



# *Compassionate* Community Care



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*Compassionate*  
Community Care

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## Our Philosophy: Why we Visit

Lack of companionship can become a way of life for seniors, those with a disability, or with serious health issues. Many seniors lose the ability to drive, which limits their access to family and friends. As we age, many friends pass away, reducing our social contact with others.

Reducing social isolation and loneliness are essential for quality of life and well-being. Everyone experiences loneliness at one time or another. We recognize that, as social beings, reaching out to others and allowing others to share our lives aids not only in keeping loneliness away but staying healthy too.

Visiting may enable a person to recognize any signs of self-neglect or elder abuse.

Our volunteers help those who may otherwise have no one to care for them. We provide a sense of belonging and value—we are here to visit them.

Volunteers are people who love helping other people. By caring for them, you improve their lives, your own, and your community.

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*The term “senior” is used throughout this document due to this being the largest demographic affected by social isolation today.*

*Compassionate Community Care (CCC) would like to thank the La Crosse Medical Health Science Consortium in La Crosse, Wisconsin, for permission to reprint Ten Commandments of Etiquette for Communicating with People with Disabilities (Appendix D).*

*CCC acknowledges the talent of artist Mohamed Hassan whose work appears throughout this document. All images were obtained from Pixabay: <https://pixabay.com/en/users/mohamed-hassan-5229782/>.*



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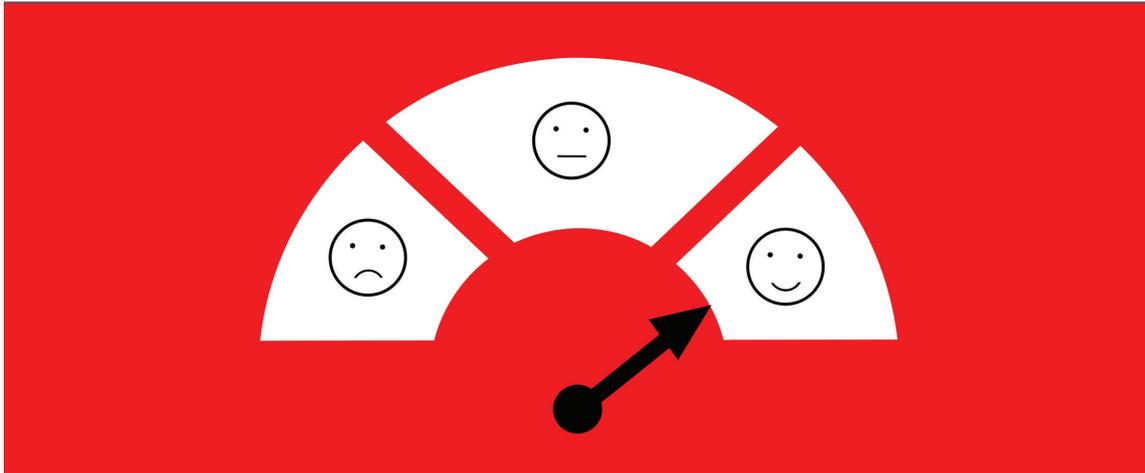
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# Chapter 1: Our Human Needs



As humans, we all have four recognizable needs:

1. Physical
2. Mental
3. Social
4. Spiritual

## **1. Physical Needs**

Our physical needs, though usually obvious, are also not often completely obtained: exercise, nutrition, hydration, and sleep.

Taking medication (prescribed and over-the-counter) plays a large role in a person's physical health.

Among people who are age 65 years or older:

- 90% take at least 1 drug per week,
- more than 40% take at least 5 different drugs per week,
- 12% take 10 or more drugs per week.

([www.merckmanuals.com](http://www.merckmanuals.com))

Women typically take more drugs than men.

As people age, there is less water in their bodies. For the elderly, medications that dissolve in water require lower dosages because they remain highly concentrated in the body.

Seniors also have more fat in their bodies; medicines that dissolve in fat therefore accumulate. Medicines remain longer in their bodies because the kidneys and liver do not work efficiently. For these reasons, seniors may require lower dosages of medicine.

All these facts account for why seniors have more side effects from medicine than any other age group.

## **2. Mental Needs**

Humans need the stimulation of new situations and problems to solve. Our brains require this stimulation to keep healthy and flexible. The brain acts much more like a muscle than an organ. Activities that simultaneously engage all your senses, such as gardening, playing a musical instrument, and walking, are great exercises for the brain. Reading and doing puzzles also stimulate it.

The Geriatric Mental Health Foundation (established by the American Association for Geriatric Psychology) lists a number of potential triggers for mental illness in the elderly: (Stevenson, 2018)

- Physical disability
- Long-term illness
- Dementia-causing illness
- Delirium (which may be caused by infection or medication) may cause a change in behavior or in the way a person perceives reality
- Physical illnesses that can affect thought, memory, and emotion
- Change of environment, like moving into assisted living
- Illness or loss of a loved one
- Medication interactions
- Alcohol or substance abuse
- Poor diet or malnutrition

**Depression** is a serious issue for seniors. Seniors with depression are four times more likely to have alcohol-related problems than those who are not depressed. The Canadian Coalition for Seniors' Mental Health estimates



### 3. Social Needs

Lack of social relationships is as strong a risk factor for mortality as smoking, obesity, or lack of physical activity (Holt-Lunstad, Smith, & Layton, 2010). We need interaction with others for proper brain function. Friendships reduce stress levels.

One in five Canadians aged 65 or older indicated that they felt **lonely** some of the time or often. The proportion is even higher among those 85 years or older: 25% felt lonely some of the time or often (McMaster University, 2016). Living alone, health problems, disability, sensory impairment such as hearing loss, and major life events such as loss of a spouse have all been identified as risk factors for social isolation and loneliness. Older women are more likely to be widowed than older men (Age Action, n.d.).

**Social isolation**, evidenced by objective indicators such as having a small social network, being unmarried, or participating in few activities with others, has been associated with increased risk of dementia and cognitive decline (Wilson et al., 2007).

Most seniors feel connected to their family but fear burdening them with their troubles, worries, and hardships. They are reluctant to talk to someone about the meaning of life or life after death. Instead, they prefer to talk about fears and worries. Unfortunately, seniors often lack close relationships to do this.

It is interesting to note that when an elderly person says they are tired, it may not mean physical tiredness. Expressing the term “tiredness” was associated with the need to “talk to others about fears and worries” (Erichsen, 2013).

Close relationships or confiding talks with other residents in a nursing home are rare. Residents often feel that other residents are impersonal or egotistical. Friendships are minimal because many of their friends are physically unable to visit or are deceased.

It is recommended that seniors be helped and encouraged to use electronic devices that have Skype (video chat or voice calls over the internet), Facetime (Apple’s video-calling service), Facebook Messenger, Snapchat or Instagram (photo and video-sharing) to enable communication with others. These platforms are particularly helpful for those who desire to communicate with younger people who may not live nearby.

According to a 2014 International Federation on Ageing report commissioned by Employment and Social Development Canada (ESDC), the most prominent emerging issue seniors are facing is finding means to become, or remain, socially included and connected to their community (Government of Canada, 2014).

## 4. Spiritual Needs

Spiritual needs involve your relationship with your God. How comfortable you are with yourself, how much you trust yourself, and how you forgive yourself are all found in this fourth need.

Though this is intrinsically a private journey, it can be shared with others. Spiritual needs can be met in church, through inspirational reading, meditation, or walks in nature. It is as varied as each individual.

The interpretation of whether a specific need is a spiritual one depends on the individual's attitudes and cultural context.

Research has shown that patients with a life-threatening or chronic disease regard their spirituality as a beneficial source for coping strategies (Erichsen & Büssing, 2013).

Because most elderly people today were raised with a specific religious background, there may be some who are skeptical about using the term "spirituality". Recognize that they may view this term as being connected to the occult.

Some people prefer to use the term "believing" instead of "religious" because they may have distanced themselves from the church as an institution. Many seniors have a desire to attend a religious ceremony but are unable to.

### Spiritual needs can be broken down in the following ways:

#### 1. Religious needs:

- praying for and with others, and by themselves,
- participating in a religious ceremony,
- reading religious/spiritual books,
- turning to a higher presence (e.g. God, angels, etc.)

#### 2. Existential needs:

- reflecting on one's previous life experiences,
- talking with someone about the meaning of life/suffering,
- talking about the possibility of life after death, etc.

#### 3. Need for inner peace: a desire to dwell in quietness, peace, and beauty. This may include talking to others about fears and worries.

4. Need for giving: the desire to pass on one's experiences to the next generation (generativity), to be assured that one's life has meaning, value, and purpose. This basic need may be fulfilled by using the "My Story" programme (see Chapter 3).

Life satisfaction entails many areas: intrinsic (my life in general, health), social (friendships, family life), external (where I live/work), and prospective (future, financial security) (Erichsen & Büssing, 2013).

Having one's physical, mental, social, and spiritual needs met results in a person being at peace with themselves and the world. Unfortunately, few seniors experience this.

Many seniors, when questioned, will regard the term "need" as too strong and replace it with "wish". Do not ask, "What are your needs?" but rather, "What do you wish for?"

This question may take a long time to answer, particularly, as many seniors or those with a disability have, due to poor life experiences, stopped wishing for anything. Encourage them to speak of what they would dream of, even ideally, wish for. You may be surprised to learn how many of their wishes are easily obtainable if someone intervenes on their behalf.

## Chapter 2: Visiting Advice



### **Before You Go**

1. You will require:

- Criminal Record Background Check
- Vulnerable Sector Check

(See Appendix A: Sample Letter Requesting Police Checks, p. 43)  
Contact your local police service for more information.

2. If you represent an organization, wear something that identifies who you are.
3. Wear clean, modest clothing—not bold.
4. Don't wear perfume.
5. Don't visit when you are not feeling well.
6. Choose a time to visit that is appropriate for the person you are visiting.
7. Know their schedule. Do not visit when others are visiting, or when there are activities.
8. If you have a set time to visit and are unable to go, let them know.
9. When visiting someone who cannot speak, go in pairs so that conversation can include the person.
10. Brainstorm creative things to do during the visit: read to them, go for a walk (ask staff if you can take them out of their room), sing songs, play games, have a cup of tea, etc.

## When You Arrive

1. **Wash your hands** before and after each visit.
2. Make sure your hands are warm (wash them in warm water). The patient may be accustomed to the warmth of a hospital and be in a weakened condition. The touch of a cold hand can be an unpleasant shock.
3. Do not wear rings on your hands (except a simple wedding band). Jewelry can scratch delicate hands and pass on germs.
4. **Always knock** or ring the doorbell before entering, even if the door is open. Give the person a sense of control by stopping at the door, calling their name, giving yours, and asking if it is okay to come in.
5. Address a senior respectfully as Mr., Ms., or Mrs. until they suggest otherwise.
6. Approach the person from the front. Coming from behind can startle them.
7. If there is a patient in another bed who does not have visitors at the moment, **introduce yourself**.
8. A person often has their television or radio on. **Ask** if you can turn it off. Remember to turn it back on when you leave.
9. Sit in a chair beside the person. Never sit on their bed or put your personal items on it (unless they tell you to).
10. If the person is hard of hearing, sit close to them without intruding on their personal space.
11. **Be attentive** to the person you are visiting.
12. **Be sensitive** to their needs.
13. **Be kind**. Your caring attitude is more important than words.
14. Tell them what you are going to do before you do it.

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## Communication

1. **Language matters.** Always use person-first language. This acknowledges that the person is not their disability or illness—it is something they have, not what they are. For example:
  - “person with a disability,” not “disabled person”
  - “child with autism,” not “autistic child”
  - “an individual with epilepsy,” not “an epileptic”
2. Treat people the way you want them to treat you.
3. Always ask first—be willing to accept no to your offer of assistance.
4. Different people have different preferences.
5. Have **respect** for personal boundaries.
6. Always communicate at eye level. Make eye contact.
7. Be aware that anything said in conversation is CONFIDENTIAL.
8. Always be **polite**. Do not use slang or swear words in your conversation.
9. Be **cheerful**—do not be the bearer of bad news. Be a ray of sunshine in their lives. Restrict your conversations to topics that will make the person feel better.
10. Be a good **listener**.
11. Let the other person set the pace of the conversation—appreciate the pleasures of real time.
12. You are visiting an adult, treat them accordingly. Don't talk to them as if they are a child.
13. Give the person the space to talk freely—do not interrupt.
14. Give them **time** to respond. Many people with severe disabilities use communication devices. It may take a little longer for them to communicate—stop and take the time.
15. Be alert to a senior who appears to have difficulty expressing their feelings regarding their situation. They may have a truth to share that is difficult to express.
16. Some people use gestures to communicate. Ask them if you are understanding their gesture properly.



17. If the person is hard of hearing, talk in a low-tone voice.
18. If the person speaks of a serious concern, inform staff or family.
19. Follow their lead—do not force conversation topics on them.
20. **Clarify** or rephrase a statement if you are unclear what they are saying (e.g. “Are you saying that...”). If you don’t understand what they said, ask them to repeat it. Don’t pretend that you understood.

## **Non-Verbal Communication**

*The way you listen, look, move, and react tells the other person whether or not you care, if you’re being truthful, and how well you’re listening (Segal, Smith, & Boose, 2018).*

### 1. Facial Expressions

Facial expression is often the first thing that’s noticed. Fear, sadness, anger, and impatience can be quickly revealed and affect the message conveyed during a conversation.

### 2. Touch

Physical touch shows the person that you care, but can easily be misunderstood. Only hold their hand or offer a hug if the person is comfortable with it. Respect the wish of those who do not want to be touched.

### 3. Voice

Be sensitive to the feelings behind the words they are speaking. Respond to intonation of voice.

### 4. Eye Contact

Avoidance of eye contact may reveal that a person is uncomfortable with the conversation. Your eye contact reveals if you are interested in what they are saying.

### 5. Body Movements

The way a person sits, walks, stands, or holds their head is not as strong an indicator of feelings as once believed. Instead, take notice of how they move their hands: are they fidgety or tightly held together?

### 6. Appearance

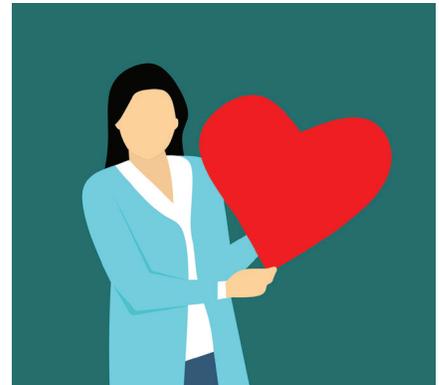
Appearance may reveal how the person feels about themselves, their self-esteem. Are their clothes clean? Is their hair combed? Clothing may reveal

one's economic status. Culture is an important influence on how appearances are judged. Appearance may also reveal if they are being cared for properly by others.

## 7. Space

Respect the person's personal space. Be aware that culture, social status prejudices and history of physical abuse may all be factors affecting one's need for personal space.

Remember, it is important to be sensitive not only to the body language and nonverbal cues of others, but also to your own.



## Emotions

1. **Recognize** that the person may be anxious, discouraged or frustrated due to their situation. Don't take their unhappiness personally.
2. When a person is angry or complaining, let them voice their frustrations. **Reflect** back to them what they have said: "So you feel that..."
3. **Be sensitive** to the pain—physical, emotional, or spiritual—that a person may have.
4. **Be aware** of their current/past illness(es). For example, a person who has suffered a stroke may become emotional.
5. **Validate** their feelings. Though you may disagree with them, say "I understand how you may feel..."



## Conversation Tips

1. Use **statements** in your conversation (e.g. "It is windy outside. It makes me feel ..."). Some people may view questions as intrusive.
2. When someone has **memory** issues (e.g. dementia), ask questions that require only "yes" or "no" responses.
3. If you want them to make a **choice**, ask one question at a time: "Would you like some tea?"(pause for their response) "Would you like a cookie?"

4. When someone speaks of their **past**, encourage them to talk about it. Memories may be clearer to them than the present.
5. Albums, conversation, home videos, music, and photos can prompt nostalgia. These memory prompts can be beneficial to those with dementia and memory loss—many of our strongest memories are connected with the sights, smells and sounds of visits which can bring back these happy times. **Sharing memories** can make the person feel young and happy.
6. Recognize the person for the unique individual he/she is. Everyone has a story.

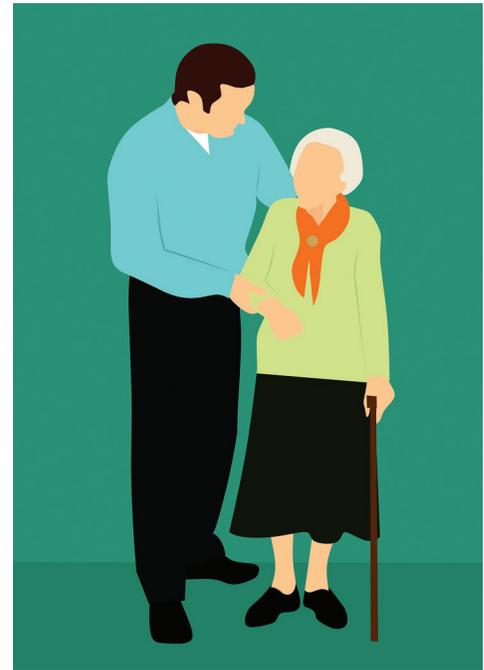


1. Don't be impatient. You may need to respond to the same question a number of times.
2. Don't argue. You are not there to give advice or solutions.
3. Don't create false hope. Medical situations do not always get better.
4. Don't be dishonest or artificial, one can always tell. It takes time to form trust and friendship.
5. Don't be judgemental. Keep an open mind.
6. Don't whisper to family members or medical personnel in the presence of the person.
7. Don't talk in front of them as if they are not there.
8. Don't discuss your own troubles or past illnesses.
9. Don't question the person about the details of their illness. If you have not been told, it is usually best not to ask. If he/she wants you to know, they will tell you. Listen carefully if they criticize doctors, nurses, institutions, or family members.
10. Don't force the person to talk. You can still offer companionship through silence.
11. Don't speak in an unnatural tone of voice.
12. Don't speak loudly. Loud noises of any kind can be very irritating to a sick person.
13. Don't point out mistakes.

14. Don't buy gifts for the person you are visiting. Don't accept gifts either.

### **Ending the Visit**

1. Everyone has good days and bad days. Adjust your visit accordingly. Be aware of signs that the person you are visiting wants the visit to end.
2. If the person requests a prayer, respect their beliefs. Ask God to comfort and sustain them. Remember to include in your prayer the person's family.
3. Short, welcome visits are better than long, strained ones.
4. **Thank them** for the visit when you leave.



### **After the Visit**

1. Keep a journal to record the details of your visit: name, date, time, and notes.
2. Evaluate each visit to determine how it can be improved upon.
3. Think of opportunities to provide life enrichment:
  - arrange for a visiting beauty or barber service,
  - pet therapy or service dogs,
  - music therapy, etc.
4. Speak to your program supervisor if you have any questions or concerns or call the Compassionate Community Care (CCC) helpline directly: 1-855-675-8749.



*see:*

Appendix A: Sample Letter Requesting Police Checks, p. 43

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## Chapter 3: My Story Matters



*During the assisted interviews, several started to weep (both women and men) because they were never confronted directly with their inmost perceptions, and they never were invited to talk about these perceptions and needs. Often the interviewees regarded these talks as “liberating...” (Erichsen & Büssing, 2013)*

**“My Story”** involves interpreting one’s memories by recalling single events, feelings, or key topics, and sharing these memories with another. These stories are recorded or written down to serve as a legacy to future generations.

For the person sharing their story, it is a form of healing. It improves cognitive function (Huang et al., 2015) and increases acceptance of events in one’s life. It provides a person with the knowledge that they have an important place in this world—they have affected others.

On a practical level, a “My Story” can reduce boredom, encourage conversation and intimacy, and make people laugh as they recall humorous moments. It is most effective when positive thoughts are added to past memories.

**Reviewing one’s life and writing down one’s story has many real benefits.**

## Depression

In Canada, **seniors are at a much higher risk for suicide than adolescents** (National Post, 2013). It is important for family members and support staff to recognize that seniors who are struggling with depression might be contemplating suicide.

A 2009 report by Statistics Canada states that men aged 85 to 89 have the highest rate of suicide among any age group in Canada. Seventy-five percent of older adults who died by suicide **had seen a primary care physician or provider within a month prior to ending their lives** (National Post, 2013).

With the legalization of euthanasia in Canada (2016), society is sending a message to seniors who suffer from depression: medically aided death is a solution.

To lower suicide numbers among the elderly, we need to help them with their depression, to give them a purpose to live.

Seniors who participate in an autobiographical workshop such as “My Story” significantly lower their symptoms of depression (Chiang et al, 2010).

A review of one’s life actually improves life satisfaction (Bohlmeijer, Roemer, Cuijpers, & Smit, 2007).

## Generativity

Seniors want to connect with those who will remember them (generativity). Generativity is one of Erik Erikson’s Stages of Psychosocial Development. The opposite of generativity is stagnation, the failure to find a way to contribute.

Generativity involves **the ability to care for others, guiding the next generation, and being assured that one’s life has meaning to others**. Unfortunately, many seniors have the attitude that no one would be interested in learning about their life.

Writing a “My Story” (reminiscence therapy) helps the person connect to their past and may serve as a “legacy” of life experiences to connect to future generations.

The older person can teach future generations and share his/her values and wisdom. It is oral history that helps a person to transmit their values and wisdom to a younger generation.

“My Story” creates a permanent personal life record to pass on to others. No one’s story is all happiness. Some seniors may want future generations to learn from their mistakes or regrets (e.g. “Don’t go down that path!”).

## Loneliness

Loneliness is a psychological state. It is the **self-perception** of having insufficient relationships. Loneliness is how one perceives oneself and not necessarily related to social isolation. It is a common source of suffering in older persons.

Older adults who are lonely have an increased risk of dying sooner and are more likely to experience a decline in their mobility, compared to those who are not lonely (Perissinotto, Stijacic Cenzer, & Covinsky, 2012).

Loneliness is strongly connected to **depression** (Marano, 2003). It is more common for those under age 25 years and over age 65 years. This suggests that having both age groups work together to create a “My Story” would be of mutual benefit.

When an older person moves from their home to a long-term care facility, feelings of loneliness increase (Jansson et al., 2017). “My Story” can ease the transition into this new stage of life.

Conversation is the first step to combat loneliness. The needs and wishes of the person must be understood. This can relate to anyone, not just to those in institutions, the elderly, or those with a disability.

## Self-Awareness and Self-Discovery

“My Story” promotes self-awareness and reinforces a person’s place in society. Our personal narrative offers us a chance not only to understand but also to reorganize our sense of self. It helps a person gain awareness of their accomplishments.

As a person explores their narrative, **encourage them to embrace their past** as part of who they are today. Help them to recognize that their struggles have taught them important life skills. Help them to **acknowledge and celebrate** what their strengths have given them.

Reminiscing is an important way for an older person to understand how their community has changed and thus perhaps remove any fear of that change.

It may make the person understand where their attitudes and behaviours come from.

## Self-Esteem

“My Story” may help a person to **reconcile** themselves with their past, giving them a greater sense of control over past events. It may improve their self-esteem, sending them a message that “Your story is important!”

Some people prefer to rewrite their history, making their lives out to be more important or happier than they were. By doing this, they are filling a psychological need. (However, the longer the conversation, the sooner the truth begins to appear.)

## Social Isolation

Social isolation arises from having too few or no social relationships. “My Story” improves the well-being of isolated older people. They become socially engaged, helping to prevent isolation.

If the person recording the story is not a relative, the process will make the senior feel like a valued member of the community. Older female participants in particular felt validated by being viewed as social historians (Cornwell & Waite, 2009).

Creating a “My Story” may encourage family and staff in nursing homes to view the person as a **unique individual** with a lifetime of experiences.

## Trauma

Reminiscent therapy enables a person to deal with past psychological traumas. Trauma shatters your sense of security, your attachment to others, and the connection of feeling hope in the world.

By writing down one’s pain, a person is **externalizing** it, often **enabling** him/her to come to terms with a traumatic event. A person is finally able to face pain that he/she has avoided his/her whole life. This telling of their story can create a sense of **peace** or relief.

Research has long shown that the key to healing from traumatic stress is the telling of your own story (Kearney, 2007). In telling one’s story, there is a huge healing component.

## **Basic questions to start a “My Story” interview:**

1. When were you born? Where?
2. What are the names of your parents?
3. Do you have any siblings? What are their names? What is the age difference?
4. Did you ever attend a family reunion?
5. Where were you raised? Where did you go to school?
6. What was the name of your best friend in school?
7. What was your first job? Did you enjoy it and why?
8. If married, when did you marry? Where? How did you meet him/her?
9. What was your first home like?
10. How did you like to spend your free time? Did you have any hobbies?
11. Have you ever travelled?
12. What is the favourite place you have visited?
13. Did you ever belong to a social organization (such as fraternal, political, religious, etc.)?
14. What is your strongest positive trait?
15. What advice would you give to a young person?



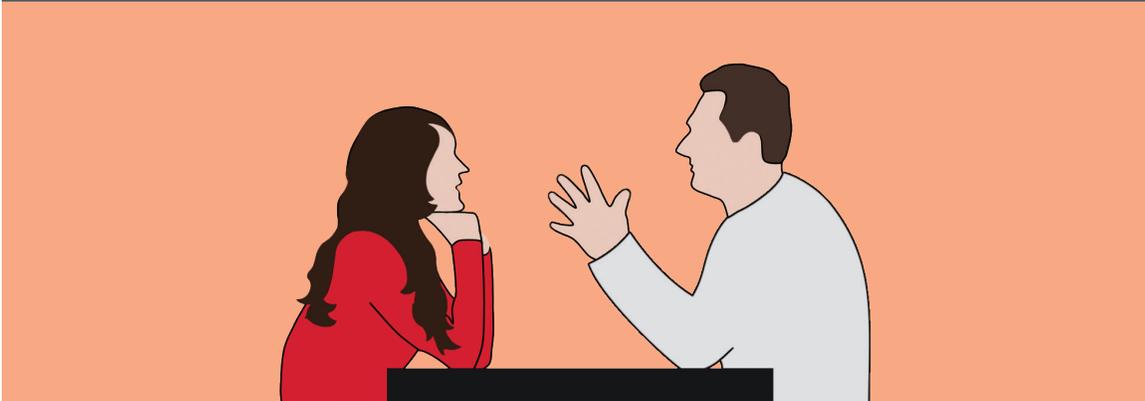
The interview can involve remembering old songs, sharing old photos, discussing feelings, or recalling happy moments growing up.

**Be considerate of the person you are interviewing.** Respect their wishes if they do not want to discuss a topic. This is rare—most people are happy to discuss their lives. Quite often they will say “I never told this to anyone, but...”

For some, it is not the big events that are important. Recalling time spent with a parent, walking in a forest, or playing a game with friends—these may be the strongest and most powerful memories they have.

Writing and sharing their story is a way to find new meaning in life. Their past life—filled with uncertainties, regrets, happiness, and surprise—is put into perspective. Their past becomes logical, the emotions understandable. They feel stronger and have a greater appreciation of their life.

## Chapter 4: Communicating with People with Disabilities



The ability to communicate effectively and to be taken seriously is important to all of us. A person with a disability wants to be treated as we all do—as an independent person.

Offer assistance only if the person appears to need it. A person with a disability will oftentimes communicate when he/she needs help. And if they do want help, ask how before you act. People with disabilities are the best judge of what they can or cannot do. **Don't make decisions for them** about participating in any activity.

Always **speak directly to the person** with a disability, not to their companion, aide, or sign language interpreter.

With any disability, avoid negative, disempowering words like “victim” or “sufferer”.

**Be sensitive about physical contact.**

A quiet environment makes communication easier.

Be a friend and follow the Golden Rule: “Do unto others as you would have them do unto you.” (Matthew 7:12)

## **People with Autism Spectrum Disorders**

- Avoid using humour, sarcasm, figures of speech or colloquialisms
- Use simple, short sentences and closed questions
- Be aware that body language may not be understood
- Use words that are flexible: “we may,” NOT “we will”

## **People with Chronic Medical Conditions**

Often you may not know a person has a medical condition and won't need to communicate any differently. If a person is showing signs of distress or being unwell:

- remain calm and keep your voice tone unhurried,
- ask the person if you can do anything to help, and
- help the person access support and tell them what you are doing.

## **People with Hearing Difficulties**

- If you have trouble understanding the speech of a person who is deaf or hard of hearing, let them know.
- If the person uses a sign language interpreter, look directly at the person who is deaf, and maintain eye contact to be polite. Talk directly to the person (not the interpreter).
- Rephrase, rather than repeat, sentences that the person does not understand.
- When talking, face the person. Do not sit in front of a light source (e.g. a window). The glare may obscure your face and make it difficult for the person who is hard of hearing to speech read.
- Speak clearly. Most people who have a hearing loss count on watching people's lips as they speak to help them understand. Avoid chewing gum or obscuring your mouth with your hand while speaking.

## **People with Learning Disabilities**

- Use short, clear, and direct sentences
- Rephrase information if it is not understood, or present it differently
- Consider using visual aids like diagrams or pictures
- Always provide opportunity to answer any questions

## **People with a Mental Illness**

Often you may not even know a person has a mental illness and won't need to communicate any differently.

If a person shows signs of agitation, anxiety, panic, fear, disorientation or aggressiveness:

- Remain calm and keep your voice unhurried
- Make time and allow the person to talk
- Show empathy without necessarily agreeing with what is being said e.g. "I understand that you are feeling..."
- Accept that hallucinations and delusions are real for the person with the disability but do not pretend they are real to you.
- Use clear, short sentences
- Help the person access support and tell them what you are doing

## **People with Mobility Issues**

- People may have needs related to their mobility. For example, a person with a respiratory or heart condition may have trouble walking long distances or walking quickly.
- Say "person who uses a wheelchair" rather than "confined to a wheelchair" or "wheelchair-bound". The wheelchair is what enables the person to get around and participate in society; it's liberating, not confining.
- When talking to a person using a wheelchair, grab your own chair and sit at their level. If that's not possible, stand at a slight distance, so that they aren't straining their neck to make eye contact with you.
- Be aware of a person's reach limits. Place as many items as possible within their grasp.
- Don't push or touch a person's wheelchair; it is part of their personal space.

## People with Speech Difficulties

- Don't assume they can't understand your speech
- Be patient; don't interrupt or finish the person's sentences
- Ask questions that only require short answers
- Ask them to repeat themselves if you don't understand, don't pretend to understand
- Give the person your full attention
- If, after trying, you still can't understand the person, ask them to write it down or to suggest another way of facilitating communication.

## People with Visual Difficulties

- Identify yourself before you make physical contact with the person
- If they have a guide dog, walk on the side opposite the dog
- Do not touch the person's guide dog; the dog is working and needs to concentrate
- As you are walking, describe the setting, noting any obstacles, such as stairs ("up" or "down") or a big crack in the sidewalk
- If you are giving directions, give specific, non-visual information
- Offer to read written information
- If you serve food to a person who is blind, let them know where it is on the plate according to a clock orientation (12 o'clock is furthest from them, 6 o'clock is nearest). Remove garnishes and anything that is not edible from the plate.
- If you need to leave a person who is blind, inform them you are leaving and ask if they need anything before you go.
- A person who has low vision may need written material in large print. It is easiest for most people with low vision to read bold white letters on a black background.

see:

Appendix B: *A way with words*, p. 45

Appendix C: *Complex communication needs*, p. 69

Appendix D: *Ten Commandments of Etiquette for Communicating with People with Disabilities*, p. 89

## Chapter 5: Advocacy at the Doctor's Office



As an advocate, you can make a difference. You can help someone understand and navigate 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. You can be their friend.

### **Why Might Someone Need an Advocate?**

Advocating for yourself is important in order to inform others about your needs, abilities, and wishes. Advocating for yourself is a form of empowerment. However, some people are unable, for various reasons, to advocate for themselves.

Some people have trouble stating their feelings and concerns; they may be afraid to speak out. They may not understand what is said or what is happening to them or they may simply be too ill to speak up. As their advocate, you can be their voice.

### **What is an Advocate?**

An advocate is someone chosen to support a person, acting and speaking on their behalf.

An advocate can help the person:

- stand up for their individual rights,
- obtain and maintain opportunities for meaningful involvement within their community,
- gain access to the supports and disability-related services they may require to have a good life, and
- talk with their healthcare provider(s).

As an advocate, you cannot make decisions that are contrary to what is best or desired by the client. **You must be able to keep the person's information confidential.**

Some people are naturally better at advocacy than others. A good advocate must not be easily intimidated by difficult people or situations. They should not have difficulty speaking up for themselves or others.

Knowledge is power. The more you inform yourself about a particular issue or situation, the better you will be able to speak on behalf of the person.

## How to be a Good Advocate

- Be a **good communicator**—be clear and concise.
- **Ask questions**—if there is something you do not understand, ask for a better explanation.
- Be a **good listener**—pay close attention to what someone is trying to tell you.
- Be **courteous and respectful**—do not interrupt when someone is talking.
- Be **assertive**—speak firmly, keeping your body upright and relaxed, and use eye contact. Remember that assertive communication is not aggressive.

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## Arrange Consent

Discuss with the person and/or family member what expectations they may have for you as their advocate. Ensure that you are willing, able, and comfortable with doing the necessary tasks before you agree to become their advocate.

To speak on behalf of someone, you must receive their consent. 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** located in Appendix G of this programme.

## Advocate versus Health Care Proxy

An advocate talks with the person, supports them, and acts on their behalf according to their instructions.

A health care proxy acts for the person if they are unable to make judgments or are unable to communicate. A health care proxy is most commonly identified in a document called a health care directive, an advance directive, or a living will.

## Before the Visit

The **time of day** for a doctor's appointment should be considered. The person may be better able to participate in the morning before the activities of the day, or in the afternoon if they sleep late.

**Gather information** from visits with other doctors or specialists. Bring this information, along with a list of questions and topics you want to discuss with the doctor.

Bring a **list of the medicines** they use, 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.

**Inform the receptionist** that you will be at the appointment to take notes.

On the day of the appointment, **call** the medical office to see if the doctor is on time with their appointments.

**Bring a bottle of water, magazine**, etc. for the person in case there is an unexpected delay.

## **Discussing What Needs to be Accomplished During the Visit**

- What are the person's concerns? Is it about physical symptoms, like pain or shortness of breath, or about feelings, such as being sad or worried?
- Is the person seeking information about the side effects of medication or the outcomes of prescribed treatments?
- Do they want to report new symptoms or concerns?
- Gently discuss how to talk with the doctor about sensitive issues.
- They 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 needs to be achieved and, if possible, what specific actions should occur.

## **During the Visit**

- Take notes
- Respect the person's privacy
- Go to the waiting room if the person requires a physical examination
- Ask questions to make sure you understand the doctor's instructions and explanations. Repeat in your own words what the doctor said to make sure you understand.
- Do not be intimidated by the doctor or any other healthcare professional—you are there to advocate.
- If the person wants to speak when the doctor asks you a question, turn towards them and suggest that they answer.
- Inquire about services 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.
- Ask for information sheets that you can take home

## Notetaking

Keep a **notebook** to record your discussions (by telephone or in person).

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

Sometimes people say or promise things verbally but never act on them. Having a written record of what was agreed to may be helpful.

Keep a **folder of written responses and other documents** (such as letters and emails). It is important to keep track of these in case you need them in the future.

## After the Visit

- Make **follow-up appointments** right away
- **Fill any prescriptions** given to you; ask for information on side effects
- **Discuss** with the person how the visit went:

Was it a good experience?

What could have been done to make it better?

Did you ask too many questions?

Did you let the person speak up for themselves?

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

This is a learning experience for everyone involved. As an advocate, you are invaluable in helping to make our world a better place for those in need. Make sure that you keep yourself healthy and happy too.

*see:*

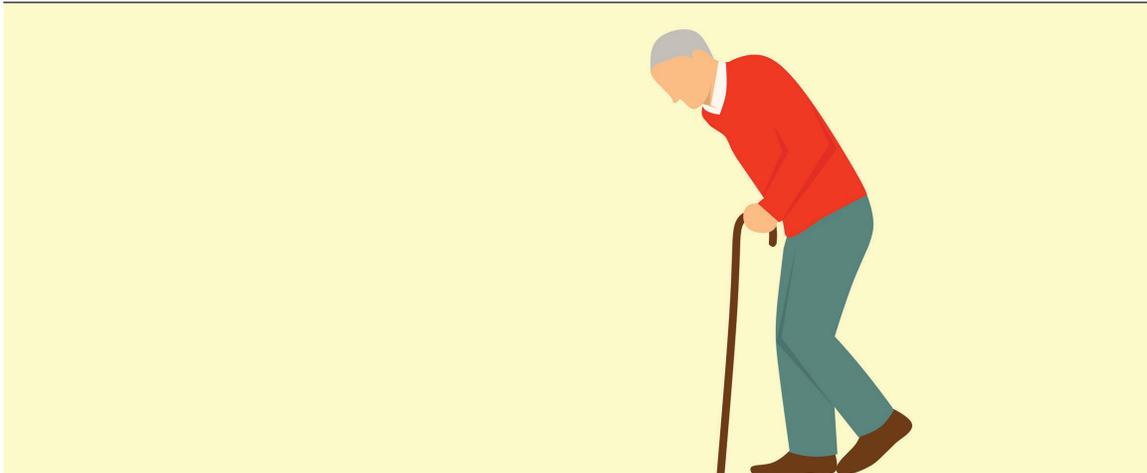
Appendix E: *Patient advocates key to navigating health system, forum hears*, p. 91

Appendix F: *Advocate's Code of Conduct*, p. 93

Appendix G: *Patient-Advocate Agreement*, p. 95



## Chapter 6: Elder Abuse and Other Problems



Your visits can help prevent elder abuse. If a person has home care assistance or lives in senior housing, a visit is the perfect time to make sure their living situation is keeping them healthy and happy. You need to be aware of the signs of common health problems as well as markers of abuse. Make a note of any sign of abuse, including the date it was observed.

### **What are the Signs of Abuse?**

- the person has sores or injuries (including burns)
- they give vague or implausible reasons for injury
- they do not seek care for an injury
- they have a messy, unclean appearance
- malnutrition, weight loss
- dehydration
- they are afraid of a person
- financial fraud
- exploitation (being pressured to give money, etc.)
- sexual abuse

**Physical abuse** is an act of violence that may result in pain, injury, impairment, or disease.

**Neglect** is the failure to provide the goods or services necessary for functioning or to avoid harm.

People do get injured and have minor accidents. You should be concerned when:

1. a doctor or other health care provider is not notified,
2. the wound is smelly or dirty, and/or
3. the person has not received any medical care.

The most common elder abuse injuries are **bruises, pressure sores, and fractures**.

**Abrasions** are superficial injuries involving the outer layer of skin. They are caused by movement of the skin over a rough surface. Abrasions are most commonly seen in cases involving physical abuse, although they can occur due to caregiver neglect.

**Bruises** happen when a blood vessel ruptures and blood escapes into the surrounding tissue.

Bruises often occur more frequently and resolve much more slowly in older persons than in younger persons and can last for months instead of the usual one to two weeks (Dyer et al., 2003).

The pattern of the bruise may suggest the cause of the injury.

Bruises may retain the shape of knuckles or fingers.

Parallel marks, called tramline bruising, indicate injury from a stick.

The site of the injury may also indicate abuse. The most common locations for non-accidental injury are the face and neck (Dyer et al., 2003).

A **burn** results from tissue injury following exposure to heat above 50° C. Burns are categorized by how much surface area is affected and by how deep the damage is.

Persons over the age of 65 have twice the national average death rate due to burns. This risk triples at age 75 and quadruples at 85 (Dyer et al., 2003). Accidents do happen, but be aware that burns may be a sign of abuse (e.g. cigarette burns).

**Fractures** occur when an external force greater than the strength of the bone is applied.

The bones of older persons are thinner and less dense, making them more susceptible to fractures as a result of bone disease or injury. Poor nutrition, vitamin D deficiency, alcoholism, and age-related sex hormone deficiencies also contribute to an increased occurrence of fractures.

The most common sites of fracture are the hip in those over the age of 75 and the wrist in persons younger than 75 (many use their hands to help break a fall) (Dyer et al., 2003).

Prolonged bed rest, chronic limb paralysis, or non-weight-bearing status put elderly persons at increased risk for spontaneous fracture.

**Lacerations** are the result of blunt force and are characterized by full-thickness splitting of the skin. They often heal with scarring.

Lacerations are most commonly seen in cases involving physical abuse, although they can occur in cases of caregiver neglect.

**Pressure sores** occur when there is inadequate blood supply to maintain proper circulation to tissues.

The standard of care for **bed sores** (decubitus ulcers) is to prevent them from occurring. Measures include turning patients regularly, performing range of motion exercises, appropriate nutritional supplementation, and bedding.

The only acceptable reason for **restraining** an elder is to prevent significant harm. Abuse or neglect occurs whenever a person is restrained in a noncritical situation and without a personal evaluation by a medical practitioner. If restraints are determined to be necessary, the restrained patient must be monitored closely and frequently. The restraints must not be so tight as to completely restrict movement.

Physical restraint is strongly associated with increased injury and death. Restraints, in fact, often do not control behaviour and instead may result in a worsening of behavioural problems (Dyer et al., 2003).

**Skin tears** in sites other than the arms and legs or multiple tears or abrasions should raise suspicion. Skin tears heal without scarring.

Malnutrition is often a marker of caregiver neglect. Nursing home residents may decline to eat when institutions do not recognize cultural food preferences. However, the most frequent cause of **malnutrition** due to neglect in an institutional setting appears to be an inadequate number of staff to assist those who need help with eating (Dyer et al., 2003).

Improper feeding techniques such as forceful assistance or other inappropriate feeding, may lead to choking, aspiration, pneumonia, or death. It may also lead to food revulsion, refusal to eat, and depression.

**Dehydration** is a common reason for emergency department visits by older persons. Older persons have decreased body water reserves.

Confusion and sleepiness are common signs of dehydration. As with malnutrition, inadequate staff support may lead to neglectful, inadequate hydration.

Older patients use three times the number of medications that younger patients use. They do not respond as predictably to most medications as younger patients and they have an increased risk of adverse side effects.

Older persons have decreased gastrointestinal absorption, and their bodies, due to age-related changes in body water, fat, and lean muscle, distribute drugs differently. Usually there is more fat and less water, leading to longer time of action of fat-soluble drugs and higher abrupt drug concentrations for water-soluble medications.

In general, older persons should receive medications in doses smaller than those received by younger persons; thus a prescription for an older person of a standard dose of medication may be an indicator of abuse (Dyer et al., 2003).

People with dementia are particularly susceptible to abuse:

- they may not recognize that they are being abused,
- they may not be able to report the abuse or talk about it, and
- they may not be believed.

**Self-neglect** often accompanies dementia and mental health problems in older people. Self-neglect makes victims more vulnerable to and less able to ward off mistreatment by others who might prey on them. As the capacity for self-care decreases, dependence on others increases. Also, someone who has been victimized by abuse or neglect may become depressed and in turn lose the desire for self-care. Thus, self-neglect may be a sign that abuse or neglect has been committed by another person.

**Alcohol abuse** is present in up to 5% of older persons and is more common in men than in women. Older adults can become inebriated at lower levels of alcohol intake than younger adults and are more susceptible to its ill effects, including malnutrition, gastritis (inflammation of the stomach lining), and alcoholic dementia (Dyer et al., 2003).

Victims of **financial abuse** are often widows or widowers, often in the seventh or eighth decade of life, and living in the community.

Experts say senior financial abuse will be the “crime of the 21st century” (Hendershot, 2014).

Unfortunately, there is a big difference in how society views child abuse compared to senior abuse. Children and younger victims of domestic violence are generally healthy and not expected to die. Seniors often have numerous underlying medical problems, are over-medicated, and have functional dependencies. Seniors are assumed to be more vulnerable to situations that can cause death (think of flu season). Thus, when a younger person dies of unexplained causes, the cause of death is almost always carefully analyzed. However, the death of an older person is rarely as carefully scrutinized, if at all, regardless of risk factors or indications of possible abuse or neglect. To complicate things further, old age often brings medical conditions and physical effects that may mimic or mask signs of elder abuse and neglect, further complicating their analysis and detection.

Incidents of mistreatment that many would perceive as minor can have a debilitating impact on an older victim. Because older victims usually have fewer support systems and reserves—physical, psychological, and economic—the impact of abuse and neglect is magnified.

A single incident of mistreatment can lead to loss of independence, serious complicating illness, and even death.



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# Appendix A

## Sample Letter Requesting Police Checks

[YOUR COMPANY LETTERHEAD]

[Date]

RE: Request for Police Record Check

[Employer name] requires the applicant to provide a current criminal record check as follows:

- Police Criminal Record Check (basic check)
- Police Information Check
- Police Vulnerable Sector Check. According to the *Criminal Records Act*, Section 6.3, “vulnerable persons” means persons who, because of their age, a disability or other circumstances, whether temporary or permanent,
  1. Are in a position of dependence on others; or
  2. Are otherwise at a greater risk than the general population of being harmed by persons in a position of authority or trust relative to them (i.e. children, elderly).

The applicant is an [employee or volunteer, must specify] with our organization.

Applicant name: \_\_\_\_\_

Applicant signature: \_\_\_\_\_

Date: \_\_\_\_\_

[Employer name, title, signature]



# Appendix B

Department of Communities, Child Safety and Disability Services



## A way with words

Guidelines for the portrayal of people with a disability





A way with words

## Acknowledgments

The Department of Communities, Child Safety and Disability Services would like to thank Joan Hume for permission to use ideas from her booklet *Media guidelines* (Disability Council of New South Wales 1994) in this publication; Cathy Wilcox for permission to reproduce her cartoons; and the Minister of Public Works and Government Services Canada for permission to use parts of the document *A way with words and images: guidelines for the portrayal of persons with disabilities* (Social Development Canada 2002).

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## Introduction

Language plays a critical role in shaping and reflecting our thoughts, beliefs and feelings. It should come as no surprise, then, that the way in which we refer to people affects the way they are seen by others and, indeed, the way in which they feel about themselves. Used over and over again, a convenient phrase is no longer an attempt to describe a person — it becomes a definition.

For decades, inappropriate terms and catchphrases were all too common in the media's portrayal of people with a disability. In recent times, however, the media and the community in general have become increasingly aware that using inappropriate language when referring to people with a disability is offensive and demeaning. While it is now uncommon for the media to use terms such as 'cripple' or 'retarded', people with a disability are still often referred to in depersonalised terms such as 'the disabled' or 'the handicapped'.

One of the most damaging effects of portraying people in this way is that they are seen by others as being 'different'. With the most recent figures available showing almost one in every five people has a disability (Australian Bureau of Statistics 2004), many people face such marginalisation daily. It is discriminatory to set people with a disability apart from the general community to which they belong.

Despite the growing number of people with a disability in the community, they are sometimes 'invisible' in the media, except when the story is about disability. The views of people with a disability as a group or individually are seldom featured in stories dealing with general interest issues such as child care, public transport or the environment.

## A way with words

The purpose of this booklet is to promote inclusiveness and the fair and accurate portrayal of people with a disability. It is intended as an aid for professional communicators, such as journalists, writers, producers and broadcasters, and provides suggestions for appropriate language, interviewing techniques and media coverage involving people with a disability.

As no set of guidelines can cover every possible contingency, professional communicators should adopt the underlying principle of positive portrayal of people with a disability — that is, put the person before the disability.



## General guidelines

The following points are a guide to help you when reporting on disability issues or portraying people with a disability in words or images.

### **Emphasise individuality, not disability**

People with a disability should be portrayed as individuals first. Like everyone else they have emotions, interests, problems, talents, frustrations and faults and have a number of roles such as parent, friend, work colleague and club member.

As each person with a disability is an individual, the disability will affect his or her life in different ways. You cannot assume that all people with a disability share the same viewpoint, interests or outlook on life. For example, you may find that one person with quadriplegia will be training for the Paralympics, while another might be studying at university, another working as a disability advocate, and yet another mostly interested in studying the racing form guide.

Using appropriate language emphasises this individuality, rather than the disability that a person happens to have. This does not mean that the disability should be hidden, ignored or deemed irrelevant but it should not be the focus of a story except when the subject is disability.

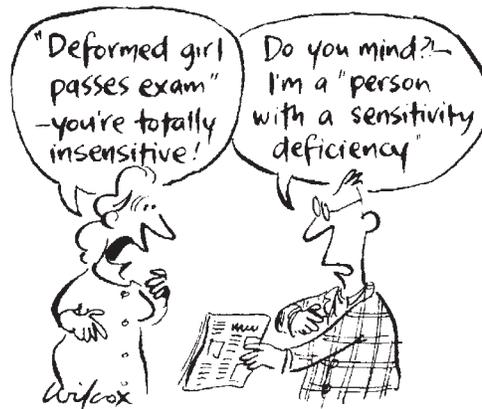
### **Avoid portraying successful people with a disability as superhuman**

Stories about superhuman over-achievers, such as those who abseil down cliff faces in wheelchairs, usually attract a lot of interest. The focus of these stories is usually on the person achieving in spite of his or her disability.

## A way with words

People with a disability who excel in a particular sport, or area of business or study are often depicted as superheroes rather than as the successful sportspeople, students or business people they are.

Portraying the achievements of people with a disability as special or superhuman sets them apart from mainstream society and is to be avoided.



### **Avoid emotive portrayals of people with a disability**

Media portrayal of people with a disability can sometimes imply that they are to be pitied for living with such 'tragedy'. These emotive, 'tear jerker' stories sometimes extend to the person's family or carers, again implying they are 'martyrs' for shouldering such a 'burden' as having to care for someone with a disability. On other occasions the media portrays people with a disability as somehow more courageous or special than other people for just living as 'normal' a life as possible. Stories sometimes refer to people as 'suffering' from, being 'afflicted' with or a 'victim' of a disability.

The reality is that for many people, having a disability is just a fact of life, not something to be dramatised or sensationalised. It would be far better to focus media stories on associated disability issues such as accessible transport and housing or employment opportunities.

### **Portray people with a disability as part of the community and in a variety of roles**

People with a disability are part of the community and should be portrayed as such. They are generally able to participate in all aspects of community life, but frequently the media report on people with a disability only in the context of disability.

People with a disability have interests, careers and families like everyone else. They also have opinions and thoughts about what is happening in their community and in other parts of the world. Be inclusive of the views of all community members by seeking out the perspectives and opinions of people with a disability on issues that affect the community as a whole.

### **Avoid stereotyping**

Stereotypes can lead to discrimination as they take away a person's individuality. Every person with a disability is an individual and should not be expected to display a specific range of personality characteristics — for example, people with Down syndrome are routinely described as 'loving'. Such stereotyping denies the person with the disability the right to express his or her individual personality.

Some common stereotypes to avoid include the following:

- Having a disability is a tragedy.
- People with a disability are objects of pity and charity.



### A way with words

- People with a disability who excel are superhuman.
- People with a disability who marry and have children are extraordinary.
- People with a disability lead boring, uneventful lives.
- Families, particularly spouses, of people with a disability are heroic.
- People with a disability are asexual.

#### **Do not focus on a person's disability unless it is important to the story**

In many media stories it is quite unnecessary to mention a person's disability, yet this characteristic is often highlighted. Focusing on a person's disability may result in your excluding other characteristics of the person. This creates the impression that the person referred to is somehow an oddity and not quite an ordinary member of the community.

Frequently, when a person with a disability is featured in a story that has several possible angles, the human interest story-line predominates — for example, how the individual has overcome overwhelming odds. This places the focus of the story on the disability.

The same is true for photographs, which can send very powerful messages. They can focus on a person's disability or equipment used for mobility or communication rather than the person. They can devalue the person by using inappropriate settings or perspectives.

### **Avoid describing disability in medical terms**

Describing a person's disability in terms of a medical 'condition' — such as epilepsy, polio, paraplegia, blindness, schizophrenia or autism — focuses attention on the disability rather than on the person as an individual. These terms also suggest sickness and imperfection and reinforce negative assumptions and stereotypes about people with a disability.

### **Broaden and deepen your understanding of disability issues**

Before writing about disability issues or a person with a disability, make sure you know what you are talking about. Speak to disability groups and organisations to develop a general understanding of their concerns, and ask them to put you in touch with some of their members.

When researching a story on disability, talk to a person with a disability about what he or she feels and thinks about a particular issue rather than relying on the opinions of doctors and government agencies.



## Appropriate language

In the general community, as well as in the disability community, there is considerable debate about how people with a disability should be described. Words and terms that are considered appropriate and acceptable change over time. For example, once the word 'cripple' was in common and respectable use. Today its use to describe a person with a disability is considered offensive and unacceptable. The same applies to words and expressions such as 'insane', 'spastic' and 'handicapped'. Also unacceptable are words which imply a lack of something or some kind of inferiority, such as 'invalid', 'infirm' or 'incapacitated'.

The following list of inappropriate terms and appropriate alternatives is a guide only. When considering which terms are most appropriate to use in any situation it is best to ask the person how he or she would like to be referred to.

Words to avoid	Acceptable alternatives
abnormal, subnormal (These are negative terms that imply failure to reach perfection.)	Specify the disability.
afflicted with (Most people with a disability do not see themselves as afflicted.)	person has (name of disability)
birth defect, congenital defect, deformity	person with a disability since birth, person with a congenital disability

Words to avoid	Acceptable alternatives
the blind, the visually impaired	person who is blind, person with a vision impairment
confined to a wheelchair, wheelchair bound (A wheelchair provides mobility, not restriction.)	uses a wheelchair
cripple, crippled (These terms convey a negative image of a twisted ugly body.)	has a physical disability, has a mobility disability
the deaf	person is deaf (This refers to people who cannot hear but do not necessarily identify with the Deaf community.) or the Deaf (This refers to people who identify themselves as part of the Deaf community and who use sign language. Using 'Deaf community' is only appropriate when referring to this particular community.)
deaf and dumb (This is sometimes used to describe an inability to hear and speak, which dos not imply any intellectual disability.)	person who is deaf and non-verbal or Deaf people (This refers to people who identify themselves as part of the Deaf community and who use sign language.)

A way with words

Words to avoid	Acceptable alternatives
defective, deformed (These are degrading terms.)	Specify the disability.
the disabled	people with a disability
dwarf (Has negative connotations.)	short-statured person
epileptic	person with epilepsy
fit, attack, spell	seizure
the handicapped	person with a disability (If referring to an environmental or attitudinal barrier then 'person who is handicapped by a disability' is appropriate.)
insane, lunatic, maniac, mental patient, mentally diseased, neurotic, psycho, schizophrenic, unsound mind (These are derogatory terms.)	person with a psychiatric disability (or specify condition)
invalid (The literal sense of the word is 'not valid'.)	person with a disability
mentally retarded, defective, feeble minded, imbecile, moron, retarded (These are offensive, inaccurate terms.)	person with an intellectual disability
mongol (This term is outdated and derogatory.)	has Down syndrome

Words to avoid	Acceptable alternatives
patient (Only use in context of doctor–patient relationship.)	person with a disability
physically challenged, intellectually challenged, vertically challenged, differently abled (These are ridiculous euphemisms for disability.)	person with a disability
people with disabilities (Refers to people who have multiple disabilities.)	person with multiple disabilities, people with a disability
spastic (Usually refers to a person with cerebral palsy or who has uncontrollable spasms. This is a derogatory term and often used as a term of abuse. Should never be used as a noun.)	person with a disability
special (This term is overused, e.g. ‘special’ person.)	Describe the person, event or achievement as you would normally.
vegetative (This is an offensive and degrading term.)	in a coma, comatose, unconscious
victim (People with a disability are not necessarily victims and prefer not to be seen as such.)	has a disability

## Interviewing a person with a disability

### Before the interview

- Ask if you should make any special arrangements in advance. An interpreter, for example, may be needed if the person has hearing loss or is not able to speak or communicate in a conventional way.
- Ask the person being interviewed to choose where to meet. Not all places are accessible to people with a mobility disability. Additionally, lack of affordable, accessible transport may be an issue. A person with a hearing impairment may find it difficult to concentrate if the surroundings are noisy.
- Try to interview the person alone, although a second person may be necessary as an attendant or an interpreter. Be aware that sometimes friends and family may interrupt and presume to speak for the person being interviewed. Stay on track and remember who you are interviewing.



### **During the interview**

- Sit at the same level as the person being interviewed. Ask if you can be heard clearly or if it is better to sit on one side rather than another.
- Speak directly to the person and maintain eye contact rather than interact directly with an interpreter or companion.
- Do not hold back from asking frank questions — for example, how the person manages certain tasks. Usually people with a disability are not precious and fragile about their disabilities. On the other hand, intrusive personal questions (for example, about a person's sex life) can be very offensive. Be matter-of-fact but remember that honest answers deserve honest treatment and should never be used in a sensational or morbid way.
- Be honest about the story angle. If the story is about discrimination in the workplace then including details about a person's medical condition, unless relevant, is quite unjustified.
- Do not gratuitously emphasise physical differences or adaptive aids and technologies in stories or photographs unless these are the focus of, or relevant to, the story. If a person in a wheelchair is being interviewed about neighbourhood environmental pollution, for example, the visual focus should be the person, not the wheelchair.
- Do not assume you understand how the person feels about having a disability. Even if you know someone with a similar condition, the person you are interviewing may not think or feel the same way. Ask the person how he or she feels.



### A way with words

- Do not feel embarrassed or guilty if you have difficulty understanding the person you are interviewing. He or she will probably have experienced this before and will have developed ways of coping. Be patient and persevere. Never pretend to understand. Instead, repeat what you have understood and allow the person to respond.
- Resist the pressure to get the 30-second grab. Allow the person you are interviewing the courtesy of telling events and particular details at his or her own pace.

### **After the interview**

Ask yourself:

- How can I portray the person I have just met in the most positive way, being mindful not to sensationalise or patronise his or her situation?
- Is a reference to a disability necessary to the story? If it is, am I using appropriate terminology?
- Is this piece accurate and unbiased? Have I avoided sensationalism?

## Providing public information to people with a disability

Relying on print media or verbal communication only to get your message out will place many people with a disability at a disadvantage. Presenting your material in a range of formats allows a wide range of groups in the community, not just people with a disability, to access information. Some formats cater to the needs of more than one disability group, and some will be of benefit to the community in general. The following is a brief description of suitable formats for different disability groups.

### People with a vision impairment

Effective ways of providing information to people who are blind or have a vision impairment include:

- **large print**

Text can be produced in a variety of sizes to meet individual needs. Printed material should ideally be in a sans serif font and 16 point, with a minimum size of 11 point. Use a text colour that contrasts with the background (avoid red type as it has poor contrast and makes it difficult for people to read). Black type on white or off-white background is optimal. Use style devices such as underlining, italics and hyphenation sparingly.

- **information and communication technology**

Providing information electronically, either on a website, through email or an electronic file/document, can be a good option if the information is prepared in an appropriate format.

Unlike sighted people, most computer users who are blind or vision impaired do not use a mouse. Many use a screen reader

or, in some cases, a braille keyboard. A screen reader is software that works with a speech synthesiser to read aloud everything on a computer screen, including icons, menus, text, punctuation and control buttons. It reads across the screen from left to right, one line at a time.

This software will attempt to 'read' any formatting — for example, instead of reading columns from top to bottom it will read the first line of text in the first column and then jump across to read the first line of the next column. For this reason, it is best to keep formatting (including tabs, tables and columns) to an absolute minimum in your document.

Information provided as a PDF file should also be available electronically as an RTF file. This will ensure it can be read by a screen reader and will also be able to be enlarged by users to suit their needs.

Advice and guidelines for creating accessible websites are available from the World Wide Web Consortium website ([www.w3.org/WAI](http://www.w3.org/WAI)).

- **audiotape/CD-ROM**

Newsletters, books and reports can be produced on audiotape or CD-ROM. It is best to use an organisation that specialises in the production of audio material for people with a print disability, such as the Queensland Narrating Service. Costs are minimal.

- **radio**

4RPH 1296AM is the Queensland radio station for the print handicapped. The station airs a wide range of printed material, including newspapers, magazines, books and journals to people who for reasons of age, disability or literacy problems cannot handle or read information in a printed format.

- **braille**

Braille is used by a small proportion of people who are blind. Documents on computer file can be converted into braille using braille conversion software and printed out by a braille embosser.

### **People with a hearing impairment**

Effective ways of providing information to people who are deaf or have a hearing impairment include:

- **written/printed information**

Printed information should be written in plain English and include cartoons, diagrams, photographs and pictures to help communicate your message clearly.

- **captioning**

Captioning films, videos, television programs and advertisements assists viewers who are deaf or hearing impaired to understand what they are not able to hear.

- **telephone typewriter (TTY) and/or National Relay Service (NRS)**

Organisations can communicate with people who are profoundly deaf through the use of a TTY or the NRS.

- **sign language**

Skilled sign-language interpreters are available for seminars, meetings, conferences and other community events. Qualified interpreters can be booked through the Deaf Services Queensland and the Far North Queensland Deaf Interpreting Service.

- **audio loop**

An audio loop in public meeting places such as halls, churches, seminar rooms, lecture theatres and schools will allow people who use hearing aids to participate.

### **People with an intellectual disability**

People with an intellectual disability may require information to be presented in a brief and clear but not patronising or childlike manner. Written information may need to be supported by symbols, pictures or photographs.

### **People with a physical disability**

People with a mobility disability, including those with a temporary disability, may find their access to mainstream information limited. They may be unable to travel to libraries or meetings or may encounter difficulties with inaccessible buildings. They too may prefer to receive information via the internet, email, radio, DVD or disk.

People with a manipulatory disability have difficulty holding and/or moving objects as a result of nerve injuries, arthritis or amputation. They may find it difficult to hold books or papers and turn pages. When providing information for this audience, the formats to consider include the internet, disk, DVD and radio.



## Communicating with a person with a disability

Some guidelines to follow when talking with a person with a disability include the following:

- Establish and maintain eye contact at the same level as much as possible.
- Face and speak directly to the person rather than through the companion, attendant or sign-language interpreter who may also be present.
- Never speak about the person as if he or she is invisible, cannot understand what is being said or cannot speak for himself or herself.
- Do not put people with a disability on a pedestal or talk to them in patronising terms as if their performing normal, everyday activities was exceptional — for example, 'Oh, you cook your own meals. How amazing!'
- Always respect the person's dignity, individuality and desire for independence. If help is required in a given situation, do not assist without asking first.
- Refer to adults with a disability in the same way you would refer to any other adult. Do not refer to them by their first names where in similar circumstances with an interviewee who does not have a disability you would use a title such as mister, ms or doctor.

## Useful resources and references

Australian Bureau of Statistics 2004, *Disability, ageing and carers, Australia: summary of findings*, cat. no. 4430, ABS, Canberra.

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# Appendix C

Department of Communities, Child Safety and Disability Services



## Complex communication needs



## Acknowledgments

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## Communication and why it is important

Communication is the act of giving or receiving information.

Communication is:

- fundamental to all aspects of life
- important for quality of life
- a foundation for learning
- a human right (United Nations Universal Declaration of Human Rights 1994).

Effective communication enables people to:

- express their thoughts, opinions and personality
- ask for and receive information
- build relationships
- make decisions
- express and meet their basic needs
- refuse or reject
- make requests and suggestions about services they receive
- take part in social activities
- be heard and understood
- participate in their community.

A person's ability to communicate effectively may have an impact on his or her ability to build relationships, make choices and participate in everyday life

## How we communicate

Everyone uses a variety of methods for communication, which can include:

- speech
- writing
- touch
- eye gaze
- tone of voice
- body language
- signing
- actions
- facial expression
- miming
- behaviour
- vocalisations
- gestures.

People may use any number of these methods, in any combination.

Both action (response) and inaction (lack of response) convey information or messages.

All forms of communication are equally valid.

## Who may have complex communication needs?

People who have complex communication needs may not have the communication skills to meet all of their needs. For some people this is temporary, while for others it is ongoing.

Some people may not have speech and will rely on other methods of communication, such as pointing or gestures.



Some people may use speech but it may be difficult to understand.



Some people may be able to communicate but have difficulties understanding what other people say.

People with complex communication needs can be of any age, of any culture and from any socioeconomic background.

Complex communication needs may be associated with developmental or acquired disabilities.

**Developmental disabilities** are present at birth or occur before the age of 18, and may affect social or cognitive development.

Some examples of developmental disabilities are:

- intellectual disability
- Down syndrome
- cerebral palsy
- autism.

**Acquired disabilities** occur as a result of illness or injury.

Some examples of acquired disabilities are:

- traumatic brain injury
- spinal cord injury
- multiple sclerosis
- stroke.



## What is it like to have complex communication needs?

It can be difficult to appreciate what it is like to be unable to communicate using speech or through writing. The following quotes provide some insight.

*I know what it's like to be fed potatoes all my life... I hate potatoes! But then, who knew that but me? I know what it is like to be dressed in red and blue when my favourite colours are mint greens, lemon yellows and pinks. I mean really, can you imagine?*

Sara Brothers in Beukelman & Mirenda 2005

*If you want to know what it is like to be unable to speak, there is a way. Go to a party and don't talk... Here is what you will find: people talking; talking behind, beside, around, over, under, through and even for you. But never with you. You are ignored...*

Rick Creech in Beukelman & Mirenda 2005

Communication is part of daily life and cannot be considered separately from other activities. Having an effective communication system influences the success of our personal interactions, our involvement in activities, and our ability to make decisions. These can range from everyday decisions, such as which shirt to wear, to life-changing decisions, such as where to live.

## The role of communication partners

A communication partner is anyone who talks or interacts with another person. We are all communication partners.

It is important for communication partners to support people with complex communication needs to identify and use the communication methods that work best for them.

Communication partners of people with complex communication needs should be aware of the following:

- Communication is a constant experience.
- For people with complex communication needs not having access to an effective communication system can be frustrating. This frustration sometimes results in challenging behaviour.
- The way we communicate with people with complex communication needs influences how they are perceived by others and how they perceive themselves.
- People with complex communication needs are more vulnerable to abuse, assault and neglect than others, as they are less able to report incidents. The ability to communicate is an important mechanism for reducing the risk of abuse, assault or neglect.
- Communication enables people to express their personality, humour, interests and dislikes.

Effective communication maximises participation and minimises limitations.



## Strategies for communication partners

To be an effective communication partner for someone with complex communication needs you should consider using the following strategies:

### **Identify the methods the person uses to communicate.**

- These may include speech, signs or gestures, or using pictures, facial expressions, the alphabet or a communication device.
- Use the person's chosen communication methods appropriate to the environment — for example, sign as you speak or point to objects in the environment.

### **Demonstrate respect and presume competence.**

- Remember that a person's expressive skills may not represent their ability.
- Use respectful and age-appropriate communication.

*Show me first by interacting with me as a person who you'd normally interact with. If you treat me like a stupid person I'm not engaging with you.*

Rodney Mills  
Trainer/Presenter

Friends, family or carers, who know the person well, will have suggestions on how you can assist the person to better understand you and to communicate effectively with you.

### **Gain and maintain attention.**

- Use the person's name.
- Use facial expressions, tone of voice and humour to add information and interest.

**Talk about things that are interesting and relevant to the here and now.**

- Talk about the current activity.
- Explain what you are doing as you do it.
- Create or use a chat book with photos and captions to help others learn about the person's interests and prompt interaction.
- Give specific examples.
- Communicate for a variety of reasons — for example, make observations, share opinions, tell jokes.

**Cue the person with complex communication needs to initiate a response.**

- Give expectant pauses.
- Provide verbal cues or physical prompts.

**Offer choices.**

- Provide real opportunities for choice within activities such as what to wear, eat or do.
- Provide visual representation of choice — for example, show cereal packets when discussing breakfast options.

To be able to make an informed choice, people need to experience and know what the alternatives are. The alternatives need to be presented in a way meaningful to them. Choice may sometimes be indicated by things such as:

- participation or non-participation
- picking up the chosen object
- looking or pointing at the desired item
- vocalising.

**Keep sentences short.**

- Chunk information together.
- Be specific.
- Talk about one step at a time.

**Support the person with complex communication needs to develop his or her communication skills across a range of environments and with different people.**

- Identify opportunities for communication to take place — think about the person's interests, activities and routines.
- Acknowledge all communication attempts.

**Listen attentively.**

- Use eye contact.
- Use gestures such as nodding your head.
- Rephrase what is being said.
- Be aware of your non-verbal communication.
- Try not to talk too much.
- Wait for the person to finish.

It is important that all communication partners have a shared understanding of how someone communicates.



## What is a communication-friendly environment?

A communication-friendly environment is one which provides opportunities for communicating about a range of topics, has communication partners that can support different ways of communicating and has a range of tools available to support communication success.

Communication partners can contribute to communication-friendly environments in the following ways.

### **Minimise distractions.**

- Consider background noise, such as TV, radio, fans and air conditioning.
- Avoid crowded or busy places. Move to a quieter location.
- Consider lighting.
- Have communication aids nearby — prepare materials in advance that will support communication in specific activities.

### **Ensure the person is comfortable.**

- Check the person's positioning.
- Consider whether equipment is required such as a more comfortable chair or a table to put communication aids on.

### **Place yourself at eye-level.**

- Face the person and use eye contact.
- Gain their attention.
- Position yourself at the same level as the person.

### **Consider involving other communication partners.**

- Is there someone else who might be interested in joining the conversation?
- What are the person's communication needs and methods?
- Bring people together through shared activities or interests.

### **Avoid talking about the person in front of him or her.**

## Supporting effective communication

The use of objects, photographs, pictures and symbols can support people to understand information they are given and to express themselves to others more effectively.

### Supporting understanding

Spoken language is fleeting — some people may miss information and not be able to follow the conversation. Using tools to aid understanding can be very effective.

For example, holding an object or pointing to a picture when you are talking reinforces the spoken message and increases the likelihood that your communication partner will understand.

Objects and pictures are present for longer than the spoken word. They can be understood more easily because they represent something tangible.



Tools can also be used to:

- jog the memory — for example, a visual calendar used as a pictorial reminder of activities for the week ahead



- assist a person to know what is expected of them — for example, holding up a set of keys to indicate that it is time to go for a drive

- help organise thinking — for example, an illustrated recipe with photos of the sequential steps to be taken to complete the task



- enable someone to feel in control and less anxious — for example, a daily schedule with photographs of people who are likely to be visiting.

### Supporting expression

People who do not use speech or whose speech may be difficult to understand can use tools to assist their communication partners to understand their ideas, thoughts and feelings.

The use of tools can help a person with complex communication needs to:

- clarify and provide information — for example, pointing to various symbols to clarify the topic he or she wishes to talk about



- ask for something — for example, holding up a towel and goggles to indicate he or she wants to go swimming



- express his or her feelings — for example, pointing to the word 'excited' from a list of emotion words.

## Communication breakdown

Communication breakdown occurs when a message is not conveyed successfully from one communication partner to another.

If someone you are communicating with does not understand you:

- repeat or rephrase the information
- reduce the amount of information in the message
- use visual supports
- seek help from communication partners who know the person well.

If you do not understand someone you are communicating with:

- let the person know that you have not understood — do not pretend to understand
- ask the person to show you what he or she means
- ask the person to say it in a different way
- check if the person's non-verbal communication supports his or her message.

To avoid communication breakdown, support your message by using visual aids such as pictures and objects in the environment. You can also demonstrate or use actions and pointing to enhance the message.

You can also help by:

- using clear, simple language and avoiding the use of slang
- slowing down and shortening the message
- saying the message in a different way.

Continue to develop your knowledge of the way a person communicates. Record successful strategies and share observations with other communication partners.

## References

- Beukelman, D and Mirenda, P 2005, *Augmentative and alternative communication: supporting children and adults with complex communication needs*, Paul H. Brookes, Baltimore, Md.
- Crossley, R and McDonald, A 1984, *Annie's coming out*, Penguin, Ringwood, Vic.
- United Nations Universal Declaration of Human Rights 1994.

### **For further information:**

**Phone** 1300 QGOV (13 74 68)\*

**Telephone Typewriter (TTY)** 13 36 77

**Email** [disabilityinfo@communities.qld.gov.au](mailto:disabilityinfo@communities.qld.gov.au)

**Website** [www.qld.gov.au/disability](http://www.qld.gov.au/disability)

**National Relay Service** 1300 555 727

**Translating and Interpreting Service** 13 14 50

(Ask to be connected to the Disability Information Service.)

This document is available in alternative formats (including large print) on request. If you would like a copy in another format, please phone 13 QGOV (13 74 68)\* or email [disabilityinfo@communities.qld.gov.au](mailto:disabilityinfo@communities.qld.gov.au)

\* Cost of a local call. Calls from mobile phones are charged at applicable rates.



## Appendix D

### **Ten Commandments of Etiquette for Communicating with People with Disabilities**

Outlined below are the Ten Commandments of Etiquette for Communicating with People with Disabilities:

1. When talking with a person with a disability, speak directly to that person rather than through a companion or sign language interpreter.
2. When introduced to a person with a disability, it is appropriate to offer to shake hands. People with limited hand use or who wear an artificial limb can usually shake hands. (Shaking hands with the left hand is an acceptable greeting.)
3. When meeting a person who is visually impaired, always identify yourself and others who may be with you. When conversing in a group, remember to identify the person to whom you are speaking.
4. If you offer assistance, wait until the offer is accepted. Then listen to or ask for instructions.
5. Treat adults as adults. Address people who have disabilities by their first names only when extending the same familiarity to all others. (Never patronize people who use wheelchairs by patting them on the head or shoulder.)
6. Leaning on or hanging on to a person's wheelchair is similar to leaning on hanging on to a person and is generally considered annoying. The chair is part of the personal body space of the person who uses it.
7. Listen attentively when you're talking with a person who has difficulty speaking. Be patient and wait for the person to finish, rather than correcting or speaking for the person. If necessary, ask short questions that require short answers, a nod or shake of the head. Never pretend to understand if you are having difficulty doing so. Instead, repeat what you have understood and allow the person to respond. The response will clue you in and guide your understanding.
8. When speaking with a person who uses a wheelchair or a person who uses crutches, place yourself at eye level in front of the person to facilitate the conversation.
9. To get the attention of a person who is deaf, tap the person on the shoulder or wave your hand. Look directly at the person and speak clearly, slowly, and expressively to determine if the person can read your lips. Not all people who are deaf can read lips. For those who do lip read, be sensitive to their needs by placing yourself so that you face the light source and keep hands, cigarettes and food away from your mouth when speaking.
10. -Relax. Don't be embarrassed if you happen to use accepted, common expressions such as "See you later," or "Did you hear about that?" that seems to relate to a person's disability. Don't be afraid to ask questions when you're unsure of what to do.

Source: Office of Disability Employment Policy (ODEP)



## Appendix E

### Patient advocates key to navigating health system, forum hears

[thesarniajournal.ca/patient-advocates-key-to-navigating-health-system-forum-hears/](http://thesarniajournal.ca/patient-advocates-key-to-navigating-health-system-forum-hears/)

Posted October 1, 2017 in Featured | Front Page | News

October 1, 2017



#### **Troy Shantz**

Sarnia's Kathy Ptaszynski worked 42 years as a nurse, but it was only after she started caring for her elderly mother that she noticed cracks in the local health-care system.

“I can speak to both sides, because I’ve recently had experiences in a long-term care home that if I wasn’t an advocate, my mother would’ve been in big trouble,” she said.

Ptaszynski was one of seven presenters at a public forum held in Sarnia last week designed to get a snapshot of senior care in the community and provide answers to questions.

She said she became suspicious last year about the medications being prescribed for her mother, 86, who was then still living independently.

Ptaszynski believes the drugs contributed to a fall her mother took and a broken hip that went undiagnosed for months.

Then she had to grapple with medication issues at the long-term care home her mother was admitted to, she told the forum organized by Community Legal Assistance Sarnia and Navigating Senior Care Lambton.

Only after she became a strong advocate (the ‘squeaky wheel’) for more effective pain medication did her mom get the attention she needed, she said.

“We have overworked PSWs in nursing homes who are giving up,” she said, noting 10 of 15 new hires at the home have already quit. “It’s almost like a warehousing situation.”

Stories like Ptaszynski’s are not uncommon and need to be told, said Jane Meadus, a lawyer with the Advocacy Centre for the Elderly and panel member facilitating the meeting.

“I think that most people think they’re doing this alone, that they’re the only ones this is happening to,” she said.

“We have to use it as a catalyst for change as well. It’s clear the system is so broken that we really need to fix it.”

A common theme during the discussion was the need for someone to help families navigate a complex health system, especially those requiring in-home and long-term care options.

What people need are advocates to guide them, said Andrew Bolter, executive director of Community Legal Assistance Sarnia.

“If every community had that, it would solve a lot of issues.”

Ptaszynski’s nursing background and networks within the system proved helpful for her mother, but many people don’t have that luxury, she said.

She hopes one day a knowledgeable advocate will be available for every family that needs one.

“We don’t have a third-party navigator built into our health system available to these people,” she said, “someone who can see, assess and give direction to people on where they need to be.”

## Appendix F

### Advocate's Code of Conduct

1. I will practice with compassion and respect for the person with whom I work.
2. My primary commitments are to promote the health, safety, and rights of the person.
3. I will be transparent in my work with the person.
4. I will maintain privacy on behalf of the person and keep confidential all activities and records (unless speaking with my supervisor for advice).
5. I will guide and assist the person in medical decision-making but at no time will make decisions about health or medical care or medical services on their behalf.
6. I will respect the person's values and belief systems as the foundation for their decision-making.



# Appendix G

## 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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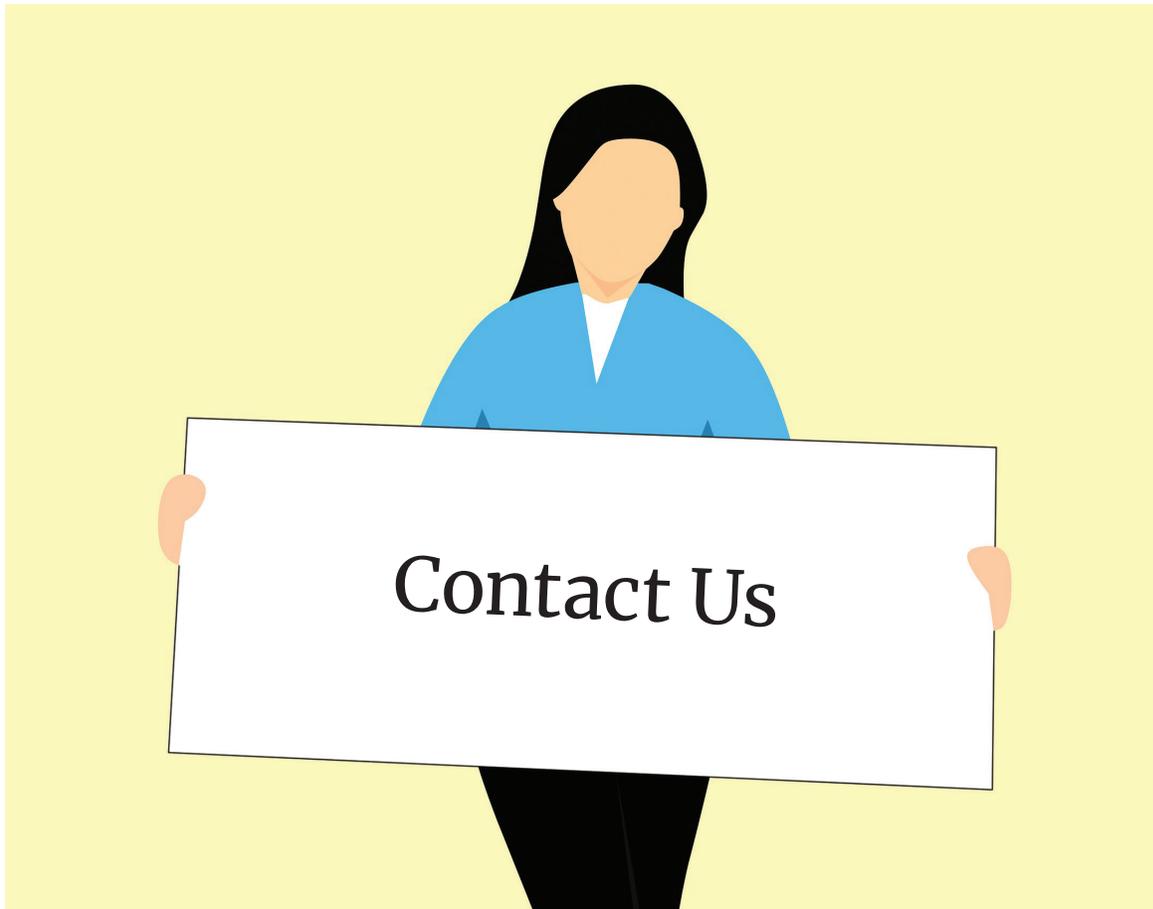
Advocate's Signature:

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Today's Date:

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This training manual was written & compiled by S. M. Schaeken



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