



*Compassionate*  
Community Care

# PATIENT ADVOCACY PROGRAM

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# *Compassionate* Community Care

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*Throughout this document, “client” refers to any person that you are advocating for. Compassionate Community Care (CCC) advocates are volunteers who do not receive payment in any form for advocacy.*

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# Table of Contents

What is an Advocate? .....	3
Advocacy: Let's get Legal .....	7
Important Terms to Know .....	8
Health Advocate's Code of Conduct .....	11
Residents' Bill of Rights .....	13
Effective Advocacy .....	17
Communication .....	19
Advocacy at the Doctor's Office .....	27
Doctors Appointments, the Coronavirus and Other Infectious Diseases .....	37
Advocating at the Hospital: Visiting and Monitoring Care .....	39
Dementia .....	41
Delirium .....	43
BIBLIOGRAPHY .....	49
APPENDICES:	
A Patient-Advocate Agreement .....	51
B Facts on Aging Quiz .....	53



Advocating for yourself and others is an important skill necessary to inform others about your needs, abilities, and wishes. Advocating is a skill that can be learned and results in *empowerment*.

Some people are unable, for various reasons, to advocate for themselves. They may have trouble stating their feelings and concerns. They may be afraid to speak out. They may not understand what is being said or what is happening to them.

### **You can be their voice.**

Just by being present, healthcare providers will view the person who you are advocating for differently. Your presence can affect what is being said, to whom, and how well this information is understood. You can listen, ask questions, and be a support when your client feels anxious or confused.

### **You can be a friend.**

You can encourage confidence and self-advocacy skills and most importantly, change the mindsets of others on how they view the person you advocate for. The person will be viewed as part of a community rather than an individual with health care needs.

### **You can make a difference!**



## What is an Advocate?

As an advocate, you talk with the person, support them, and act or speak on their behalf according to their instructions. An advocate empowers their client by helping them to understand the systems that affect their lives, access the care they need, and make intelligent, informed decisions regarding their goals.

### You can help the person:

- Stand up for his/her individual rights.
- Obtain and maintain opportunities to have meaningful involvement within their community.
- Gain access to the supports and disability-related services that he or she may require to have a good life.
- Speak to their health care providers.

An advocate can help by clarifying options, helping their client make their own choice based on their own values, communicating that choice, and doing the practical things necessary to implement the choice.

The person that you are advocating for may have multiple health conditions and be seeing a variety of doctors and specialists. A medical professional may not be aware of your client's complete health and treatments. You can help coordinate information. You can help each medical professional understand the full situation of your client.

When you act as an advocate, you improve the quality of life and overall health of your client.

**Advocacy is NOT:**

- Providing counselling,
- making decisions for another person,
- providing medication, or
- providing case management.

**To be a good advocate:**

**Be a good communicator.** Be clear and concrete. This means making sure that your messages or requests are stated as clearly and briefly as possible. An advocate should not have difficulty in speaking up for themselves, or others.

**Ask questions.** If there is something that you do not understand, ask for a better explanation or more information.

**Be a good listener.** One of the most important aspects of being an advocate is being a good listener. Before you can begin to advocate for someone you have to know what they want to achieve. Pay close attention to what people are trying to tell you.

**Be courteous and respectful.** Do not interrupt when other people are talking. Patience is important especially since some people have difficulty putting their thoughts together.

**Be assertive and persistent.** Talk in a firm and clear (but not harsh) tone of voice. Keep your body erect but also relaxed and maintain eye contact. Remember that assertive communication is not aggressive. A good advocate must not be easily intimidated by difficult people or situations. To be a good advocate you have to be willing to stand up for what the person you are advocating for wants or needs. This may feel uncomfortable, but it is important to remember that you are doing this for your client and not for yourself.



**Respect privacy.** You must be able to keep the person's information confidential. You are advocating for them; all of the information you may be privy to is private.

**Knowledge is power.** To be an advocate for someone you must stay informed of any and all medical information and concerns, support systems (whether or not they have family or friends in their life), and any other information necessary to advocate for that person. The more that you inform yourself about a particular issue or situation the better you will be able to speak on behalf of the person.

**Identify or anticipate the client's unmet needs,** and make recommendations for how to meet them, or how to advocate for them.

Some people are naturally better at advocacy than others. To be an advocate for yourself or others is a skill that can be learned with practice.

This is a learning experience for everyone involved.

You are a valuable volunteer.

You are helping to make your community a better place for those in need.

Make sure that you are keeping yourself healthy and happy too!



## Advocacy: Let's get Legal

An advocate is a person that supports or promotes the interests of another person. An advocacy relationship, on its own, carries no legal authority and is never meant to interfere with or supersede the judgement of the other person but rather to help them with their needs.

### Arrange Consent

To speak on behalf of another person, you must receive consent from them. Written permission is necessary before anyone can act on another person's behalf in obtaining documents or discussing personal information.

Once you both agree that you will be the person's advocate, complete the Patient-Advocate Agreement (Appendix A, p. 51).



## Important Terms to Know

As an advocate, you talk with your client, support them, and act on their behalf according to their instructions. There are differences between the roles and powers of an **advocate**, a **healthcare proxy**, an **agent**, and a **guardian** as follows:

1. An **advocate** is a person that supports or promotes the interests of another. An advocacy relationship, on its own, carries no legal authority. An advocate does not interfere with or supersede the judgement of the other person.
2. A **healthcare proxy** acts for a person if he/she is unable to make judgments or is unable to communicate. A healthcare proxy is most commonly part of a document called a healthcare directive, an advance directive, or a “living will”.
3. An **agent** (under power of attorney) is someone to whom the client has given legal authority to conduct business on their behalf. Power of attorney agents are not authorized to make decisions or take actions that go against the expressed or written wishes of their client.

If a person experiences cognitive decline, their ability to make decisions may be compromised—either temporarily or permanently. If you are acting as an advocate for someone with cognitive decline, speak to their family. Find out if the client has any powers of attorney:

- 1) Healthcare power of attorney, also known as a healthcare proxy. In this document, a person is legally named to make medical decisions on behalf of the client.
- 2) Financial powers of attorney:
  - a) A general power of attorney is set up to name a person who will handle all financial affairs.
  - b) A specific power of attorney is set up to handle a particular transaction.

4. A **guardian** is a person who has been appointed by a judge to take care of an incompetent adult personally and/or manage that person's affairs. Guardians are authorized to make decisions without the knowledge or consent of their "ward".

Always remember that if you are an advocate, you are NOT authorized to make decisions for the other person.  
You are only to represent their wishes.





## Health Advocate's Code of Conduct

Being an effective advocate means upholding the highest ethics and standards of practice:

- To practice with compassion and respect for your client and their family.
- To promote the health, safety, and rights of your client.
- To foster the autonomy of the person.
- To be transparent.
- To maintain privacy on behalf of your client and keep confidential all activities and records according to agreements with them and any applicable laws.
- To guide and assist your client in medical decision-making but at no time make decisions about health or medical care on their behalf.
- To promote use of your client's values and belief systems as the foundation for your decision-making.
- To practice within your competency. Any requests for services outside your expertise should be referred to someone who is equipped to provide those services.
- Not to accept money or gifts.
- Not to fulfill requests to perform illegal or unethical actions.
- Not to develop a romantic or sexual relationship with a client or someone related to the client.
- Not to agree to perform any duties without the disclosure or input needed from the client.
- Not to discriminate due to the person's age, race, religion, culture or ethnic background, gender, sexual orientation, or immigration status.
- To continue to further your knowledge base and skillset in order to provide your client with the best care.





## **Residents' Bill of Rights**

Taken from the Long-Term Care Homes Act, 2007, Part II. Retrieved from [www.ontario.ca/laws/statute/07l08#BK5](http://www.ontario.ca/laws/statute/07l08#BK5)

“Resident” means a person admitted to and living in a long-term care home.

### **Every resident has the right:**

1. To be treated with courtesy and respect and in a way that fully recognizes the resident’s individuality and respects the resident’s dignity.
2. To be protected from abuse.
3. Not to be neglected by the licensee or staff.
4. To be properly sheltered, fed, clothed, groomed, and cared for in a manner consistent with his or her needs.
5. To live in a safe and clean environment.
6. To exercise the rights of a citizen.
7. To be told who is responsible for and who is providing the resident’s direct care.
8. To be afforded privacy in treatment and in caring for his or her personal needs.
9. To have his or her participation in decision-making respected.
10. To keep and display personal possessions, pictures, and furnishings in his or her room subject to safety requirements and the rights of other residents.

11. To:
  - i. Participate fully in the development, implementation, review, and revision of his or her plan of care,
  - ii. give or refuse consent to any treatment, care or services for which his or her consent is required by law and to be informed of the consequences of giving or refusing consent,
  - iii. participate fully in making any decision concerning any aspect of his or her care, including any decision concerning his or her admission, discharge or transfer to or from a long-term care home and to obtain an independent opinion regarding any of those matters, and
  - iv. have his or her personal health information within the meaning of the *Personal Health Information Protection Act, 2004* kept confidential in accordance with that Act, and to have access to his or her records of personal health information, including his or her plan of care, in accordance with that Act.
12. To receive care and assistance towards independence based on a restorative care philosophy to maximize independence to the greatest extent possible.
13. Not to be restrained or confined, except in the limited circumstances provided for under this Act and subject to the requirements provided for under this Act.
14. To communicate in confidence, receive visitors of his or her choice and consult in private with any person without interference.
15. People who are dying or very ill have the right to have family and friends present 24 hours per day.
16. To designate a person to receive information concerning any transfer or any hospitalization of the resident and to have that person receive that information immediately.

17. To raise concerns or recommend changes in policies and services on behalf of himself or herself or others to the following persons and organizations without interference and without fear of coercion, discrimination or reprisal, whether directed at the resident or anyone else,
  - i. the Residents' Council,
  - ii. the Family Council,
  - iii. the licensee, and, if the licensee is a corporation, the directors and officers of the corporation, a member of the committee of management for the home or of the board of management for the home,
  - iv. staff members,
  - v. government officials,
  - vi. any other person inside or outside the long-term care home.
18. To form friendships and relationships and to participate in the life of the long-term care home.
19. To have his or her lifestyle and choices respected.
20. To participate in the Residents' Council.
21. To meet privately with his or her spouse or another person in a room that assures privacy.
22. To share a room with another resident according to their mutual wishes, if appropriate accommodation is available.
23. To pursue social, cultural, religious, spiritual, and other interests, to develop his or her potential and to be given reasonable assistance by the licensee to pursue these interests and to develop his or her potential.

24. To be informed in writing of any law, rule or policy affecting services provided to the resident and of the procedures for initiating complaints.
25. To manage his or her own financial affairs unless the resident lacks the legal capacity to do so.
26. To be given access to protected outdoor areas in order to enjoy outdoor activity unless the physical setting makes this impossible.
27. To have any friend, family member, or other person of importance to the resident attend any meeting with the licensee or the staff of the home.

# Effective Advocacy

There may be times when your client finds themselves in situations where they feel powerless and vulnerable. They may not want to risk angering people whom they fear could make their lives difficult. This is particularly the case for residents in medical or long-term care facilities. As their advocate, you can help them through these stressful situations.

## How You Can Help

### Be Present

Be present physically, mentally, and emotionally. As an advocate, give your client your complete attention. An understanding listener can be a great source of comfort. You can provide a fresh outlook on their situation.

### Create Empowering Solutions

For many older adults, life can become unmanageable when they can no longer drive to the places they need to go, organize medications effectively, work with modern technology (e.g. bank machines, computers, and cell phones) or remember the steps necessary to do things like paying bills on time. As an advocate, you can help them find solutions to their daily problems.



## **Be Aware of Options**

As options become more complex and service providers become more specialized, it can be difficult for your client to be aware of all their options. Be careful not to overstep your own expertise. Explain all available options to your client. Try to offer alternative solutions to their dilemmas.

## **Communicate Choices**

Many things can become confused when someone has trouble hearing, seeing, and/or remembering. An effective advocate can make a significant improvement in the life of their client by simply preventing breakdowns in communication.

When communicating, always keep in mind the privacy of the person for whom you are advocating. Many service providers—especially health care providers and financial professionals—require permission to speak with an advocate. If your client has asked you to advocate for them in a healthcare setting, sign the Patient-Advocate Agreement (Appendix A, p. 51).

An advocate's role is to help their client make their own choice, then help them carry out that choice. It is not the role of the advocate to make the choice or lobby for a particular choice.

Remember that if you feel that the person you are advocating for is putting themselves in danger, you can obtain assistance from the Compassionate Community Care helpline: 1-855-675-8749.

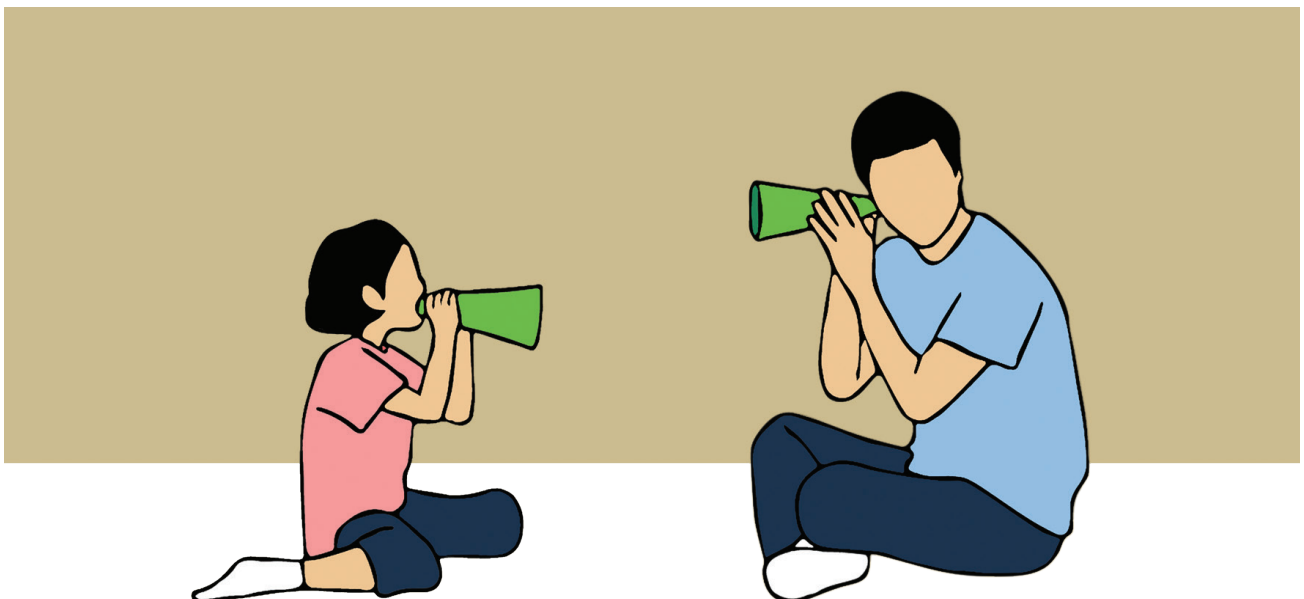
Effective advocates should look for positive solutions to problems. In protecting the people you care for, it is easy (and sometimes understandable) to criticize the people, organizations, or systems involved.

Always speak positively and constructively.

# Communication

Clear communication is critical to successful advocacy. Here are some tips to keep in mind:

- Always be polite.
- Be clear about your position and/or that of the organization you represent.
- Be helpful.
- Be patient but persistent.
- Decide what you are trying to communicate. What do you want them to do?
- If you have been misunderstood, correct and rephrase.
- If you do not know an answer, say so. If you do not understand a question, ask for clarification.
- Listen carefully to the question.
- Make it very clear what you want them to do.
- Speak slowly.



## Key Active Listening Skills

- **Encourage**: Let them know it is okay to talk, and that you want to hear what they have to say. Try using brief prompts such as, “Go on” or, “How did that make you feel?”
- **Inquire**: To get to the heart of a matter, you may need to ask direct questions.
- **Name the emotion**: By helping a person recognize and name their emotions, emotions become more manageable.
- **Redirect**: Older adults sometimes veer off topic easily. By bringing their attention back to the matter at hand, you help them focus on what is important, such as the subject being discussed, or the problem to be resolved.
- **Reflect**: Validate the speaker’s opinion; it shows that you are listening and processing the information received.
- **Rephrase**: Summarize their comments into your own words to show that you are listening.
- **Silence**: Allow space for others to talk and think. Do not be quick to jump in with what you think the other person will say.
- **Summarize**: This is a good way to make sure you understand a situation correctly.
- **Use “I” statements** instead of “YOU”: Using “I” statements to share your feelings can invite the other person to do the same. “YOU” statements can seem accusing.
- **Validate**: By valuing a person’s feelings, you can push past any emotional barriers that might prevent them from speaking honestly.



When you disagree:

1. Acknowledge the impact of the past.
2. Focus on the present.
3. Focus on the problem.
4. Do not generalize.
5. Listen.
6. Be kind and compassionate.

## Communicating with Different Personality Types

The words Aggressor, Contemplator, Mediator, and Socializer describe how different people interact with others, solve problems, and deal with stress. Here are some guidelines for communicating with these personality types.

### Aggressor

Aggressors ask the “What?” questions. Their biggest fear is losing control.

These individuals are competitive, goal-oriented, and demanding. They are blunt and direct in their communication and make quick decisions.

#### Tips for communicating with Aggressors:

- Be factual and accurate; do not exaggerate.
- Be straightforward and ask challenging questions; do not tiptoe.
- Use simple language that educates them about the situation.
- Have structured conversations with tasks and goals for making decisions and achieving objectives.
- Have conversations in a timely fashion; do not rush.
- Stand your ground; be strong and confident.
- Use indisputable “I” messages rather than judgmental “you” messages.
- Remember that you do not have to agree.
- Keep them active in the decision-making. Give them guides that they can follow and manage on their own.

## Contemplator

Contemplators ask the “Why?” questions. Their biggest fear is criticism of their work or ideas.

These individuals are meticulous, introverted, and detail-orientated. They can be perfectionists, and they are suspicious of others. They may answer a question with a question. Contemplators are good problem solvers.

### Tips for communicating with Contemplators:

- Lay out problems in a detailed and orderly manner.
- Be truthful and forthright in your conversations.
- Give breathing space before you expect a response.
- Ask them what they are thinking and feeling.
- Show empathy when they share concerns and worries.
- Try to bring a big-picture view to the discussion.
- Use humor to bring them out of themselves and their worries.
- Speak in a way that shows your appreciation and affirmation.

## **Mediator**

Mediators ask the “How?” questions. Their biggest fear is loss of stability.

These individuals are calm, level-headed, and great listeners. Mediators like to contemplate questions—you will not get an answer immediately. They dislike conflict so they will internalize and tolerate it. Mediators try to keep everyone happy, often at the expense of their own happiness.

### **Tips for communicating with Mediators:**

- Show appreciation before difficult discussions.
- Let them take charge of planning.
- Put discussions on the calendar. “Think, plan, and think some more” sums up the Mediator.
- Combine facts and feelings.
- Give them space to express their opinions before you give your take on the situation.
- Avoid criticism and nagging.
- State the rules for the conversation at the outset.
- Be prepared to take your time.

## **Socializer**

Socializers ask the “Who?” questions. Their biggest fear is social rejection.

These individuals are charismatic, enthusiastic, persuasive, talkative, and social. They are also visual and creative. Socializers do not keep track of time well. They enjoy being the center of attention.

### **Tips for communicating with Socializers:**

- Begin with a compliment.
- Gently redirect the conversation from tangents.
- Be spontaneous.
- Start with feelings.
- Focus on the big picture, save details for later.
- Stay positive, talk about what can go right in a situation.
- Work together on plans.
- Be prepared to move on quickly.





You can help a person to understand and navigate through the healthcare system. Just by being present, you can affect what is being said, to whom, and how well this information is understood. You can listen, ask questions, and be a support when your client feels anxious or confused.

### **As a Health Advocate You:**

1. Help medical professionals understand the complete health situation of your client.
2. Keep track of old and new symptoms, problems with current treatments, or significant changes to discuss with the doctor.
3. Manage current medications and making sure all medications and supplements are reviewed on a regular basis.
4. Go together to appointments and take notes, bringing up important questions for the doctor, and ensuring that critical details are not overlooked.

**To be a health advocate, you require  
the written permission of your client.**

### **Arrange Consent**

Discuss with the person what expectations he/she may have for you as their advocate. Ensure that you are willing, able, and comfortable with doing these tasks before you agree to become their advocate.

To speak on behalf of another person, you must receive consent from that person. Written permission is necessary before anyone can act on another person's behalf in obtaining documents or discussing personal information.

Once you both agree that you will be the person's advocate, complete the Patient-Advocate Agreement (Appendix A, p. 51).

Before your client's appointment, ask them about how they have been feeling and if anything is bothering them. You may get more information when they are relaxed and have time to think, than when they are questioned at the doctor's office. Asking a few separate times over a couple of weeks might help you collect more information as they remember different things.

### **Before You Go**

The time of day for the appointment is important. The person may be better able to participate in the doctor's visit in the morning before the activities of the day, or in the afternoon because they sleep late.

You and your client should be well-informed about their health care needs. Understand the condition, treatments, and any terms the doctor may use.



## **Review the following with your client:**

These points will help you maintain positive, productive relationships with your client's medical providers. As an advocate, you and your client are partners. Doctors should listen to your concerns and answer your questions, so you feel comfortable. The doctor should be sure that your client understands and feels comfortable with decisions regarding their health.

- What are the person's concerns? Is it about physical symptoms, like pain or shortness of breath, or feelings, such as being sad and worried?
- Is the person seeking information about medication side effects or the outcomes of prescribed treatments?
- Does the person want to report new symptoms or concerns?
- Gently discuss how to talk with the doctor about sensitive issues.
- He or she might prefer that you do not talk to the doctor. Your presence may be support enough.
- Find out if the person wants to have some time alone with the doctor.

Good preparation involves being as specific as possible about what you want to achieve and, if possible, what specific actions should occur.

## **Gather information from visits with other doctors or specialists:**

- List of symptoms.
- List of prescriptions: Bring a list of medicines he or she uses, or put them in a bag to take with you. This includes herbal remedies, creams, supplements, and other over-the-counter medicines.
- Test results: Gather information from visits with other doctors and/or specialists.
- Drug allergies.

Bring this information along with the list of questions and topics that you and your client want to discuss with the doctor.

Have a notebook designated specifically for meetings with medical personnel. Taking notes at each appointment/phone call will help you and your client understand why certain decisions were made or what the doctor said.

Record the date and time of every meeting/telephone call.

Record your discussions.

Write the speaker's name, title or position, phone number, date, time, and information obtained from the conversation.

Sometimes people will say or promise things verbally that they do not act on. Having a written record of what was agreed to will be helpful.

Keep a file of written responses and other documents (e.g. letters, emails). It is important to keep track of these in case you need them in the future.

Write down your questions. If you or your client become too upset to talk, you can hand the written list over to the doctor to read.



## **The Day of the Appointment**

1. Call the office to see if the doctor is on time with his or her appointments. Inform the receptionist that you will be at the appointment to be a notetaker.
2. Bring a bottle of water, magazine, etc. for your client in case there is an unexpected delay.
3. Bring the list of medicines he or she uses, or put them in a bag to take with you. This includes prescriptions as well as herbal remedies, creams, supplements, and other over-the-counter medicines.

## **The Visit**

1. Be on time for appointments.
2. Introduce yourself to new doctors or nurses.
3. Respect your client's privacy.
4. Go to the waiting room if the person requires a physical examination.
5. Let the doctor know if your client has any hearing or vision problems that make it hard to communicate with them.
6. Be aware of your body language. Sit up straight, look the doctor in the eye.
7. Take notes.
8. Be kind, even if the doctor is not.
9. If you feel upset, take a deep breath and count to ten before expressing yourself. This will calm you down.
10. Listen. Do not move on to your next thought or retort before the doctor is finished speaking. Once they are finished, ask questions or bring up your concerns.

11. Do not be intimidated by the doctor or any other health care professional—you are there to advocate.
12. If your client wants to speak when the doctor asks you a question, turn towards him/her and suggest that he/she answer.
13. Let the doctor know of any changes in your client's health since the last visit.
14. Keep the discussion focused on problem solving.
15. Have the following questions answered:
  - a. How serious is the condition?
  - b. How will it impact your client's daily life?
  - c. Is it chronic? Will it worsen over time, or go away with treatment?
  - d. What causes the condition?
  - e. What are signs and symptoms to watch for?
  - f. Is it contagious?
16. Do not be embarrassed about asking questions. Ask questions to make sure you understand the doctor's instructions and explanations. Repeat in your own words what the doctor said just to make sure you understand.
17. If new medication is prescribed:
  - a. How effective is this treatment?
  - b. How will the medication(s) that your client is currently taking interact in the body?
  - c. How is the medication taken?
  - d. How long will your client need to take it?
  - e. How much will it cost?

- f. Does your client's insurance (provincial or private) cover the cost?
  - g. What are the side effects?
  - h. Will this affect your client's ability to function independently?
  - i. How long will it take for the medication to work?
  - j. Are there any alternative treatments?
  - k. What if they decide not to take the medication?
  - l. Read up on any new medications the doctor prescribes.
18. Tests:
- a. What tests do you recommend? (e.g. lab tests, x-rays, CT scans, MRI, etc.)
  - b. How accurate is the test?
  - c. When and how will the client get the results?
  - d. What happens then?
19. Ask the doctor whether he or she has any recommendations with respect to lifestyle factors including diet, stress management, and exercise.
20. Inquire about services that may be offered that may be beneficial to the person (dietitian, Meals on Wheels, outings, etc.) The doctor may be able to refer you to a counselor or community agency to help.
21. Write down all instructions given by the doctor and have him or her review it before you leave the office.
22. Do not have your client sign any consent form until he or she understands it completely and the doctor has answered all their questions.

23. Ask for information sheets that you can take home.
24. Ask when your client should next contact the doctor to monitor progress, get results, determine if the treatment is working, etc.
25. Ask the doctor to do a full medication review at least once a year. This is to ensure that the medications are working well together, being taken at the right times and in the right combinations, and to check if all medications are still needed.

### **After the Visit**

Make follow-up appointments right away. If necessary, help your client fill any prescriptions. Ask the pharmacist for information on side effects of the medication. They may also have information sheets.

Discuss with your client how the meeting/visit went.

*Was the visit a good experience?*

*What could have been done to make it better?*

*Did I (the advocate) ask too many questions?*

*Did I let my client speak up for himself or herself?*

*Did they feel that they had enough time to ask the doctor questions?*

**Remember, a successful interaction with the healthcare system requires persistence.**

“The healthcare system can be very challenging to navigate. There are a lot of regulations than can impact your access to care, and they can be confusing. Sometimes your technique does not work the first time. You need to keep at it when accessing certain services, and you need to speak up. There is also an interesting dynamic with older adults when it comes to health care: They often say they do not want to bother their doctor, or they want to be a ‘good patient.’ We have to help them understand that being a good patient or a good advocate for someone else means getting what you need to make sure you get quality care.”

Dr. John Whyte, WebMD Chief Medical Officer





## Doctors Appointments, the Coronavirus and Other Infectious Diseases

A visit to the doctor's office will be different during the coronavirus outbreak. Here is what to expect:

1. Doctors and staff will wear personal protective equipment like masks and gloves.
2. Offices are disinfected and sanitized regularly.
3. Offices are set up for social distancing (six feet apart).
4. You might check in by phone, wait in your car instead of the waiting room, and be the only patient in the office.
5. You will have to answer questions based on possible contact with infected individuals.
6. You will have to wear a mask.

To limit your risk of getting sick:

- Wear a mask.
- Keep your hands away from your face.
- Wash your hands often and well.





As an advocate, you may find yourself advocating for someone who is in the hospital. Your primary role may be to visit the person. Observe anything that may be happening and advocate for what they would like based on prior discussions. You may need to inform a family member or their decision maker (if they have one) about a situation or treatment you have observed.

In many cases, the person you are advocating for will be fully aware and may not need you to speak on their behalf. However, your presence should improve the psychological wellbeing of the patient and may speed up their recovery time. In addition, being there may result in better health care from doctors and nurses.

### **At the hospital:**

1. Visit as often as possible.
2. Monitor medication. Take notes of the medication they are being given to make sure it is the correct drug at the correct dose, given at the right time. Check that your client is getting the right levels of medication. They should not be in pain or overmedicated.

3. Inform hospital staff of any special needs of your client.
4. Make your client more comfortable. If permitted, bring in skin moisturizer, lip balm, a personal item (e.g. blanket, stuffed animal, or family photo), and favourite books or magazines.
5. Throughout their stay, you may wish to read aloud a favourite book to them.

### **When discharged:**

Before leaving the hospital, make sure you understand how the medication regimen is different from your client's pre-hospitalization medications and why the changes are being made.

“Studies found that the median rate of medication error or unintentional medication discrepancy was nearly 50% in adult and elderly patients after hospital discharge. Nearly 20% of adult and elderly patients in studies were reported to be affected by adverse drug events (ADEs) after hospital discharge.” (Alqenae et al., 2020)

# Dementia

Dementia develops gradually and gets progressively worse.

Being in an unfamiliar hospital environment can be disorienting and confusing. Hospitals can be noisy and are full of unfamiliar people, bright lights, and reflective surfaces. Your client may not be feeling well. He or she will be touched and questioned by medical staff.

Someone with dementia often cannot or will not accurately report symptoms or pain. They may not remember what happened or why they need to be in the hospital. This can cause agitation, delirium, aggression, worsening of symptoms, and other challenging behaviors. Hospital stays can bring out these behaviors.

## **As an advocate, you can help relieve these stressors:**

- Ask if harsh lighting can be dimmed.
- Ask to be moved to a quieter area.
- Bring a simple, calming activity for your client to focus on and help them stay busy while they wait for treatment or tests.
- Take notes if you notice expressions of pain or changes in their symptoms so you can update doctors and nurses.



# Delirium

Delirium happens suddenly and typically changes throughout the day.

If an older adult with no history of cognitive impairment suddenly starts having cognitive issues during or after a hospitalization, it is most likely not dementia—it may be delirium.

People with delirium often have terrifying hallucinations, delusions, and are unable to think clearly or focus. In older hospital patients, these symptoms can be misdiagnosed as dementia.

Some patients with delirium are agitated and combative and others are sleepy and cannot pay attention. They may show symptoms of post-traumatic stress disorder (PTSD).

It can happen at any age, but delirium is more common in hospitalized persons older than age 65.

Research has linked delirium to longer hospital stays, greater risk of falls, increased risk of developing dementia and an increased death rate.

## **Delirium is more likely to develop when:**

- Large doses of anti-anxiety drugs and narcotics are given. Tranquilizers used to treat anxiety, called benzodiazepines, are known to trigger or exacerbate the problem.
- Patients are in intensive care.
- Patients are heavily sedated.
- The patient is on a ventilator.

- The environment is busy, noisy, and brightly lit.
- Sleep is constantly interrupted, and the staff keeps changing.

### **Warning signs of delirium:**

- Acute changes in concentration,
- inattention,
- disordered thinking,
- disorganized speech,
- excessive drowsiness,
- disorientation,
- inappropriate behaviour,
- unexplained difficulty with feeding oneself, and
- unexplained difficulty with mobility (or movement if the person is immobile).

### **What you can do:**

- Speak with the doctor to minimize the amount of medication. If you notice negative side effects, ask them to make changes immediately.
- Ask staff to dim the lights and turn down noisy machines if possible.
- Close the door to reduce noise.
- Keep your client hydrated.
- Stay with your client so they have a familiar face.
- Arrange for your client to get a maximum amount of undisturbed sleep. Ask doctors and nurses if their visits can be coordinated or less frequent (without harm to health).



- Have a large-print clock and calendar visible so your client can see the time and date.
- Bring a family photo so they have familiar faces to look at.
- Whenever possible, ask your client to take short walks or practice therapy exercises.

A study by Harvard researchers found that a variety of non-drug interventions—making sure patients' sleep-wake cycles were preserved, that they had their eye-glasses and hearing aids, and that they were not dehydrated—reduced delirium by 53%. As a result, falls among hospitalized patients was reduced by 62%.  
(Hshieh et al., 2015)



## Delirium Detection Questionnaire<sup>20</sup>

This tool is a simple way for you to communicate what you are seeing to a health care professional. Review and complete the following table.

<b>During your interaction with the person today, have you observed any of the following?</b>	<b>YES</b>	<b>NO</b>
<b>Circle the corresponding value in the answer boxes.</b>		
1. Altered level of awareness to the environment in any way different than being normally awake.	3	0
2. Reduced attentiveness; inability to focus on you during the interaction	4	0
3. Fluctuation in awareness and attentiveness, such as drifting in and out during an interaction or through the day.	3	0
4. Disordered thinking; the response (whether verbal or action) is unrelated to the question or request.	3	0
5. Disorganized behaviour; purposeless, irrational, under-responsive or overresponsive to requests.	2	0
6. Unexplained impaired eating or drinking (excluding appetite); unable to perform the actions to feed oneself.	2	0
7. Unexplained difficulty with mobility or movement.	1	0
<b>Score</b>	<input style="width: 50px; height: 30px;" type="text"/>	
Scoring information for health professional use:		
<b>Score</b>	<b>Predictive Value</b>	<b>Description</b>
4	89%	Possible delirium: evaluate potential medical causes, medications, substances, etc.
9	100%	Delirium: immediate medical evaluation required.

<sup>20</sup> Shulman, R. & Trillium Health Partners. (2014). *The Sour Seven: Delirium Detection Questionnaire for Caregivers*. Retrieved from: [https://static-content.springer.com/esm/art%3A10.1186%2Fs12877-016-0217-2/MediaObjects/12877\\_2016\\_217\\_MOESM1\\_ESM.pdf](https://static-content.springer.com/esm/art%3A10.1186%2Fs12877-016-0217-2/MediaObjects/12877_2016_217_MOESM1_ESM.pdf)



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# Appendix A: Patient-Advocate Agreement

The Advocate should discuss the information contained here with the Patient before completing this agreement.

Both Advocate and Patient must review and sign this agreement.

After signing, ensure that each person has a copy of the agreement. Provide a copy for the Patient's healthcare provider and family.

The Advocate should take this document with them when they go with the Patient to a medical facility.

This agreement can be ended at any time by the Patient and/or Advocate.

**I, the Patient, give permission to my Advocate to do the following (check all that apply):**

- Access and review my medical health records during my current care (as per the Personal Health Information Protection Act).
- Arrange medical appointments for me.
- Attend appointments, tests and treatments with me.
- Be present when the doctor or healthcare provider speaks with me.
- Be present in the room after an exam to write down information and instructions.
- Review the doctor's or healthcare provider's handwritten information to be sure I can read and understand it.
- Ask questions of my healthcare provider(s) about my healthcare and test results.
- Check, confirm and keep track of my medications.
- Get information on my behalf to support my healthcare decisions.

- Review with me my choices for doctors, tests and treatments.
- Communicate my needs and requests.
- Other:

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**Disclaimer**

***The information in this agreement is given to help you. It is not professional, legal or medical advice. Compassionate Community Care is not responsible for any loss, damage, or injury arising from a person acting as a patient advocate.***

***Signing this agreement means that you have read the entire agreement, and that you accept this disclaimer.***

Patient's Name (please print):

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Patient's Signature:

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Patient's Ontario Health Insurance Plan # (OHIP):

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Advocate's Name (please print):

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Advocate's Signature:

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Today's Date:

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## Appendix B: Facts on Aging Quiz

Taken from the quiz by Linda Breytspraak and Lynn Badura, 2015.

True (T) or False (F):

- T F 1. As people grow older, their intelligence declines significantly.
- T F 2. It is very difficult for older adults to learn new things.
- T F 3. Personality changes with age.
- T F 4. Memory loss is a normal part of aging.
- T F 5. As adults grow older, reaction time increases.
- T F 6. Older adults have more trouble sleeping than younger adults do.
- T F 7. Older people perspire less, so they are more likely to suffer from hyperthermia (having a body temp. above normal).
- T F 8. All five senses tend to decline with age.
- T F 9. As people live longer, they face fewer acute conditions and more chronic health conditions.
- T F 10. People tend to become more spiritual as they grow older.
- T F 11. Older persons take longer to recover from physical and psychological stress.
- T F 12. Older females exhibit better health care practices than older males.



## *Answers to* **Facts on Aging Quiz**

- 1. As people grow older, their intelligence declines significantly.**

**False.** Although there are some circumstances where this statement may hold true, current research suggests that intellectual performance in healthy individuals holds up well into old age. The average magnitude of intellectual decline is typically small in the 60s and 70s and is probably of little significance for competent behavior. There is more average decline for most abilities observed once the 80s are reached, although even in this age range there are substantial individual differences. The good news is that research data now indicates that this is a life stage programmed for plasticity and the development of unique capacities and that intellectual decline can be modified by lifestyle interventions, such as physical activity, a healthy diet, mental stimulation, and social interaction.

- 2. It is very difficult for older adults to learn new things.**

**False.** Although learning performance tends on average to decline with age, all age groups can learn. Studies have shown that learning performance can be improved with instruction and practice, extra time to learn information or skills, and relevance of the learning task to interests and expertise. It is well established that those who regularly practice their learning skills maintain their learning efficiency over their life span.

- 3. Personality changes with age.**

**False.** Personality remains consistent in men and women throughout life. It impacts roles and life satisfaction. Particular traits in youth and middle age will not only persist but may be more pronounced in later life.

**4. Memory loss is a normal part of aging.**

**True.** As one ages there is modest memory loss, primarily short-term memory (recent events). Older adults are more likely to retain past or new information that is based on knowledge acquired or builds upon their life course or events. Retrieval of information may slow with age. The causes of these changes are unknown, but may include stress, loss, physical disease, medication effects, depression, and age-related brain changes. Lack of attention, fatigue, hearing loss, and misunderstanding are among factors impacting memory loss in persons of all ages. Strategies such as activity and exercise, association, visualization, environmental cueing, organization by category and connection to a place may help to prompt memory.

**5. As adults grow older, reaction time increases.**

**True.** Reaction time is the interval that elapses between the onset of a stimulus and the completion of a motor response, such as hitting the brake pedal of a car when the traffic light turns yellow or red. When processing ordinary stimuli, adults do show large increases in response time with increasing age.

**6. Older adults have more trouble sleeping than younger adults do.**

**True.** Older adults often experience sleep changes such as taking longer to fall asleep, frequent awakenings, daytime napping, circadian rhythm changes, lighter sleep (less time in deep sleep and REM sleep), more abnormal breathing events, and increased frequency of leg movements. The overall quality of sleep may decline with age even though more time may be spent in bed.

**7. Older people perspire less, so they are more likely to suffer from hyperthermia.**

**True.** Perspiration and quenching of thirst help to combat overheating. Older adults perspire less, are less aware of thirst and less able to feel or adapt to extremes in temperature than younger persons. Less sensitive skin sensors and less insulation

of fatty deposits under the skin and the less-efficient functioning of the hypothalamus (the temperature-regulating mechanism in the brain) occur in older adults. Prolonged time for older adults to return to core temperature after exposure to extreme heat or cold begins at age 70 years and increases thereafter.

**8. All five senses tend to decline with age.**

**True.** While there is considerable individual variation, on average, sensory processes (vision, hearing, taste, smell, and touch) do not work as well as people get older. Another way to say it is that the threshold at which we take in stimuli increases with age. The eye lens, for example, is less able to change shape to adjust to close and far objects, and the size of the pupil narrows to let in less light. Hearing loss begins at age 20, and for many involves growing inability to hear higher frequencies as sensory receptors in the ear and nerve cells in the auditory pathway to the brain are lost. Taste buds become less sensitive with aging and after age 80 more than 75% of older adults show major impairment in their sense of smell.

**9. As people live longer, they face fewer acute conditions and more chronic health conditions.**

**True.** The incidence of acute (temporary) conditions decreases with age, although those that do occur can be more debilitating and require more care. Older people are much more likely than the young to suffer from chronic conditions. These are longterm (more than three months), often permanent, and leave a residual disability that may require longterm management or care rather than cure. The likelihood of multiple chronic conditions increases with age.

**10. People tend to become more spiritual as they grow older.**

**True.** Spirituality is distinguished from religion and participation in religion as a social institution. Spirituality, according to Robert Atchley (2008), refers to “an inner, subjective region of life that revolves around individual experiences of being, transcending the personal self, and connecting with the sacred.” It may occur in or

outside of religious contexts, although people born before World War II seem more likely to see the two linked. Continuing to grow spiritually seems to be an especially important frontier as people move into the middle and later years.

**11. Older persons take longer to recover from physical and psychological stress.**

**True.** Older adults experience multiple losses of loved ones and friends, illness, relocation, retirement, income, change, and decline in abilities. It may take them longer to adjust to a major change or recover from prolonged and intense physical and emotional stress.

**12. Older females exhibit better health care practices than older males.**

**True.** In general, women throughout adulthood are more likely to attend to minor symptoms than are men. Men are more likely to have been socialized even as children to be stoical, and consequently are less likely to see a doctor for health problems until they become clearly symptomatic. When they do get sick, they are likely to have more and longer hospital visits. Women, on the other hand, are more likely to have had regular contact with the healthcare system through childbirth and attending to their children's health. Although women report more chronic conditions than men in later life, the severity of their problems tends to be less than that of same age men, probably due to earlier health care interventions—hence the phrase “women get sicker, but men die quicker.”





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