control impulsiveness, hyperactivity and inattentiveness which can lead to accidents and injury. You can talk to a healthcare professional who provides care to the person with ADHD for more information on medication.

Case Story

Shane is 9 years old and living with ADHD. Shane's caregiver is concerned as he has run into the street and into traffic on numerous occasions in recent weeks. Shane's caregiver is worried he will be seriously hurt by a car on the road.

Response:

- The caregiver should communicate with Shane about road safety only when they have his full attention. Ensure there is no noise or other distractions. Sit down with Shane and make sure he is maintaining eye contact and listening carefully.
- Frequent reminders are necessary to keep Shane safe. The caregiver should instruct Shane each time he leaves the house about the danger of the road.
- Clear instructions should be given to Shane to stay away from the road. Short and direct instructions are needed for example: stay away from the road.
- Give Shane rewards for positive behaviour relating to road safety. The caregiver should acknowledge each time Shane listens and stays away from the road.
- The caregiver should supervise Shane when there is a risk relating to his safety. If Shane has access to the road and oncoming traffic, the caregiver needs to be vigilant and keep Shane in their sight at all times.
- Holding Shane's hand when walking near the road is necessary. The caregiver may also need to react quickly and physically prevent Shane from running on to the road if necessary.

Self-care: Caring for yourself as the caregiver is essential. Taking time to relax, getting enough sleep, getting regular exercise and eating a healthy diet can help you to cope with the stresses of caregiving. Respite or relief care can give caregivers the opportunity for self-care and the space to recharge their batteries. Asking family members for more help and support to allow for respite is important. Keeping in contact with your own friends as a caregiver is also useful to prevent feelings





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of loneliness and isolation. Support groups for parents and caregivers can provide a space to meet other people who understand and share your feelings and concerns. Counselling may help caregivers with stress and provide an outlet for emotions. Caregivers who care for themselves are better able to care for the person who is taken care of too.

Advice for other family members:

When caring for siblings or other family members affected by living with someone with ADHD, respite and asking for more support are the key. Try to get some time with your other children away from the home. Sharing information with siblings about ADHD and how this affects their loved one can be helpful. It is important for other children to understand what it means to have ADHD and that their sibling is not just misbehaving. Siblings may also benefit from groups set up to support siblings of people with ADHD. It is important to acknowledge the feelings of siblings and talk to them about their emotions.

Sleep: Creating a routine time for sleeping and waking can help the individual to create a better sleeping pattern. Two hours prior to sleep any screen time, caffeine or high sugar drinks or snacks and intense physical activity should be avoided. Lighting should be dimmed and quiet and calming activities should take place in the hour before bed time. The temperature and lighting in the bedroom should be adjusted to suit the person's needs.

A heavier blanket may help to encourage sleep for an individual with ADHD. Weighted blankets aim to promote restfulness and relaxation by reducing experiences of sensory overload of such as noise, light or clothing. Weighted blankets provide deep pressure and help to relax the individual, reduce anxiety and promote rest and sleep.

Medication may be considered to help with sleep for individuals living with ADHD. Caregivers should talk with the doctor of the person they care for to discuss this. Natural sleep aids may also be helpful and are available in health food stores. Again this should only be considered after speaking to a medical professional. Avoid naps and maintain the sleep routine even if the person you are caring for is tired or not tired at bed time. Increasing physical activity will help the individual to work through the hyperactivity or restlessness they feel. And spending time outdoors everyday may help the person to sleep better.





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Case Story

Kate is 19 years old and living with ADHD. Kate has been suffering from insomnia for a number of weeks. Kate's caregiver spends much of the night awake with her, in order to be supportive and keep Kate safe. The caregiver is concerned that s/he will become overwhelmed if this insomnia continues and this may prevent continuing to provide care at home.

Response:

- Increase low arousal techniques in the hour before sleep. No screen time, no loud noise, low lighting and a calming environment.
- Kate may benefit from using a heavy blanket. This promotes sleep by reducing sensory overload.
- Ask Kate if she is happy that the temperature, bedding and lighting in the room are to her preference for sleeping.
- Ask Kate to keep a sleep diary, noting nights where she slept well, and what was different about those nights? Or what had happened earlier that may have impacted her sleep? The caregiver can use this to support Kate to sleep well going forward.
- The caregiver should discuss Kate's insomnia with their doctor. The doctor will be able to advise on methods for promoting sleep and possibly discuss options for medication.
- Self-care is key. The caregiver should discuss how they feel with their doctor or at a support group meeting. Looking after your own needs is essential to enable you to continue providing care to Kate.
- Avail of respite care if possible. Having a night of uninterrupted sleep could make a major difference to your ability to cope with continuing to support Kate with her insomnia.





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AUTISM





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7 AUTISM

Compiled by Health Promotion Research Centre at the National University of Ireland

7.1 WHAT IS AUTISM?

Autism, or Autistic Spectrum Disorder (ASD) is a disorder which causes people to have difficulties with social skills, repetitive behaviours, speech and nonverbal communication. Autism is usually diagnosed in childhood and will last throughout the lifespan. People with Autism might be seen as strange or unusual by other people at first. People with Autism are on a spectrum, which means that how they communicate and the behaviours they display will vary greatly. Some people with mild Autism may attend mainstream school with supports. Other individuals may be non-verbal and could need a lot of extra support with care needs and may attend schools for children with additional needs.

Sensory issues are common for people living with Autism. This means that sights, sounds, smells, tastes and touch can be overwhelming for the person. People with Autism may be more likely to act impulsively (without thinking first) and have less awareness about how to keep themselves safe. Times of change can be stressful for people with Autism and routine is very important. Meeting new people and being in new places can also cause distress and lead to emotional outbursts or stimming and repetitive behaviours. Stimming (or self-stimulating behaviours) such as rocking, hand flapping or clicking fingers helps the person with Autism to feel safe in a place or situation that they are uncomfortable with.

7.2 BEHAVIOURS TO EXPECT

- Avoids eye contact;
 - Poor social skills;
 - Hypersensitivity;
 - Distress at times of change / transition.
-
- Impulsivity;
 - Self injuring;
 - Physical violence;
 - Aggression;
 - Difficulty following instructions





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- Obsessive fixations with certain objects or topics;
- Sensory issues;
- Stimming;
- Communication difficulties.

- Emotional outbursts;
- Sleep difficulties;
- Repetitive behaviours;
- Dietary problems.

7.3 CONCERNS OF THE CAREGIVER

7.3.1 ACCEPTING THE DIAGNOSIS

Some caregivers may struggle to accept the diagnosis of Autism for the person who is taken care for. Common reactions might be denial, feelings of guilt, worry and anxiety about what will happen next and what this means long-term. The caregiver may feel the need to grieve as they feel loss and sadness at the life they had planned and expected for the person who is taken care for. This can cause stress, upset and worry for caregivers.

7.3.2 EFFECTS ON PARENTS AND SIBLINGS

Caring for an individual with Autism can be stressful compared to caring for someone with another disability. Caregivers may be at risk of physical injuries and burnout as they provide care, which can be 24 hours per day. If the person you care for has sleep difficulties or challenging behaviour, this may be very demanding for parents and place strain on their relationship with each other and other children. Mental illness is more common in caregivers for people with Autism. When care giver mental health is not addressed this can lead to poorer outcomes and less successful interventions for the individual living with Autism. As such, it is very important for caregivers to look after their mental and emotional health.

Siblings may feel they are living in a chaotic home environment where they feel anxious or worried about what may happen next. Siblings may feel left out or not as important as their sibling who has been diagnosed with Autism. Parents may need to give more time and attention to the person with Autism. Coping with violent outbursts and physical harm can be very difficult for siblings. Parent's stress levels and how they cope can also cause siblings distress and worry.





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7.3.3 SAFETY

The safety of the person with Autism can be of major concern for caregivers. Depending on the severity of the condition, the individual may not understand danger or be aware of how to prevent injury to themselves. Wandering/absconding affects up to 50% of people living with Autism and is a major concern for caregivers. Concerns of caregivers in the home may relate to: burns from touching hot surfaces or open fires, cuts from sharp objects or glass plates or cups, falls down stairs or from an upstairs window and self-injuries from head-banging or biting. Safety may also cause concern for the caregiver outside the home as injuries and accidents are more common for people living with Autism. Walking in to traffic, water safety and drowning are more common issues for people living with Autism. The person may not understand how to keep themselves safe in relation to strangers or dangerous social situations. Caregivers may worry about the person who is taken care for and suffer sleep problems, stress and anxiety in trying to keep the person they care for safe and supervised at all times.

7.3.4 SENSORY ISSUES

Sensory issues are concerned with sights, sounds, touch, smell and taste. The person living with Autism may become overwhelmed and distressed by some senses. The texture and taste of food or smells which are strong or disliked by the person may cause a reaction. Some individuals living with Autism may have a very limited diet and only eat certain foods for example: dry food, breakfast cereal or chicken nuggets. This can create major challenges for caregivers who try to provide a healthy and balanced diet.

Sounds can cause distress to some people living with Autism. Sudden loud noises, sounds they are not familiar with or generally noisy places can be overwhelming for the person. Touch may be a sensory issue for the individual and some can find that how clothes, bedding or furniture feels causes distress. This may be the textures of clothing, tags on clothing, seams on socks, fitting and fastening of shoes or hats which cover ears. The textures of bedcovers, chairs, couches, pillows/cushions or flooring may prompt a sensory reaction from the person you care for. Touch may also cause distress in crowded environments such as school or public transport. When someone else is too close to the person with Autism, or touches them, this may be a distressing and overwhelming feeling.

When reacting to sensory issues the individual with Autism may have emotional outbursts, may become aggressive, may become distressed or upset, may attempt to leave a safe environment, refuse to eat, refuse to get dressed or have difficulty sleeping.

7.3.5 AGGRESSIVE VIOLENT OUTBURSTS

People living with Autism may display aggression or violent outbursts as they may not have the ability to communicate their needs. This can be challenging for the caregiver. Kicking, biting, hitting, destruction of property and threatening behaviours may be displayed by the individual. Caregivers





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may need to protect themselves and other family members from physical violence. Such behaviours also affect the emotional and mental well-being of the caregiver and other family members.

7.3.6 SOCIAL EXCLUSION

People living with Autism have difficulties with communication. This can lead to challenges in making friends and keeping friendships. The individual may not understand how to start a conversation, keep a conversation going or how to behave within a group of people. A person with Autism may have difficulty understanding facial expressions, sarcasm or if the person they are talking to is not interested in the conversation. Impulsive behaviours and emotional outbursts may cause the person with Autism to feel isolated if they are not invited to events or if they do not have friends. Stimming (self-stimulating behaviour) such as rocking, hand flapping, clicking fingers or jumping are a way the person with Autism feels safe in a place or situation that they are uncomfortable with. Stimming actions are repetitive and can sometimes cause other people to avoid the person with Autism as they see stimming as unusual.

When the person is excluded socially this can make caregivers worried for their well-being. The less opportunities the person has to interact with other people, the harder it will be for them to develop their social skills. Caregivers may worry about what the future holds for the individual if they are unable to maintain friendships or be included in social events. Social exclusion can then lead to feelings of loneliness, low mood and greater risk of mental ill-health. In the long term social exclusion can lead to poorer opportunities for employment and greater social disadvantage.

7.3.7 TRANSITIONS AND CHANGES

A person with Autism may find transitions or changes difficult to process. This means that if the person has to move from one place to another, or needs to adjust to a new experience, it may be very distressing for them. A change in routine, for instance, such as a last minute doctor's appointment, or an activity being cancelled can cause the person with Autism to become upset or unable to cope with the change. Other changes such as new clothes, bed covers or a new family car can also be distressing for the person with Autism. Knowing what to expect and having a planned routine is reassuring for the person and can help them to feel safe.

7.4 STRATEGIES FOR THE PATIENT

7.4.1 ACCEPTING THE DIAGNOSIS

When the person who is taken care for is diagnosed with Autism, it can help to acknowledge to yourself that he/she is still the same person and their care needs are the same. After diagnosis you may also have more information on how to meet their individual care needs and how best to help





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the person to reach their full potential. A diagnosis may also mean the individual can get the correct care for their condition.

It is important not to let your struggle to accept the diagnosis delay any therapies or support the person who is taken care of may need. The sooner support is given the better in the long-term for the person you are caring for. Allowing yourself the space to feel upset, sad, or angry about the diagnosis of Autism will allow you to work through your feelings and accept the diagnosis. Attending a counsellor, talking to a healthcare professional or friend can also be helpful. Support groups for caregivers of people living with Autism may be helpful as an opportunity to meet other parents and caregivers who know how you may be feeling. Support groups can often be found locally or online.

7.4.2 SELF-CARE AND CARING FOR OTHER CHILDREN

Caring for yourself as the caregiver is essential. Taking time to relax, getting enough sleep, getting regular exercise and eating a balanced diet can help you to cope with the stresses of caregiving. Respite care (when someone else looks after the person who is taken care of – for a short period of time) can give caregivers the opportunity for self-care and enable them to recharge their batteries. Asking family members for more help and support to allow for respite is important. Autism service providers of the person you care for may also offer respite services.

Keeping in contact with your own friends as a caregiver is important as this reduces feelings of loneliness and isolation. Support groups for parents and caregivers can provide space to meet other people who understand and share your feelings and concerns. Counselling may help caregivers with stress and provide an outlet for emotions. Talking to a counsellor may provide relief for the caregiver and help them to feel they are being listened to. Caregivers who care for themselves are better able to care for others.

When caring for siblings or other family members affected by living with someone with Autism, respite and asking for more support from family members are key. Try to get some time with your other children away from the home. Sharing information with siblings about Autism and how this affects their family member can be helpful. It is important for other children to understand that the person with Autism is trying to communicate and is not just misbehaving. Siblings may also benefit from groups set up to support siblings of people with Autism. It is important to acknowledge the feelings of siblings and talk to them about their emotions. Include sibling at appointments and therapy sessions with their family member, as this can help them to feel included and valued as they have detailed insight on their siblings needs and wishes.

7.4.3 SAFETY PLANNING

Safety planning can help caregivers to support the person with Autism to cope when a dangerous situation occurs. Having the person who is taken care of wear an identity bracelet may help them to be identified should they wander off. The bracelet could contain their name, your contact





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information and that they have Autism. This may help someone who finds the person to respond to them sensitively and keep them safe while they make contact with you.

Speaking to neighbours and people in your local community can increase safety for the person living with Autism. Telling neighbours and shop assistants or people who work in the local library or café about your family member and Autism, may help to keep the person safe if he/she wanders off. Showing staff who work nearby a picture of the person you care for and giving them your contact information may also help to keep the person safe.

Practical things to make your home environment safer include: locks on windows and doors (eg. the bathroom), the use of a safety gate for stairs, the use of plastic cutlery and plates and cups. Keep sharp or dangerous objects such as medications safely locked away and remove any other item that may cause injury to the person with Autism or anyone else in the home.

Sensory issues:

Preparing the person you are caring for prior to a situation that may cause sensory distress is helpful.

- If you are going to a crowded place or will be in a noisy environment, explaining this in advance with words or pictures can help the person to know what to expect.
- Explain the sensory needs of the person you care for to other people so that they can give the person extra space and avoid touching them if this causes them distress. This may be useful in a classroom setting.
- Experiment with different types of clothing to find out which type the person you care for finds more comfortable. Remove tags from clothes if necessary.
- Using ear plugs or headphones may help the person with Autism to reduce the distress they feel in noisy environments.
- Offering rewards to the person you care for when they try new foods may be helpful. Including their favourite foods alongside new types of food may make it easier for them to try it. Visiting a dietician may help you to improve the diet of the person you care for. Dieticians will be experienced in supporting people with Autism and may be able to help you to introduce new foods for the person you care for.
- Allow time for unexpected delays caring for the person with Autism. Allowing for regular breaks from activities or actions can help the person to feel less affected by sensory issues. For example if getting on a bus the person you care for becomes distressed, wait for another bus and spend time explaining what will happen next.

7.4.4 AGGRESSION AND VIOLENCE

The most important thing a caregiver can do when responding to aggressive or violent outbursts is stay calm.

- Speak in low and calm tone of voice and remove any other children or vulnerable people from the situation.





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- Ask the person why they are upset.
- Repeat what they have told you so they know that you are listening and you have heard them. If the person is non-verbal, try to use pictures or another method to help them to express how they feel.
- Ask the person or gently guide them to come to a different room or outside.
- A change in environment can help to calm the situation.
- Rewards for good behaviours may be useful in reducing violent outbursts and aggression. If the person who is taken care for has something they would like to buy, or an activity they would like to do like going to the cinema, they can work towards this with good behaviour. It is important to recognise and praise the individual when they are calm and interacting well.
- Spend time with the person to try to work out what they are trying to communicate when they are displaying aggression. They may be feeling overwhelmed in relation to sensory issues. They may be feeling pain, or hunger or discomfort and be trying to communicate this to you. Looking back on times of violence and aggression may help you as the caregiver to understand the cause of the outburst and try to help the person to have their needs met if this happens again.

Case Story

Daniel is 13 years old and attends secondary school. Daniel has ASD and finds the noise levels in the school very distressing. The bell as each class ends, and the noise made by chairs moving, have caused Daniel to react with aggression towards other students. The caregiver is concerned that Daniel will be no longer be allowed to attend school if this behaviour persists.

Response:

- Inform Daniel prior to the bell ringing so he can feel more prepared.
- Give Daniel the option to sit away from the bell at the back or side of the class so this may reduce the volume and Daniel's sensory reaction.
- Open a window next to Daniel to provide a distraction and also provide less daunting sounds (children playing, traffic, birds etc.).
- Offer noise cancelling headphones prior to the school bell ringing and chairs moving.
- Involve Daniel in the process of ringing the bell, this could provide greater control and reduce sensitivity to the noise.
- Give Daniel other options about how to cope with the noise, for example:
- Leave the building (with a teacher or support person) until he is feeling less distressed by the noise.
- Have access to something comforting such as a favourite book or electronics.





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7.4.5 SOCIAL EXCLUSION:

By connecting with other caregivers through services you attend with the person who is taken care for, attending support groups or chatting online, you can create social opportunities for the person you care for. Other caregivers of people with Autism will be happy to arrange social activities and outings where the people you care for can spend time with one another. Every opportunity to interact and socialise is a step toward more opportunities.

Social skills groups are often made available for people living with Autism and will be based usually on their age range (children, teenagers, adults). This can be a great way for the person who is taken care for to meet other people and learn ways to communicate with people their own age. Community groups, clubs and societies in your area may be useful for the person with Autism to interact with people who live locally. Drama, dance and craft groups often welcome people of all abilities and provide a safe place for the person to meet new people and learn new skills.

Sharing information with other people about Autism may help them to be more understanding of unusual behaviours and more welcoming to the person you care for. Teachers, students and people working in local shops/cafes will be better able to communicate with the person you care for if they know more about Autism and the special communication needs.

7.4.6 TRANSITIONS AND CHANGES:

Preparing the person you care for of possible changes which may affect them may help to make the change easier for them. Talking to the person about changes at home such as moving bedrooms, or rearranging furniture can be helpful. The use of pictures showing what the change will look like and the steps that will happen to make this change may help the person to prepare. When changes happen that are unplanned, caregivers need to try to support the person with Autism through this distressing time. For example, if a scheduled activity such as swimming is cancelled at short notice, the person you care for may react with anger, aggression or sadness. Caregivers should allow and support the person to express these emotions and take the time to show they understand how hard this is for them. Offer alternatives to the person you care for about what they can do instead of the planned activity. Assure the person you care for that they are safe and offer them something they like to help them to cope such as a favourite blanket, toy or book. Allow the person to calm themselves through stimming or whatever works for them.





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Case Story

Sarah is 18 years old and living with Autism. Sarah follows a strict routine, and this helps her to cope with everyday life. Sarah's family are moving house and her caregiver is concerned about how this major transition may negatively affect Sarah as they have lived in the same house since Sarah was born.

Response:

- As soon as you the caregiver know for certain that they house move will be happening, begin explaining this to Sarah.
- Explain why you are moving home and the positives the move will bring to your family and to Sarah.
- Take Sarah to visit the new house as frequently as possible prior to the move.
- Use a chart or calendar to show Sarah the timeline of the move and how long you have left in your old home: starting with months, weeks and days.
- Use pictures to show Sarah exactly what will happen for example: a picture of your house now, of Sarah's room and belongings; a picture of boxes and a moving van; followed by a picture of your new home, and a picture of your family.
- Involve Sarah in the moving process. Support her to choose items to pack, and include Sarah in decisions about the new house such as where furniture will go and which bedroom she will have.
- Reassure Sarah that she is safe, and you will be there with her as you move homes.
- Keep Sarah's routine as normal as possible before, during and after the move.





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EATING DISORDERS





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8 EATING DISORDERS

Compiled by School of Allied Health Technologies, Instituto Politécnico do Porto

8.1 WHAT ARE EATING DISORDERS?

Eating disorders affect several million people at any given time, most often women between the ages of 12 and 35. There are three main types of eating disorders: anorexia nervosa, bulimia nervosa and binge eating disorder

Eating disorders are illnesses in which the people experience severe disturbances in their eating behaviours and related thoughts and emotions. People with eating disorders typically become pre-occupied with food and their body weight.

People with anorexia nervosa and bulimia nervosa tend to be perfectionists with low self-esteem and are extremely critical of themselves and their bodies. They usually “feel fat” and see themselves as overweight, sometimes even despite life-threatening semi-starvation (or malnutrition). An intense fear of gaining weight and of being fat may become all-pervasive. In early stages of these disorders, patients often deny that they have a problem.

In many cases, eating disorders occur together with other psychiatric disorders like anxiety, panic, obsessive compulsive disorder and alcohol and drug abuse problems. New evidence suggests that heredity may play a part in why certain people develop eating disorders, but these disorders also afflict many people who have no prior family history. Without treatment of both the emotional and physical symptoms of these disorders, malnutrition, heart problems and other potentially fatal conditions can result. However, with proper medical care, those with eating disorders can resume suitable eating habits, and return to better emotional and psychological health.

8.1.1 ANOREXIA NERVOSA

Anorexia nervosa is diagnosed when patients weigh at least 15 percent less than the normal healthy weight expected for their height. Hallmarks of anorexia include:

- Limited food intake
- Fear of being “fat”
- Problems with body image or denial of low body weight





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People with anorexia nervosa don't maintain a normal weight because they refuse to eat enough, often exercise obsessively, and sometimes force themselves to vomit, or use laxatives to lose weight. Over time, the following symptoms may develop as the body goes into starvation:

- Menstrual periods cease;
- Osteopenia or osteoporosis (thinning of the bones) through loss of calcium;
- Hair/nails become brittle;
- Skin dries and can take on a yellowish cast;
- Mild anaemia; and muscles, including the heart muscle, waste away;
- Severe constipation;
- Drop in blood pressure, slowed breathing and pulse rates;
- Internal body temperature falls, causing person to feel cold all the time;
- Depression and lethargy.

8.1.2 BULIMIA NERVOSA

Although they may frequently diet and vigorously exercise, individuals with bulimia nervosa can be slightly underweight, normal weight, overweight or even obese. But they are not as underweight as people with anorexia nervosa. Patients with bulimia nervosa eat frequently, and during these times sufferers may eat an astounding amount of food in a short time, often consuming thousands of calories that are high in sugars, carbohydrates and fat. They can eat very rapidly, sometimes gulping down food without even tasting it.

Their binges often end only when they are interrupted by another person, or they fall asleep or their stomach hurts from being stretched beyond normal capacity. During an eating binge sufferers feel out of control. After a binge, stomach pains and the fear of weight gain are common reasons that those with bulimia nervosa purge by throwing up or using a laxative. This cycle is usually repeated at least several times a week or, in serious cases, several times a day.

Many people don't know when a family member or friend has bulimia nervosa because people almost always hide their binges. Since they don't become drastically thin, their behaviours may go unnoticed by those closest to them. But bulimia nervosa does have symptoms that should raise red flags:

- Chronically inflamed and sore throat;
- Salivary glands in the neck and below the jaw become swollen; cheeks and face often become puffy, causing sufferers to develop a "chipmunk" looking face;
- Tooth enamel wears off; teeth begin to decay from exposure to stomach acids;
- Constant vomiting causes gastroesophageal reflux disorder;
- Laxative abuse causes irritation, leading to intestinal problems;
- Diuretics (water pills) cause kidney problems;
- Severe dehydration from purging of fluids.





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Bulimia can lead to rare but potentially fatal complications including esophageal tears, gastric rupture, and cardiac arrhythmias.

8.1.3 BINGE EATING DISORDER

People with binge eating disorder have episodes of binge eating in which they consume very large quantities of food in a brief period and feel out of control during the binge. Unlike people with bulimia nervosa, they do not try to get rid of the food by inducing vomiting or by using other unsafe practices such as fasting or laxative abuse. The binge eating is chronic and can lead to serious health complications, particularly severe obesity, diabetes, hypertension and cardiovascular diseases.

Binge eating disorder involves frequent overeating during a discreet period of time (at least once a week for three months), combined with lack of control and associated with three or more of the following:

- Eating more rapidly than normal;
- Eating until feeling uncomfortably full;
- Eating large amounts of food when not feeling physically hungry;
- Eating alone because of feeling embarrassed by how much one is eating;
- Feeling disgusted with oneself, depressed or very guilty afterward.

Binge Eating Disorder also causes significant distress.

8.2 BEHAVIOUR TO EXPECT

Those struggling with an eating disorder may have some, but not all, of the following emotional and behavioural signs. Presence of any of the signs that your family member may be struggling is cause for serious concern and you should encourage them to seek professional help.

- Intense fear of gaining weight;
- Negative or distorted self-image;
- Frequent checking in the mirror for perceived flaws;
- Self-worth and self-esteem dependent on body shape and weight;
- Fear of eating in public or with others;
- Preoccupation with food;
- Eating tiny portions or refusing to eat;
- Avoiding eating with others;
- Hoarding and hiding food;
- Eating in secret;
- Disappearing after eating—often to the bathroom;
- Unusual food rituals (cutting food into small pieces, chewing each bite an unusually large number of times, eating very slowly);





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- Any new practice with food or fad diets, including cutting out entire food groups (no sugar, no carbs, no dairy, vegetarianism/veganism);
- Little concern over extreme weight loss;
- Obsessive interest in cooking shows on television and collecting recipes;
- Consumption of only “safe” or “healthy” foods;
- Social withdrawal;
- Making excuses for not eating;
- Cooking elaborate meals for others, but refusing to eat them themselves;
- Eating strange combinations of foods;
- Elaborate food rituals;
- Withdrawing from normal social activities;
- Hiding weight loss by wearing bulky clothes;
- Flat mood or lack of emotion;
- Irritability;
- Mood swings;
- Hyperactivity and restlessness (unable to sit down, etc.);
- Rigidity in behaviours and routines, and experience of extreme anxiety if these are interrupted;
- Excessive exercising;
- Exercising even when ill or injured, or for the sole purpose of burning calories.

Individuals with eating disorders may be at risk for co-occurring conditions such as mood and anxiety disorders, substance abuse (alcohol, marijuana, cocaine, heroin, methamphetamines, etc.), self-harm (cutting, etc.) and suicidal thoughts and behaviours.

8.3 WARNING SIGNS OF EATING DISORDER

It is important to be aware of eating disorder warning signs. While eating disorder behaviours can vary from person to person, there are some common warning signs to watch out for, including:

8.3.1 ALTERATIONS IN WEIGHT

If the person weighs less than 85 percent of their ideal body weight and exhibits other characteristic signs of an eating disorder, they can be diagnosed with anorexia nervosa. Someone can still be close to, at, or even above their ideal body weight and have an eating disorder. This is common in those diagnosed with bulimia nervosa, marked by bingeing and purging.

8.3.2 PREOCCUPATION WITH BODY IMAGE

If a person spends an inordinate amount of time looking in the mirror, makes negative comments about her physical appearance and insists that they are overweight, that behaviour alone doesn't





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necessarily constitute an eating disorder. But if they become preoccupied with certain celebrities and models, compare themselves unfavourably to them, or wear baggy clothing to hide their body shape, these actions can be cause for concern.

8.3.3 DISRUPTIONS IN EATING PATTERNS

You may notice that someone stops eating with the family, dislikes previously enjoyed foods, is preoccupied with counting calories and fat grams, drinks excessive amounts of water and caffeine to suppress their appetite, eats noticeably smaller portions, or refuses to eat at all. Or maybe they start bingeing on certain foods and going to the bathroom immediately after meals to vomit what they just ate. Also be on the lookout for newly developed eating rituals such as chewing for long periods before swallowing, cutting food into small portions, moving food around on the plate, or hiding food in a napkin to dispose of later.

8.3.4 PREOCCUPATION WITH NUTRITIONAL CONTENT

A dedication to eating nutritious food is admirable, but if a person begins to classify foods as good or bad, healthy or unhealthy, safe or unsafe, and is constantly searching out organic, low-fat diet foods, frequently visits websites focused on nutrition, or suddenly declares they are vegetarian or vegan, this, in conjunction with other behaviours, could be a sign that they need help.

8.3.5 CHANGES IN EXERCISE PATTERNS

Another warning sign is when someone becomes preoccupied with physical fitness, spends hours exercising in a ritualistic way, talks excessively about the number of calories they've burned, or gets upset if their exercise routine is disrupted.

8.3.6 MOOD FLUCTUATIONS

As an eating disorder gains momentum, it may lead to signs of irritability, depression, and anxiety, causing the individual to stop socializing and lose interest in previously enjoyed activities.

8.3.7 USE OF LAXATIVES, DIURETICS, OR DIET PILLS

There is tremendous pressure on young girls and women today to look a certain way, but when they are willing to risk their health resorting to laxatives, diuretics, or diet pills, that can be a sign they need help.





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8.4 TREATMENT

Eating disorders clearly illustrate the close links between emotional and physical health. The first step in treating anorexia nervosa is to assist patients with regaining weight to a healthy level; for patients with bulimia nervosa interrupting the binge-purge cycle is the key. For patients with binge eating disorder it is important to help them interrupt and stop binges.

However, restoring a person to normal weight or temporarily ending the binge-purge cycle does not address the underlying emotional problems that cause or are made worse by the abnormal eating behaviour. Psychotherapy helps individuals with eating disorders to understand the thoughts, emotions and behaviours that trigger these disorders. In addition, some medications have also proven to be effective in the treatment process.

Because of the serious physical problems caused by these illnesses, it is important that any treatment plan for a person with anorexia nervosa, bulimia nervosa or binge eating disorder include general medical care, nutritional management and nutritional counselling. These measures begin to rebuild physical well-being and healthy eating practices.

8.5 WHAT CAN BE DONE

8.5.1 WHAT CAN BE DONE FOR INDIVIDUALS WITH EATING DISORDER

In recent decades there has been a growing interest in the practice of cognitive behavioural approach in various mental illnesses, particularly in terms of eating disorders. The objectives of cognitive behavioural theory in the treatment of eating disorders relate to the identification and modification of the behaviours and processes of thinking and perceiving that maintain the disease, such as the identification and modification of automatic negative thoughts and distorted assumptions about food, eating, weight and body shape.

It is important for the person suffering from eating disorders to be able to perceive their problematic behaviours, to know why they happen, and what emotions and beliefs are associated with these behaviours that can contribute to their triggering. It is also essential for a person to develop a clear knowledge about the problems that surround him. Cognitive behavioural therapy, in its most improved version, has been the most empirically supported current treatment for bulimia nervosa and binge eating.

Mindfulness and acceptance-based treatments have emerged in the last two decades to treat a variety of disorders. Mindful Awareness in Body-oriented Therapy are techniques that aim to change the behaviour through changes in psychological processes, such as acceptance, mindfulness, psychological flexibility, cognitive distancing, and emotion regulation. In other words, Mindful Awareness in Body-oriented Therapy combines manual, mindfulness, and psycho-educational approaches to teach awareness of body stimuli and self-care skills. Mindful Awareness in Body-





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oriented Therapy tested for bulimia nervosa and binge eating includes the following therapeutic approaches: Acceptance and Commitment Therapy (ACT), Dialectical Behavioural Therapy (DBT), and Mindfulness Based Interventions (MBIs) to increase self-awareness. and reduce stress.

In parallel with these treatments, doctors or health care professionals should always help the patient to become familiar with their body's vision and sensation. In this way, the person with eating disorders will learn to accept it and be able to expose it to others, eliminating some behaviours such as wearing and undressing in the dark and wearing loose cloths in order to disguise body shape. It should be noted that the sensation of feeling fat tends to be triggered by both the occurrence of certain negative moods (depressed) and physical sensations that increase body consciousness (feeling full, swollen, feeling of tight clothes).

Healthcare professionals should also explain to patients that knowledge and experience that emotions are fleeting can reduce the need to act on them immediately. In general, people with eating disorders when they are able to accept their emotions will realize that it is not necessary to try to change them immediately and consequently, they will be able to make more adaptive choices about how to react in order to cope with strong emotional states.

8.5.2 WHAT CAN BE DONE WITH FAMILIES OF PATIENTS WITH EATING DISORDER

Inclusion of the family in treatment is an important therapeutic tool as it allows the family nucleus to become an ally of the multidisciplinary team in efforts undertaken for the recovery of the patient. Family group interventions have been an effective alternative in providing support to caregivers. Family therapy offers a safety framework for parents, since in addition to providing the development of feelings of self-esteem, affection and hope, it also acts as a guide where parents receive and exchange information with therapists as well as with other parents. Family groups are not a solution to a child's eating disorder, but they can be considered an efficient and useful tool for treatment. Family therapy allows for a restructuring of the family organization, a modification of the confrontation strategies between parents and children, and the correction of dysfunctional communication between family members.

However, there are many strategies and behaviours that the family can adopt to deal with the disease in the most appropriate way. In everyday life the family can practice the following topics:

- Getting close to the sick person without getting into a confrontation because of the disease;
- Family caregivers should talk to the sick person when they are calm and aware of what they are going to say; An aggressive approach will not allow communication between the family and the sick person;
- Parents and siblings should reflect on their own eating habits, their body vision, and how food is treated within the family environment. Ask yourself, "Do I promote my son / brother's self-esteem or am I constantly criticizing his body and way of being? "Do I inspire healthy habits?" Or "Do I share the admiration for perfect bodies and social standards of beauty?"





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- Show that they understand what the person is going through and that they care deeply about the situation;
- Ask what they can do to help, be flexible and never accuse or provoke feelings of guilt;
- Do not insist that the person eat at the table or in public;
- **Take food out of the focus of the conversation:** The main reason must always be the **person** suffering from the disturbance. He or She is extremely sensitive to any comments related to body, weight or appearance;
- Make sure that your interventions are not prejudiced, avoid fighting with the patient about the importance of food, mentioning that he is obliged to feed: no one is obliged to anything if they do not want to.

8.5.3 STRATEGIES FOR CAREGIVERS TO ADOPT

Case Story

Carolina is 18 years old. You are in your first year of college. One of her friends noticed the following:

"Carolina is very different from the time I met her. It lost a lot of weight. She is really too thin for her height, but even so, she is constantly saying that she is fat and never satisfied with it. Sometimes she even gets cruel to herself. Nothing she does or has ever satisfied her. A few years ago, she did not like to exercise, but now she trains twice a day and heavy training. She used to be very social and fun, but now, it seems she no longer has that joy that characterized her. She is obsessed with counting calories and is constantly telling which foods are good or bad. She's never had lunch with us in a group again. Close to lunchtime or teatime she's starting to get very agitated and anxious. And as soon as we get out of class, no one sees her anymore. She used to spend a lot more time with us, it was nice to talk to her. Not now. She's moved too far away from us."

Response:

- As a friend or family member, the first thing you can do is approach the sick person to try to understand what is going on and how long they have been feeling this way;
- Then they should encourage the person to seek treatment and accompany them in the process;
- The characteristic malnutrition of anorexia causes changes in the functioning and structure of the brain that will cause the person to have sudden swings in mood, irritability, sadness, obsessive thoughts about food, calories, weight, mood, tiredness and social isolation. These symptoms can be confused with those of the depression. That is why doctors usually wait for the person to regain some weight before diagnosing and treating a depression with medication along with eating disorder;
- People with anorexia when they look in the mirror see a body that doesn't correspond to reality or are constantly complaining that they are fat. In fact, it is very difficult to understand such a situation. This is called body image distortion and is one of the





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symptoms of anorexia nervosa. It is something complex and the family should not roughly contradict that perception. As soon as there is an improvement in the eating condition, this symptom also tends to improve.

- Easily the family can find that the practice of physical exercise is something beneficial for anyone. However, the physical exercise practiced by people with anorexia is done in an attempt to control the weight excessively. This practice arises to eliminate the food that the person has eaten and, in some way, relieve their sense of guilt. When the patient is in physical condition and free from this control of the disease, he or she will be advised to practice indicated exercise in a healthy way.
- So far, there is no "medicine" to stop the person from thinking about losing weight or being afraid of getting fat. The way forward is for the person to regain proper nutrition, regain weight and control his or her thoughts regarding the obsession to control the weight, with the help of professionals.
- Eating disorders are characterized by changes in dietary and nutritional intake (what food, quantity and quality is eaten), and also in people's eating behaviour and relationship with food. Consumption changes can lead to several clinical consequences and, together with the multidisciplinary team, the nutritionist will help the person and the family with these nutritional changes. The nutritionist will also assess and discuss the dietary behavioural changes and work with the person on their thoughts, beliefs and relationship to food.
- During meals, when the person with anorexia complains that there is too much food on the plate, the family should follow the nutritionist's instructions to the letter. Something that helps families is to say the following: "I only put in 2 spoons of rice, as it says in your plan, I did not put in an extra grain. This way, when the person says that there is a lot of food on the plate, the family should explain that they are only following the nutritionist's instructions. The family should mention that, in a next consultation with the professional, the person should discuss this aspect with the nutritionist. However, now, the family does not have the duty to change the amount of meals, neither to more nor less.

Case Story

Susana, 16 years old. Mother's Testimony:

"Susana has been playing volleyball for about 3 years ago in a team near home. She was never thin, but I always thought my daughter was well-built and had a beautiful body. She always liked to play volleyball, it is her passion, but about a year ago I noticed that things are different. She's never commented as much on her team friends' bodies as she does now. She says they're all elegant and that the clothes look good on them and she only sees "the fat coming out of her shorts". And if I try to say something to the contrary, she answers me aggressively. I notice that her weight has started to vary a lot. Both lose and gain. She has the most swollen face in her cheek area and argues that the marks on her back of hands are caused by volleyball. I often notice that at mealtimes she eats with pleasure, but in the end, she blames herself for eating so much or certain foods. It makes me confused when she cuts the food into very small pieces, but she says she likes it better that way. Sometimes she does not want to have dinner with us





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because she says she's already eaten. And when she does, she always has to go to the bathroom immediately after the meal. She's even changed her look now. She used to like to dress up and wear tight clothes, now the only tight clothes she wears is when she has volleyball games and has to wear the equipment. Otherwise, she only wears loose clothes. She says it's better for her to go in a tracksuit. Whether it's summer or winter."

Response:

- Compensatory behaviours cause chemical changes in the brain and body functioning, although the patient appears "normal". The diet-compulsions-vomiting cycle should be stopped completely as soon as possible to ensure complete recovery. This task is laborious and requires a joint effort of the patient, the family and the professionals involved.
- After this achievement, the other major challenge is to prevent these altered behaviours from returning.
- Chaotic eating compulsions and compensatory and purgative behaviours (vomiting) alter the mood, sleep, concentration, memory and mood of patients with bulimia nervosa. In general, with the readjustment of diet and the elimination of vomiting and weight control behaviours, these changes are resolved.
- The family should not decide what the person with bulimia will eat. Meal planning should be done individually considering all aspects of each patient, with the professionals indicated. Thus, besides planning what food and how much should be consumed (not always in an absolutely closed way, but with some exceptions), it is important to define mealtimes.
- Ideally, patients should eat accompanied so that they can have some supervision and have the guarantee that they are following the treatment.
- Family meals are especially recommended, especially for underage patients; For the meal happens in the best possible way – this includes a pleasant quiet environment.
- Having a food ritual is essential. The family should sit at the table, preferably without distractions from television or mobile phones. It is important that the mealtime is controlled, avoiding that it is too short or extends over hours.
- It is not convenient for the person with bulimia to go to the bathroom, during or at the end of meals. If there is even a need, a member of the family should find some strategy to use the same space at that time in order to be able to accompany the person to the bathroom. If such a situation is too instructive for the person's privacy, the family may encourage the person to leave the bathroom door ajar to facilitate communication if they are not feeling well or need to ask for help.





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8.5.4 RECOMMENDATIONS FOR CAREGIVERS

Family caregivers with members who are affected by eating disorders will face a roller coaster of emotions. This is even more so for those who are directly care-giving for a family member with an eating disorder. Very often, and depending on the severity of the disease, a person with an eating disorder will require ongoing and consistent caregiving.

This might be due to the need for supervision, meal support, or assistance with day to day activities. In the case of damaging physical and psychiatric consequences associated with eating disorders, an individual recovering from a disease, such as anorexia, bulimia, or binge eating disorder, might be dependent on a caregiver around the clock.

There is often a misconception that eating disorders are not “real” diseases, but this could not be farther from the truth.

Eating disorders are psychiatric illnesses with biological influences that have a drastic impact on a person’s life. Some individuals who are severely malnourished as a result of their eating disorder have severely altered cognitive function that may put them at fatal risk, particularly if left to themselves.

A caregiver for an eating disorder sufferer may provide care and support on various levels, depending on the severity of the disease and the issues at hand. Some family members may be caregivers for a child, adolescent or teenager that requires needed supervision and meal support to ensure that adequate food is being consumed or that eating disordered behaviours are not present.

Whatever role a caregiver may be providing, this is an incredibly challenging role. A caregiver is engaged in a disease that is not only physical, but mental and emotional as well.

8.5.5 TIPS FOR CAREGIVERS REGARDING THEMSELVES

Caregivers need to know that THEY need support too. Caregivers should have their own therapists and should make sure to set time aside for their own self-care. Caring for someone with an eating disorder is extremely challenging and they need to know they need and deserve support, too.

A message to caregivers:

Recovery from an eating disorder wouldn’t be possible without you.

You have been doing the incredibly hard job of being present for the many different aspects of recovery and for facing the truth of the pain that eating disorders bring to those that have them and to those who care for them.





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There is no doubt that, at some point, you will experience caregiver stress. This stress may come in the form of one or more of the following experiences:

- Having a desire to want to control everything;
- Feeling anxiety, depression, frustration or worry;
- Experiencing the burden of always being “on call”;
- Avoiding your own life and experiences;
- Seeking your own ways of “checking out”.

Please don’t judge yourself harshly for this.

You have had the courage to hang in there when others may have not recognized the illness as serious or dismissed it as a vain character trait. Eating disorders thrive in secrecy and isolation. We caregivers do better when we support each other.





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POSTTRAUMATIC STRESS DISORDER





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9 POSTTRAUMATIC STRESS DISORDER

Compiled by Department for Psychiatry and Psychological Medicine, Medical University Rijeka

9.1 WHAT IS POST-TRAUMATIC STRESS DISORDER?

What is posttraumatic stress disorder?

Post-traumatic stress disorder (PTSD) is a set of emotional, cognitive and behavioural disturbances that occur as a result of being exposed to a single or multiple traumatic event.

It is characterized by a triade of symptoms:

- the re-experiencing symptoms;
- avoidance symptoms;
- and hyperarousal symptoms or heightened sense of threat.

Symptoms can occur soon after the exposure as well as years later. It is a chronic condition which causes social, work- and health related problems. One of the basic hallmarks of traumatic experience and its consequences is a destructive and an indelible feeling of loneliness and separation from others. By its very nature, post-traumatic stress disorder can destroy an individual's ability to establish and maintain interpersonal relationships. Having a person who is taken care for affected with PTSD can be thus very burdensome for the partner or the family as a whole. At the same time, family support is a key role in recovery from PTSD.

Unlike other psychiatric illnesses, PTSD is caused by an external event. Even though what is considered traumatic is subject to personal appraisal, in general, traumatic events are those that involve death or threatened death, actual or threatened serious injury, and actual or threatened sexual violation. Important characteristics of traumatic events are the feelings of fear, helplessness and overwhelming stress. One can be directly exposed to traumatic event, learn about the traumatic exposure of a close one (family member, close friend), or be continuously directly or indirectly exposed to traumatic events through their work (for example, emergency workers or those who work with traumatized populations). Most of us will experience at least one traumatic event in our life, with the sudden unexpected loss of a loved one being the most common one. Traumatic events that include interpersonal violence such as war related trauma and sexual violations are the one's which are more likely to cause posttraumatic stress symptoms. It is also important to notice that almost 80% of individuals with PTSD have at least one more mental health disorder, most commonly depression and substance abuse. In most cases PTSD symptoms spontaneously disappear or go into remission five to seven years after the trauma but reappear around the time of anniversary of the event.





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PTSD symptoms	
Re-experiencing symptoms (known as cluster B symptoms)	<ul style="list-style-type: none"> • Frequently having upsetting thoughts or memories about the traumatic event; • Having recurrent nightmares; • Acting or feeling as though the traumatic event is happening again (<i>sometimes called a "flashback"</i>); • Having very strong feelings of distress when reminded of the traumatic event; • Being physically responsive, such as experiencing a surge in your heart rate or sweating, when reminded of the traumatic event.
Avoidance symptoms (known as cluster C symptoms)	<ul style="list-style-type: none"> • Making an effort to avoid thoughts, feelings, or conversations about the traumatic event; • Making an effort to avoid places or people that remind you of the traumatic event; • Having a difficult time remembering important parts of the traumatic event; • A loss of interest in important, once positive, activities; • Feeling distant from others; • Experiencing difficulties having positive feelings, such as happiness or love; • Feeling as though your life may be cut short.
Hyperarousal symptoms (known as cluster D symptoms)	<ul style="list-style-type: none"> • Having a difficult time falling or staying asleep; • Feeling more irritable or having outbursts of anger; • Having difficulty concentrating; • Feeling constantly on guard or like danger is lurking around every corner; • Being jumpy or easily startled.

9.2 BEHAVIOURS TO EXPECT

To understand the process of PTSD development it is important to know basic concepts of reactions to stress. All organisms tend to preserve themselves and to be in the state of homeostasis – a state of steady equilibrium. When something from the inside or the outside endangers i.e. “stresses” the homeostasis, the organism sets in motion complex biological and psychological mechanisms to adapt and restore the original state. Often an event is defined as stressful if its impact surpasses organism’s ability to cope and adapt effortlessly. Furthermore, traumatic events have the quality of danger as





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they include threatened death and/or serious injury. When faced with threatening situation human brain sends out all kinds of alarms and we become hyper aroused in order to preserve ourselves. Hyperarousal is characterized by heart racing, sweating, changes in attention and sensory awareness (we look for specific clues, get easily startled, etc.), and we feel fear or anger. Basically, our system is preparing us for fight of flight actions. In most cases, we recover shortly after the event and we go back to homeostasis. However, after prolonged and/or repetitive exposure to traumatic events a homeostatic condition may not be re-established. The organism stays in the state of prolonged hyperarousal and continuous to function as if the trauma is ongoing meaning that the “red alarm” is still on even though the crisis has long ended. In cases when homeostasis is not re-established the organism stays in a state of allostasis in which re-experiencing, avoidance and hyperarousal symptoms are dynamically interrelated in an attempt to seek stability in functioning following a change in the homeostatic baseline.

For example, a reminder of traumatic stressor like seeing news footage on the sexual abuse case will activate the memories on the trauma (re-experiencing) which in turn will active physiological response of fight or flight such as changes in heart rate and affect (hyperarousal). The unpleasantness of the feelings leads to conscious effort not to think about trauma or for example to alcohol abuse (avoidance).

Intense and prolonged exposure to traumatic events combined with other risk factors such as older age, pre-trauma mental health issues, early life trauma and lack of social support can lead to significant changes in personality development. This long-term effect of trauma is called complex PTSD. In addition to PTSD symptoms, complex form emphasizes changes on the personality level through alterations in regulation of affect and impulses, attention or consciousness, self-perception, relations with others, systems of meaning and somatizations. One of the features of complex PTSD are cognitive distortions. Trauma, and hence PTSD, have the ability to alter sense of identity, self-worth and core beliefs about the world. Those who suffer from complex PTSD have persistent negative beliefs about themselves (i.e. “I am no good”) and the world (“I cannot trust anyone”) and an exaggerated blame of self or others for causing the trauma (“I deserved this to happen to me”).

9.3 CONCERNS OF CAREGIVERS

Living with PTSD is not only difficult for the one who has it but for the family as well. As described earlier, person with PTSD functions in the survival mode, he/she is constantly on the guard, troubled by memories and physical reactions they cannot control, have problems sleeping, easily become irritated, and often feel better when they are isolated from the world. Symptoms of re-experiencing the traumatic event impact the survivor’s ability to be in the present, avoidance symptoms and symptoms of emotional numbing interfere with their ability to identify, modulate and express their feelings, and hyperarousal symptoms impact the feelings of security and the capacity of trusting others. All of the symptoms have a great effect on interpersonal bonding. Some of the features of PTSD pose an additional burden on relationships: unresolved mourning and the fear of possible





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future loss, demoralizing effect of trauma and of PTSD, unresolved sense of guilt, self-hatred, low self-esteem and shame.

One of the most serious consequences of PTSD on the family members is the feeling of an emotional void and a sensation of living with a stranger. Personal accounts of family members say that what they find the most difficult is the lack of emotional responsiveness and lack of involvement in family activities ranging from not paying attention to watching numerous hours of TV, not attending family weddings or even physical absence for couple of days without any notice. The consequence of emotional absence of the one suffering from PTSD is serious functional loss of a family member as they stop being active and often miss out on family events, ceremonies and rituals essential to the feeling of belonging and family identity. Family members sometimes feel the need to fill up that “emotional void” with their own feelings of guilt and responsibility. More often than not, another family member becomes overly functional and runs the family covering for the affected member as he/she takes a passive role and stays beside.

Other important PTSD related issues that greatly affect the family are anger outbursts and violent destructive behaviours. In some more serious cases it can become physical violence. PTSD can lead to difficulties managing emotions and impulses and this may manifest as extreme irritability, moodiness, or explosions of rage. In addition to constant state of physical and emotional stress, people with PTSD have troubles sleeping and are often exhausted, on the edge and physically strung out. All of these usually makes them overreact to daily stressors. Anger can also be a cover for feelings such as grief, helplessness, or guilt as anger can make one feel powerful instead of weak and vulnerable. The person who is taken care for may try hard to repress their angry feelings but usually they erupt when least expected. The volatility of the outbursts leaves the family members fearful, hurt and angry and family atmosphere of tension, anxiety, and hypervigilance builds up. Feelings are not expressed, and everyone feels like walking on eggshells. Such atmosphere in turn can lead to depression, somatic complaints and destructive behaviour in the family.

Persons suffering from PTSD can experience the present as the endless source of demands and expectations that they do not feel capable of living up to. Traumatized persons often experience a strong feeling of guilt as they view themselves as if they have not given enough to the family. They view themselves as a burden to others and feel like they are hurting their family members and important ones with their behaviour. At the same time, the guilt is stopping them from leaving the family as they do not want to hurt and/or disappoint them once more. In addition, symptoms of PTSD can also lead to job loss, substance abuse, and other problems that affect the entire family.





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9.4 RECOMMENDATIONS FOR CAREGIVERS

9.4.1 TIPS FOR CAREGIVERS REGARDING FAMILY MEMBER WITH PTSD

First of all, it is not your job or duty to cure their PTSD, but you can offer the support which is a key element in recovery from PTSD. As “support” is a very wide concept here are some tips on how you can support the person you take care for on their way of recovery:

- Do not force the care receiver to talk about the traumatic event. It is quite possible it will only make them feel worse, as talking about it will trigger symptoms. Also, some traumatized people do not want to recount the event(s) as a form of protecting the caregiver. And they might be right, as knowing the traumatic events makes the other susceptible for secondary traumatic stress disorder.
- Instead of talking, just spend time with the person who is taken care for, go for a walk, or sit on the terrace. It may feel like doing nothing but comfort for someone with PTSD comes from feeling engaged and accepted not necessarily from talking.
- If the care receivers do want to talk about their experience, try to listen without expectations or judgments. Do not worry that you have to give advice as it is the act of listening that is helpful. Respect their feelings and reactions even if you feel tempted to tell them that they should not feel that way. If you come across as disapproving or judgmental, they are unlikely to open up to you again.

Communication pitfalls to avoid ¹

Don't ...

- Give an easy answer or blithely tell the person who is taken care for, that everything is going to be okay;
- Stop the care receiver from talking about their feelings or fears;
- Offer unsolicited advice or tell what they “should” do;
- Blame all of your relationship or family problems on the PTSD of the person who is taken care for;
- Invalidate, minimize, or deny the traumatic experience;
- Give ultimatums or make threats or demands;
- Make the care receiver feel weak because they aren't coping as well as others;
- Tell the person who is taken care for that they were lucky it wasn't worse;
- Take over with your own personal experiences or feelings.

¹ Taken from: M. Smith & L. Robinson (2019) Helping someone with PTSD. Helguide. Available from: <https://www.helpguide.org/articles/ptsd-trauma/helping-someone-with-ptsd.htm?pdf=13688>.





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- Encourage the care receiver to join a support group with others who have gone through similar traumatic experiences. Often people with PTSD feel as if only those who have went through something similar can truly understand them. Such support groups can help them feel less alone.
- Do “normal” things with the person who is taken care for, things that have nothing to do with PTSD or the traumatic experience. Encourage the care receiver to participate in rhythmic exercise, seek out friends, and pursue hobbies that bring pleasure. Take a fitness class together, go dancing, or set a regular lunch date with friends and family.
- Trauma makes the world dangerous and frightening place causing those with PTSD to have trust issues with others and themselves. Often, they are worried you might leave them, so let them know that you’re here for the long run so they feel loved and supported.
- Just because you plan to stay and be there for him/her it does not mean they do not have to take on some family responsibilities. Come up with routines and schedules with tasks which create sense of stability and predictability and get the person who is taken care for involved in family activities and chores. For example, regular dinner time with everyone present, cleaning tasks, groceries shopping, etc.
- Minimize stress at home. Do not expect that he/she will be active or emotionally present all of the time. It is important that they have the space and the time for rest and relaxation.
- Individuals with PTSD get easily startled and aroused, and trauma triggers can take them right back in the past. Learn what are the triggers and try to minimize them. Some triggers are obvious, like firecrackers for veterans with PTSD, witnessing a car accident, watching news report on a sexual violence case. Other triggers can be more subtle such as hearing a song that was playing when the traumatic event happened, some smells like of fire or perfume of the perpetrator, and so on.





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Examples of external and internal PTSD triggers ²

<i>External</i>	<i>Internal</i>
<ul style="list-style-type: none"> • Sights, sounds, or smells associated with the trauma; • People, locations, or things that recall the trauma; • Significant dates or times, such as anniversaries or a specific time of day; • Nature (certain types of weather, seasons, etc.); • Conversations or media coverage about trauma or negative news events; • Situations that feel confining (stuck in traffic, at the doctor's office, in a crowd); • Relationship, family, school, work, or money pressures or arguments • Funerals, hospitals, or medical treatment. 	<ul style="list-style-type: none"> • Physical discomfort, such as hunger, thirst, fatigue, sickness, and sexual frustration; • Any bodily sensation that recalls the trauma, including pain, old wounds and scars, or a similar injury; • Strong emotions, especially feeling helpless, out of control, or trapped; • Dreams.

- Have a conversation with the loved one about the triggers and how they may have coped in the past, what has and what has not been helpful and come up with a game plan. The plan will help the loved one cope more efficiently in and at the same time helps you in knowing what to do.
- Anniversaries are special types of triggers which you have already learned by yourself. As "that time of year" approaches the care receiver is feeling worse and shows many disturbing behaviours. Just know that this period will pass and be there for them.
- Similar to PTSD triggers, you and the person who is taken care of should decide on how to respond when they have a nightmare, flashback, or panic attack. Having a plan in place will make the situation less scary for both of you. In cases of panic attacks and flashback a state of detachment from the body happens and a good way of helping is through "grounding" activities.
- If the care receiver has PTSD, most likely they have sleeping problems. They struggle falling asleep, are easily awoken, and have recurrent nightmares. Sleeping in different rooms might be good for the partner's sleep, but it might diminish the already escaping feeling of

² Adapted from: M. Smith & L. Robinson (2019) Helping someone with PTSD. Helpguide. Available from: <https://www.helpguide.org/articles/ptsd-trauma/helping-someone-with-ptsd.htm?pdf=13688>.





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intimacy. You should discuss what is the best solution, separate rooms or ear plugs. It is a good idea if the entire family follows sleep hygiene like creating a bedtime routine, creating pleasant environment for sleep, and avoid foods and drinks in the evening that interfere with sleep.

- In general, keep your promises. Help rebuild trust by showing that you're trustworthy. Be consistent and follow through on what you say you're going to do.
- The person who is taken care of probably has a feeling of shortened future and has difficulties making plans for the future. You should make plans for both and be sure to talk about them so your loved one can regain some sense of it.
- How to deal with anger outbursts and violent behaviour is an important topic and a major concern. Keep in mind that your safety comes first and if necessary, call the emergency number.

Grounding activities ³

- Tell the person you care for that they're having a flashback and that even though it feels real, the event is not actually happening again
 - Help remind them of their surroundings (for example, ask them to look around the room and describe out loud what they see)
 - Encourage them to take deep, slow breaths (hyperventilating will increase feelings of panic)
 - Avoid sudden movements or anything that might startle them
- Ask before you touch them. Touching or putting your arms around the person might make them feel trapped, which can lead to greater agitation and even violence

Dealing with volatility and anger

- **Watch for signs** that the care receiver is angry (clenching jaw or fists, talking louder, or getting agitated) and take steps to defuse the situation as soon as you see the initial warning signs.
- During an emotional outburst, try your best **to stay calm**. This will communicate to the person you care for, that you are "safe," and prevent the situation from escalating.
- **Give the person space**. Avoid crowding or grabbing the person. This can make a traumatized person feel threatened.
- Ask how you can help. For example: **"What can I do to help you right now?"** You can also suggest a time out or change of scenery.
- Put **safety first**. If the person gets more upset despite your attempts to calm him or her down, leave the house or lock yourself in a room. Call the emergency number (e.g. 112) if you fear that the person you care for may hurt himself or others.

³ Adapted from: M. Smith & L. Robinson (2019) Helping someone with PTSD. Helpguide. Available from: <https://www.helpguide.org/articles/ptsd-trauma/helping-someone-with-ptsd.htm?pdf=13688>.





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- Help the person cared for to **manage their anger**. Anger is a normal, healthy emotion, but when chronic, explosive anger spirals out of control, it can have serious consequences on a person's relationships, health, and state of mind. The person taken care for can get anger under control by exploring the root issues and learning healthier ways to express their feelings.

9.4.2 TIPS FOR CAREGIVERS REGARDING THEMSELVES

Taking care of the ill family member can cause emotional burnout – taking care of the family member with PTSD can even lead to secondary traumatization and PTSD on your own. So, first of all, you should educate yourself about PTSD. The more you know about it the easier it will be for you to help your loved and to keep things in perspective. As hard as it sometimes is try not to take the symptoms personally. More often than not, it is the disorder that makes them behave and interact as they do. That being said, it is very important that you do not let your family member's PTSD dominate your life while ignoring your own needs so try and take care of yourself:

- Take care of your basic needs.
- Ask other family members and friends for assistance so you can take a break. Learn to share responsibilities even with the person who has PTSD.
- Set boundaries and be realistic about what you're capable of giving. Know your limits, communicate them to your family member and others involved, and stick to them.
- Manage your own stress. The more calm, relaxed, and focused you are, the better you'll be able to help the person taken care for.
- Accept (and expect) mixed feelings. As you go through the emotional wringer, be prepared for a complicated mix of feelings—some of which you'll never want to admit. Just remember, having negative feelings toward your family member doesn't mean you don't love them.
- Be patient. Recovery is a process that takes time and often involves setbacks. The important thing is to stay positive and maintain support for the person taken care for.

Case Story

Jim is a war veteran in his late forties who lives his wife Anita and their 12-year-old son. He has been retired after his last mission which was almost two years ago. In the last month, his sleeping problems worsened which made him easily irritated during the day, even small things such as schoolbooks not put away can make him snap. Knowing that he might yell or be unnecessary rude towards his son and wife he stays out of the house even more than usual. Also, the anniversary of his mission is coming up and some celebrations are being organized at the veteran's association that he takes part in. Anita is very proud of her husband but at the same time worried about his bad dreams and angry when he stays with his friends instead of taking their son to his football game on Saturdays.





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Response:

- As caregiver, Anita should learn about PTSD triggers and how her husband has coped with them in the past; anniversaries are especially difficult periods and she should be encouraging him to talk about it but without putting pressure.
- If the person one cares for doesn't want to talk about the trauma or the anniversary of a significant event, respect that.
- Instead of talking of painful memories, do something else together such as offer to go for a walk with them or maybe even ask if you can participate in the celebration preparations.
- Caregivers should be encouraged to take care of themselves and to express their emotions in a nonaggressive way and to openly ask what they expect from their partner, e.g. to take care of football games.
- If happening with a lot of people (such as football games) are at the moment too much to cope with, the caregiver should ask for help from other family members or friends.
- A traumatized person with PTSD should be encouraged to learn about sleep hygiene and other stress relaxation techniques which can help them to better cope with symptoms and challenging situations.





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APPENDIX: REFERENCES

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