



**L'ARCHE ONTARIO REGION**

**MANUAL FOR HELPING**

**PEOPLE WITH INTELLECTUAL DISABILITIES**

**CHOOSE**

**AN ATTORNEY FOR PERSONAL CARE**

*This booklet's purpose is to **provide information**. It is **not legal advice**, and should not be relied upon as legal advice. If you are choosing an attorney for personal care or helping someone choose an attorney for personal care and have any questions or doubts you should consult with a lawyer.*

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Compiled- Sept 2005  
By Jane Powell

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**Appendix #1:** “The Role of Attorney for Personal Care” by Jan Goddard is **not to be changed or translated**

## **Basic Information Sheet Concerning Power of Attorney for Personal Care**

Hopefully the following information is useful in helping the members of your community understand the role of attorney for personal care is and enables them to name someone if that is possible. If there is anything you are unsure or are concerned about consult a lawyer.

Never assume someone's capacity. Consult a lawyer if you have any doubt that others (doctors) would believe the person capable or if family may question the capacity at some point.

This is one more step in supporting our people to have control over their lives and to have their wishes respected. **It is important to note that this information is Ontario specific. It would be important to find out the laws that apply in your province. This information is not legal advice, and if you have questions about how to interpret this information, you should consult with a lawyer. Different terms may be used in your province.**

It would be recommended that in each community an experienced long-term person work with the community leader to ensure that there is something in place for each community member with an intellectual disability concerning a substitute decision maker.

Please find **included** a **pictorial tool** to help explain Attorney for Personal Care to people with intellectual disabilities. Again this is not a legal document.

There is an article that explains the responsibilities of being an Attorney for Personal Care available included as an **appendix** in this package. It could be helpful to people considering taking on this role. **It is not to be changed or translated.**

If you are in Ontario the Office of the Public Guardian and Trustee for Ontario at 1-800 366-0335 can send you a booklet that contains an actual form.

This booklet explains who someone can or cannot name but generally someone being paid to provide direct care for the person cannot be named. (Page10) It is generally better to name someone who is not community member if at all possible. This provides an outside advocate for people and helps to avoid situations of conflict of interest.

It is important for people to be aware that if they do not name someone that their parents or siblings would be called upon to be the substitute decision maker if they are no longer able to make their wishes known. Reassure people they will receive emergency treatment.

People need to feel free to name a Power of Attorney for Personal Care. It is important to explain the reasons for naming someone but it remains their choice.

Two people can be named if the person desires and the person naming can say if they can act separately or need to act together. Unless there is a particular reason for people to act together (i.e. one is a family member but does not know the person with a disability very well) it is usually more practical to have people able to act independently if needed in case one is away when an emergency occurs. The people named are obligated to work with the family and others who provide care to the person. There is a clause that needs to be added to the actual document if the person with an intellectual disability is unable to read. See page 14 in the book from the Ministry of the Attorney General)

**When a Person with an intellectual disability, clearly able to choose, is choosing appropriate family members who are willing and able to assume the responsibility**

These are the often the easiest situations. Legally family members are automatically substitute decisions makers in the following order - spouse, parents or children, siblings, any other relatives.

- 1) Make sure the person is interested in doing his process. If so - an experienced person in the community would go through the **Pictorial Power of Attorney for Personal Care Booklet** to help the person with an intellectual disability understand what types of decisions their family members would be making. The person with an intellectual disability would then be asked if they are happy to have their family members take on this role for them and believe that they would act in their best interest.
- 2) Explain that currently the people making decisions for them would legally be first the parents and then siblings. This makes the core member aware of the situation and also provides the opportunity to encourage them to make known their wishes known. The person with an intellectual disability and their family may need to be reassured that in an emergency the doctors would do whatever needed to be done.
- 3) The person facilitating the process will be in touch with the family to explain the process thus far. Some people with an intellectual disability will choose to name their parents and then list one of the siblings as the substitute on a actual power of attorney form. Or the family should be encouraged to talk and then fill out the form on page seven; giving consideration to knowing the person with an intellectual disability well and geographical proximity is important in both cases. If the parents are alive but unable to assume the responsibility it would be important to do an actual power of attorney for personal care form naming the siblings.
- 4) The original copy or whichever form is used is put in the file of the person with a disability in the office and a copy kept in their file at home

Or

The other option is to look at the pictorial book with the person with an intellectual disability and ask them if they agree to you asking the family to fill out the form. Use this option if the person seems comfortable with the family but doesn't particularly like paper stuff.

**When a Person with an Intellectual Disability is Unable to Clearly Name a Substitute Decision Maker or make a Particular Treatment or Placement Decision and has no Family or the Family is unable or unwilling to assume the role.**

**No one can name an attorney for personal care for someone so.....**

There appear to be two possible plans of action that may provide an ongoing substitute for a person with a disability who is consistently unable to choose a substitute decision maker.

- 1) For an appropriate person to apply to the courts and be named the legal guardian under the Substitute Decision Act. This would normally cost between \$3,000 and \$5,000 depending on the lawyer and the complexity of the situation. The process could take three to six months. It may involve one or two capacity assessments and usually only one court appearance. The parent for example could be jointly named with someone else so that they could take over when the parent was no longer able to assume this responsibility.
- 2) The other plan involves going to the Consent and Capacity Board. Apparently they still respond quickly to urgent situations. When there is no family willing or able to make a necessary decision someone who knows the person well can apply to the board to the representative to make the decisions. This board would most likely name the person making the application. It may be helpful to think ahead of time who this person might be. It could possibly be someone in the community if necessary. It is probably best if it is someone outside the community. Unfortunately the Board of Consent and Capacity can normally only be approached when there is a particular treatment or placement decision to be made. They can be reached through the office of the Public Guardian and Trustee at 1 800 366-0335. They also have a website- [www.ccboard.on.ca](http://www.ccboard.on.ca) If there is an appointment coming up where consent may be needed; the person with an intellectual disability is unable to give consent; there is no family and it is not clear who can give consent call ahead to the Board of Consent and Capacity. They will speak to the doctor and with us and decide who will give the consent. It seems that the board will not normally name someone to make decisions on an ongoing basis but they have at times named a representative for a person's "plan of treatment" which covers most things. There is normally no cost for this process. They have actually provided a lawyer for the person with an intellectual disability through legal aid.

**When a person with an intellectual disability is clearly unable to clearly choose or when medical people may not be able to understand their ability to choose but there is appropriate and able family.**

**Again no one can name an attorney for personal for anyone else so ....**

Once again it is legally automatically the person's parents, then their siblings and then other relatives who would be substitute decision makers if the person is considered unable to make the particular decision. So the documentation that we would have in the community would be for medical people involved so they know that we have discussed the situation and with whom they would need to speak for consent.

If the person is unable to articulate their choice but has family that is involved and appropriate the following is a simple process for documentation.

The person is given the opportunity to go through the pictorial if they are interested. This gives them the opportunity to take in what information they are able. Explain that you will talk to their family and get them to sign a paper so that there is something on file.

After the above conversation had taken place the family would be contacted. The family should be encouraged to have a discussion around this topic. They should keep in mind who knows the person with an intellectual disability the best and who would be the most likely to be available when a need arose. They would then be given the simple form on page seven to record the information. This form should be put on file in the office and the person's home.

If at some point there is no longer appropriate family one of the other strategies on the preceding page would need to be considered.

**L'Arche** \_\_\_\_\_

**Substitute Decision Maker/Attorney for Personal Care for** \_\_\_\_\_

**Date** \_\_\_\_\_

Family Members in order priority (with phone #s and addresses)

1

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2

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3

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4

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**When a person with an intellectual disability is able to choose but is not choosing family.**

- 1) The person facilitating the process should check with the director to determine who would be appropriate for an individual to name if they are not likely to name family. Or if this becomes apparent during the conversation the director should be consulted.
- 2) Use the same process as would be used for the person who is likely to choose family. But if you suspect that the person may be more comfortable choosing a friend, or a friend might be more appropriate, be clear about that option in the conversation. It should be mentioned with everyone anyway. Encourage the person to come up with the names themselves. Again if it is someone that the person facilitating and the director have not thought of it is important to check it out. People often seem to want to name someone in the community. They may need to be reminded that it is likely best to name someone who is not a community member.
- 3) Have a meeting with the person with an intellectual disability, and those they have chosen, to go through the booklet again so that everyone is on the same page. If there is any question of the family contesting the person's ability to choose at any time it would be wise to consult a lawyer. If it is not likely that the family will contest the form could be signed and witnessed.
- 4) The family does not legally need to be informed but it would be important to do so. In situations where the family is likely to question the decision or the person's ability to make the decision it would be important to formalize the choice of the person with a lawyer.
- 5) It is important to let everyone know that whoever the person chooses needs to consult with the family.



## **Information for Using Pictorial Power of Attorney Concerning Personal Care Booklet**

### GENERAL NOTES

Please read the rest of the information in the Power of Attorney for Personal care package.

#### **This booklet is a tool only it is not a legal document.**

If there are any doubts about the person's ability to understand the information or the family is likely to oppose their choice the next step is probably to consult with a lawyer.

The booklet could be used simply as another way of explaining to someone the concepts even if they are not choosing a Power of Attorney. (E.g.: someone whose has limited communication skills but their sister is automatically and appropriately the person who would legally take on this role if the person is unable to name someone.)

The process below is only one possibility. Sometimes it takes more than two meetings! We have also been surprised by people who we assumed capable of choosing being unable to do so for more emotional than intellectual reasons. Again consult a lawyer if this situation arises.

The director of the community needs to be aware of the process and the people being named. They may have more information and may also be the one needing to work with the people named.

The booklet can be printed in color and this seems helpful for many people.

#### **POSSIBLE PROCESS FOR USING THE BOOKLET AND HELPING A PERSON WITH A DISABILITY NAME SOMEONE.** (Particularly when the person does not want to choose family)

1) The person with an intellectual disability is generally felt to be able to understand the concepts in the booklet or you would use a different process.

2) The person with an intellectual disability meets with someone who will help animate the process and someone who knows them well within the community. After explaining why naming a power of attorney is important (so your wishes can be respected) the group would go through the booklet. It is important to ask questions to help determine if person with an intellectual disability is actually understanding the concepts or not and what areas might need more explanation. It might be helpful to give examples of types of situations in which a power of attorney has made decisions or share stories that the person with an intellectual disability might be familiar with. Near the end of the conversation if it seems appropriate ask person if they have any ideas about friends or family they might want to name.(It can't be someone in the community who is paid) Then the person animating the process could ask permission to talk to these people if they seem appropriate and to send them the information so they can consider if they are able to say yes to this or not. If more than one person is being asked the person with an intellectual disability needs to decide if they can make decisions alone or need to do it together. These two people would also need to agree to work together.

3 If the people approached agree to being named, talk to the person with an intellectual disability and set up another meeting which includes him/her, the person or people they want to ask, and two people who know the person well and can act as witnesses. The witness should be people who will probably be around and who have the confidence and ability to advocate for the person with an

intellectual disability if necessary. At this meeting we have simply gone through the book again and signed the forms from the Public guardian and trustee's office.

Hopefully the same person who helped animate the first meeting could help animate this one.

Or

If the people say no then the person with an intellectual disability would need to have that information explained to them, come up with other ideas, and set a time to have the meeting previously referred to.

4. If the person chooses someone other than family it is usually a good idea to inform the family of the choice made by the person with an intellectual disability. Again, if you expect that the choice will be met with opposition but is clearly the choice the person with an intellectual disability has made, it is important to consult a lawyer in the process.

4) A copy is placed in the person's house and office file and a copy given to each of the people named. Phone numbers and addresses of the people named should be attached. The team supporting the person needs to be made aware of who is named.

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## **Information for each page of the Pictorial Booklet**

### **Page 1**

You can add a picture of the person with an intellectual disability to this page to personalize it. This seems helpful in getting the person's attentions. Photocopy this page after adding a picture to it.

### **Page 2**

This page is to help the person with an intellectual disability understand what type of person they should choose. It is also helpful at this point to tell the person with an intellectual disability that the person they are choosing will only make decisions when they are unable and that they will continue to be supported to make whatever decisions they are able to make.

### **Page 3**

This page is to help the person with a disability consider whom they may want to choose as their attorney for personal care. It is essential that the person believe that the people they are choosing will act in their best interest. People will often name someone in the community first. So it is also important to let the person with intellectual disabilities know that normally they cannot choose someone who is paid to support them. The person also needs to realize that this is a big responsibility for someone to take on and that the person they choose may say that they are unable to do it.

### **Page 4**

This page is to help people understand the types of decisions that the people they choose will make for them. It is important for people with intellectual disabilities to understand that it is only these types of decisions that the people they choose will make and not any others (i.e. finances).

### **Page 5**

This page is to illustrate for people some of the things or situations they might want to talk about with the person they are choosing, so that their wishes can be made known and respected. This is difficult for most people to do and it is not necessary but obviously helpful. It is good to use examples that are known and understood by the person.

### **Page 6**

It is important to facilitate a meeting with the lawyer or doctor if that is what the person wants. In a situation where the person with an intellectual disability may be able to choose but the family is not chosen a lawyer may be helpful. The family may later claim that the person with an intellectual disability was unable to make that decision

Who can help take care of me when I am no longer able to care for myself?

take care of



I can say who I want to make decisions for me while I am healthy.

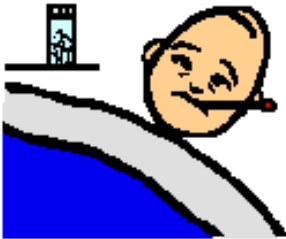
I'm fine



So they can make decisions for me when I am:

too sick

sick



too confused

confused



or when the doctor doesn't understand me

can't understand



## Two important things to be aware of

- 1) The people you choose should be people who know you and care about you and that you trust.

family



friend



safe

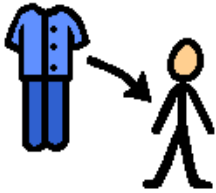


listen



2) They will make decisions about your personal care.

get dressed



eat



where I live



bathing



be sure you are safe



They will make decisions about medical things with your doctor and other health care providers.

doctor



oxygen



operation

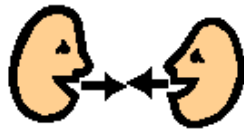


medicine



You can talk about some of the things that you want or don't want when you are sick. That way the people you have chosen would be sure of your wishes. You can put this information on the form too but you do not need to.

Let's talk



I like that

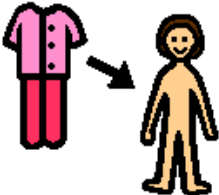


I don't like that



You can tell people what you want or don't want concerning the following things or anything else you are thinking about.

get dressed



medicine



eat



oxygen



operation



where I live





You should sign the form only after you:

- 1) Are sure that you understand what types of decisions those you name will make for you
- 2) Believe that they will act in a way that shows they care about you
- 3) Are sure that you want to name an attorney for personal care and don't feel someone is making you do it
- 4) Have thought about if you want to talk to your doctor or you lawyer about this

# The Role of an Attorney for Personal Care

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## Introduction

The purpose of this fact sheet is to explain the important role of an attorney for personal care. It explains what is involved in being an attorney for personal care, what the attorney is allowed to do and how the attorney is supposed to meet his or her obligations to an incapable person.

The powers and duties of an attorney for personal care are fully set out in the *Substitute Decisions Act, 1992* and the *Health Care Consent Act, 1996*. **This fact sheet is a summary only.** It is not legal advice and, if you have questions about how to interpret this information, you should consult with a lawyer.

## The purpose of a power of attorney for personal care

Most people make their own personal care decisions. Personal care decisions can include decisions about where to live, what to eat, safety, clothing, personal hygiene and health care, including treatment.

Making a power of attorney for personal care is an important step in planning for mental incapacity. By making a power of attorney for personal care, a person selects **who** he or she wants to make personal care decisions if he or she becomes incapable.

A power of attorney for personal care may also include wishes or instructions regarding how the person wants decisions to be made about him or her if he or she becomes incapable. These wishes or instructions can apply to decisions about the person's health care, including treatment, where the person lives, what the person eats as well as matters such as safety, clothing and hygiene.

The essential role of any attorney for personal care is to be a **substitute decision maker**.

The attorney "steps into the shoes" of the person, if he or she becomes incapable, and makes personal care decisions when necessary. These need to be made carefully and sensitively.

## When a power of attorney for personal care is used

An attorney for personal care only makes personal care decisions that the person is incapable of making for himself or herself. For example, a person may be incapable of making decisions about a

complicated medical treatment, such as surgery under a general anesthetic. If such surgery is recommended, the surgeon may ask the attorney to consent.

However, the person may be capable of consenting to a routine physical examination.

The fact that the attorney has been asked to consent to the surgery does not mean that the attorney will be asked to consent to all treatment given to the person. In most cases, it is up to the individual health practitioner to decide whether the person is incapable and the attorney is needed to make a decision.

Most frequently, an attorney for personal care is asked to make a decision for an incapable person regarding treatment or placement in a long-term care facility. However, a power of attorney for personal care that covers all types of personal care decisions extends beyond these situations. An attorney for personal care may need to assist an incapable person by making decisions regarding the person's safety, where the person lives, what he or she eats and matters of personal grooming.

An attorney for personal care is a decision maker, and is not expected to provide personal care services directly to the incapable person. However, the attorney may sometimes have to be involved in making arrangements for an incapable person. For example, an attorney for personal care may be the one who arranges for home care services, although these are actually provided by someone else.

A typical power of attorney for personal care does not give an attorney the power to force the incapable person to go along with his or her decisions. For example, an attorney cannot make the person eat food delivered by Meals-on-Wheels.

Some powers of attorney for personal care require that it be confirmed that the person is incapable of making personal care decisions before the attorney can make decisions.

Some powers of attorney for personal care contain special provisions that allow an attorney to use force, if necessary, to require the person to undergo a capacity assessment or be admitted to hospital. Attorneys who have been appointed under such powers of attorney should consult with a lawyer before starting to make decisions.

### Legal responsibilities of an attorney for personal care

An attorney for personal care must exercise his or her duties and powers diligently, and in good faith. When an attorney steps in and makes a personal care decision for an incapable person, that decision must be made solely for the benefit of the incapable person.

The following are some of the legal responsibilities of an attorney for personal care:

- The attorney must explain his or her powers and duties to the incapable person
- The attorney must encourage the incapable person to participate in decisions the attorney makes, to the best of the incapable person's ability to do so
- The attorney must seek to foster the incapable person's independence

- The attorney must choose the least restrictive and intrusive course of action that is available and is appropriate
- The attorney must seek to foster regular personal contact between the incapable person and supportive family members and friends
- The attorney must consult from time to time with supportive family members and friends who are in regular personal contact with the incapable person and with the persons from whom the incapable person receives personal care
- The attorney must keep records of decisions he or she makes on the incapable person's behalf
- The attorney must make reasonable efforts to find out if the incapable person expressed any wishes and instructions, while capable, that apply to the decision the attorney is making
- The attorney must not use confinement, monitoring devices or physical or chemical restraints on the incapable person or consent to their use unless doing so is essential to prevent serious bodily harm to the incapable person or others, or allows the incapable person greater freedom or enjoyment  
An attorney who is asked to consent to electric shock as aversive conditioning, sterilization or the removal of tissue for transplantation, or the incapable person's participation in a procedure whose primary purpose is research, should consult with a lawyer before making a decision.

#### Guiding principles for decision making

In making a decision for an incapable person, an attorney for personal care must follow these principles:

1. If the attorney knows of a **wish** the person expressed when capable, and the wish applies to the circumstances, the attorney must make the decision in accordance with the wish. For example, if the attorney knows that the incapable person did not wish to receive antibiotics for the treatment of pneumonia, the attorney must refuse to consent to treatment with antibiotics.  
The wish can be in writing, such as in a "living will", but it does not have to be.
2. If the attorney does not know of any wish, or if it is impossible to comply with the wish, the attorney must act in the incapable person's **best interests**. In doing so, the attorney must consider:
  - The values and beliefs the attorney knows the person held when capable and believes the person would still act on if capable
  - The person's current wishes (if they can be ascertained)
  - Whether the decision is likely to improve the person's situation, prevent the person's situation from deteriorating or reduce the extent to which, or the rate at which, the person's situation is deteriorating. The person's situation could include his or her condition and well being (where a treatment decision is being made) or his or her quality of life (where a placement decision or other personal care decision is being made).
  - Whether the incapable person's situation is likely to improve, remain the same or deteriorate if the attorney does not choose the course of action under consideration.

- Whether the benefit to the incapable person from the proposed course of action outweighs the risk of harm to him or her
- Whether there is a more desirable alternative to the course of action under consideration (for example, a less restrictive or intrusive course of treatment, or a less restrictive option than admission to a long-term care facility)

An attorney for personal care is entitled to receive the information relating to the incapable person that is necessary for the attorney to make a decision regarding the treatment or admission to a long-term care facility. This may include medical reports, hospital records and reports and records from a community care access center.

#### Assistance from the Consent and Capacity Board

Sometimes an attorney may find it difficult to interpret a wish, or may believe that if the incapable person were capable at the present time and asked to make the decision, he or she would now make a decision contrary to the wish.

If the decision is about treatment or admission to a long term care facility, the attorney may ask the Consent and Capacity Board to assist him or her in interpreting the wish or deciding whether the attorney may depart from the wish

An attorney who wants to ask the Consent and Capacity Board for assistance may wish to consult with a lawyer before doing so.

#### Records to be kept by an attorney for personal care

An attorney should always keep a copy of the power of attorney for personal care in a safe place.

The records that an attorney must keep include:

- A list of all decisions regarding health care, safety and shelter made on behalf of the incapable person, including the nature of each decision, the reason for it and the date
- A copy of medical reports or other documents, if any, relating to each decision
- The names of any persons consulted, including the incapable person, in respect of each decision and the date
- A description of the incapable person's wishes, if any, relevant to each decision, that he or she expressed when capable and the manner in which they were expressed
- A description of the incapable person's current wishes, if these can be ascertained, and if they are relevant to the decision
- For each decision taken, the attorney's opinion on each of the guiding principles listed above

### Maintaining confidentiality

An attorney is not allowed to disclose any information contained in his or her records unless required to do so in order to make decisions on the incapable person's behalf or otherwise fulfill the attorney's duties, or if ordered to do so by a court.

An attorney must produce copies of his or her records to:

- The incapable person
- The incapable person's attorney under a continuing power of attorney for property or guardian of property
- The Public Guardian and Trustee

### Conclusion

The role of an attorney for personal care is to take on the important responsibility of making decisions for an incapable person about shelter, diet, clothing, safety, hygiene and health care, including treatment. These decisions must be made sensitively, with respect for the incapable persons and in consultation with supportive family members and friends.

The attorney also has a duty to follow the guiding principles for decision making set out in the law.

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*This Fact Sheet was presented at the Ontario Elder Abuse Conference, "Sharing Solutions: Defining the Future," Toronto, Nov. 18-20, 2002. Its purpose is to provide information to clients of Jan Goddard and others. The Fact Sheet is not legal advice, and should not be relied upon as legal advice. If you are choosing an attorney for personal care, you should consult with a lawyer.*

*This fact sheet is not to be changed or translated*