

THE U L T I M A T E HEALTH RIGHTS SURVIVAL GUIDE

A STEP-BY-STEP GUIDE FOR YOUNG PEOPLE FOR MAKING YOUR OWN HEALTH
DECISIONS AND WHAT TO DO WHEN YOU CAN'T MAKE YOUR OWN DECISIONS



Provincial Advocate
for Children & Youth



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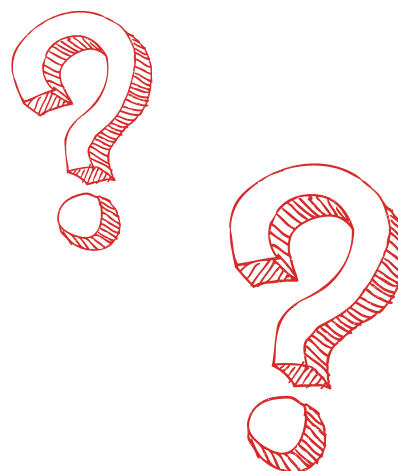
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INTRODUCTIONS

ABOUT THE SURVIVAL GUIDE

Thank you for picking up *The Ultimate Health Rights Survival Guide*. It was created by the I Do Care (IDC) Project at the Office of the Provincial Advocate for Children and Youth. It is a combination of **information** about health rights and **activities** that guide you through the processes to do with your health rights, as you need them.

Young people have equal treatment in law. The first sections of the guide outline your basic health rights on the topics of **Informed Consent, Decision Making, When You Can't Make a Decision**, and being **Locked In for Mental Health Reasons**. The next sections on **Understanding My Own Health** and **The Plan of Care** help you to apply the information and activities about rights to you and your own health and health care.

This practical guide is meant for both young people and service providers in the care systems of the province of Ontario, Canada, including child welfare (Children's Aid), youth justice, children's mental health, as well as the foster homes, group homes, residences, and facilities within these systems. **It will help young people to learn about their basic health rights, apply these rights to their own situations, track their progress, and learn the steps to make a decision about their health care.** It will help service providers to understand the basic health rights, know more about their roles, open up conversations about health, and support young people through the decision-making process. Ultimately, we hope that it will create a change in the care systems so everyone knows and follows the rules, young people and service providers feel comfortable working together, and health rights are realized all of the time.

MESSAGES

"Being involved in an ongoing conversation about their health and giving consent for treatment means that young people get to experience and learn the steps to making a decision. This builds their own skills for when they will have to make all of their decisions on their own, often at a young age. Understanding what is happening with their health and giving informed consent results in greater control over their lives and stronger relationships with supportive adults. Treatment decisions reached this way reflect what young people want to happen in their lives, the things that are important to them, and their everyday reality. In this way the process of consent is ongoing and is based in a relationship that becomes trusting." - **Irwin Elman, Provincial Advocate for Children and Youth**

"This book can help you understand that you have rights and that your voice matters." - **Phoenix, Guide•Participate•Support Youth Advisory Group member**

"It is full of information and I hope it helps you understand your rights better as well as change the way the system does work with young people." - **Benster, Guide•Participate•Support Youth Advisory Group member**

"This activity book is important for young people in the care system because a lot of us don't know our health rights, do not have all the information, do not have a voice, and are not heard." - **Elizabeth, Guide•Participate•Support Youth Advisory Group member**

"We created this book to make sure young people and service systems understand and achieve the health rights of young people in the care systems. It will help service providers rethink how they do their work and encourage excellent practice to make health rights real for our young people." - **The I Do Care Project team**

ABOUT PROJECT I DO CARE

HISTORY

Since 2007, the Advocate's Office has been tracking calls from young people regarding their health rights. Young people tell us that decisions regarding their health are generally made by the adults in their lives. Many young people also feel that requests to take control of their own health are not taken seriously. Some feel that they are forced into treatment or they can't get the treatment they want, their personal information is disclosed, they are overmedicated, and they receive little or no information regarding their health services.

WHAT ARE WE HOPING TO ACHIEVE?

1. Identify issues in the care systems that keep young people from knowing and realizing their rights to make decisions about their health and bodies.
2. Make specific plans for changes that can be made easily now and continued into the future.
3. Have young people within our office's mandate be involved in the project in a meaningful way and feel that they own the project with us.
4. Begin to build connections across issues, communities, and involved people.

WHAT ARE WE DOING?

GROUPS

- We held seven groups with young people across the province to:
 - explain health rights in understandable language
 - figure out what the blocks are in the care systems that keep young people from knowing and realizing their rights
 - look at what causes the blocks

YOUTH ADVISORY GROUP GUIDE•PARTICIPATE•SUPPORT

- Youth representatives from our groups are:
 - involved in making decisions about the project
 - co-creating The Ultimate Health Rights Survival Guide with the IDC Project team

ON-LINE

Website: provincialadvocate.on.ca



Facebook: [/idocareproject](https://www.facebook.com/idocareproject)



Twitter: [@projectIDC](https://twitter.com/projectIDC)



Blog: idocareproject.wordpress.com

- Guest blogs from professionals and young people about health rights

SURVEYS

- Online surveys with people in the care systems
 - 113 responses from service and care providers
 - 37 responses from young people

PARTNER AGENCIES

- Evaluations and interviews with staff
 - they gave detailed information about some of the barriers to achieving health rights



WORDS TO KNOW

CHILD AND FAMILY SERVICES ACT, 1990

The **Child and Family Services Act, 1990**, is the law in Ontario for Children's Aid Societies, children's mental health centres, youth criminal justice facilities (open and secure), and group homes. Although it does have a few sections about medical treatment, it is no longer correct to follow those sections. Since 1996, the Health Care Consent Act is the correct law to follow for the rules around medical treatment.

CONSENT AND CAPACITY BOARD CCB

The **Consent and Capacity Board (CCB)** is an independent tribunal (like a court) in Ontario that has the authority to hold hearings to take another look at whether a person is able to consent to or refuse treatment, issues about substitute decision making, and whether a person should be held in a mental health unit in a hospital.

FORM 1, FORM 3, FORM 4

A **Form 1** is a form filled out by a doctor to keep a person in a hospital for up to 72 hours (three days) for a mental health (psychiatric) assessment. The person must stay—even if they do not want to stay. The doctor who signed the Form 1 must have seen and talked to the person within the past seven days.

A **Form 3** is filled out by a doctor to keep a person in a hospital for up to 14 days (two weeks) for mental health reasons. It is also called a **certificate of involuntary admission**, meaning the person is not agreeing to stay in the hospital. The doctor still has to get consent in order to give the person any treatment.

A **Form 4** is filled out by a doctor to continue to keep a person in a hospital after the two week period under a Form 3. It is also called a **certificate of renewal**. The first Form 4 renewal is for up to one month, the second Form 4 is for up to two months, and the third Form 4 and all the rest after that can each keep you in hospital for three months at a time. The doctor still has to get consent in order to give the person any treatment. A **Rights Advisor** must explain your rights to you every time you are placed on a Form 3 or Form 4, or a Form 4 is renewed.



HEALTH CARE CONSENT ACT, 1996

The **Health Care Consent Act, 1996**, has been the law in Ontario since 1996 and it says what informed consent means, who makes treatment decisions, and what the rules are for Substitute Decision Makers. It applies to everyone in the province of Ontario. There is no separate law for young people in care. Throughout this guide, we refer to it as the *Health Care Consent Act*.

HEALTH CARE PROFESSIONAL

A **Health Care Professional**, who can decide whether you are able to make your own health decisions, must be a member of a profession listed in the Regulated Health Professions Act and includes physicians, surgeons, nurses, and psychologists. Social workers, child and youth workers, and foster parents are not included and **CANNOT** decide whether you are able to make your own health decisions.

See the full list in the Health Care Professions list under the Important Resources section of this guide on page 71.



POWER OF ATTORNEY FOR PERSONAL CARE

A **Power of Attorney for Personal Care** is a document you can sign to appoint someone as your "attorney" (this person does not have to be a lawyer). It is one way for you to choose the person who can make health and other personal decisions for you if you are not able to make them yourself. You must be at least 16 years old to do this.



SUBSTITUTE DECISION MAKER

A **Substitute Decision Maker** is someone who can give or refuse consent for treatment on behalf of a person who has been found unable to understand the treatment information and what might happen if they take or don't take the treatment.

TREATMENT

Treatment means anything that is done for any of these reasons:

Therapeutic: to make you better when you are already sick or injured (for example, medication, operation, or a cast)

Preventive: to keep you from getting sick (for example, the flu shot)

Palliative: to keep you comfortable if you are dying (for example, pain medication or a feeding tube)

Diagnostic: to understand the illness or injury (for example, an X ray or blood test)

Cosmetic: to change your looks (for example, braces on teeth, when done to change looks rather than because they are not working properly)

Treatment can include a course of treatment, a plan of treatment, or a community treatment plan. Treatment does not include an assessment to see if you can make your own health decisions or an exam to see your general health condition (for example, an annual medical checkup).

INFORMED CONSENT

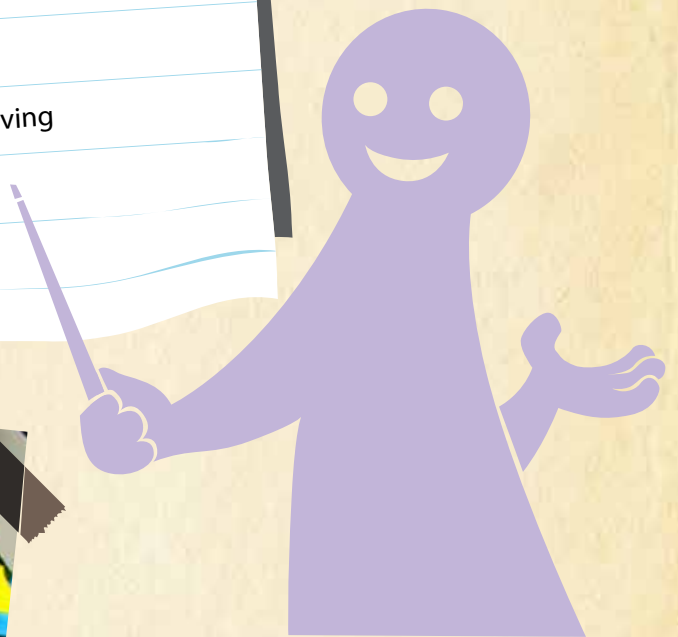
KEY POINTS

You must be given **all** information about a treatment

- It's not just signing a form
- There must be a **conversation**
- Your doctor must explain the treatment, effects, and other options
- Your doctor must explain in a way you can **understand**

Consent means **giving permission**

- Nobody can **force or trick** you into giving permission



THE FACTS

INFORMED CONSENT

WHAT IS CONSENT?

**CONSENT MEANS
THAT YOU GIVE
SOMEBODY
PERMISSION
TO DO SOMETHING.**



REMEMBER!

Let's say you get sick and go to the doctor. After some tests, your doctor tells you that they think you need surgery. Before the doctor can perform the operation, they need to talk to you about the surgery and make sure it is what you want. If you tell your doctor that you want them to do the surgery, it means you are giving your consent to do the operation. If you tell the doctor you don't want them to do the surgery, it means you are refusing to consent to the operation and they cannot do it.

HOW MUCH INFORMATION SHOULD I GET WHEN DECISIONS ARE BEING MADE ABOUT MY HEALTH AND BODY?

In order for you to be able to make a decision about what you want, **the law** (Health Care Consent Act) says you should:

- Have the treatment explained to you in a way that makes sense for you
- Be given all the information about the treatment, including:
 - Why your doctor thinks it is a good idea
 - What might happen if you take it
 - What might happen if you don't take it
 - How it will affect you, including the side effects
 - What are your other options for treatment?
- Be given information about the treatment that is true and accurate
- Be allowed to make the decision without anyone forcing or tricking you into it
- Have a conversation about the treatment! Get your questions answered!

Make sure you **ask as many questions as you need**. Sometimes it is uncomfortable to ask adults for information. But it is very important that you understand everything that is happening, and will happen to you, in order for you to agree.

No one is allowed to force you into giving permission for a treatment. That means that no one is allowed to threaten you, or mislead you, or say that you will be punished, consequence or removed from program for asking for information or making your own decisions.

**ASK AS MANY
QUESTIONS AS
YOU NEED.**



GETTING READY FOR AN APPOINTMENT



Many young people tell us that they don't get much time with their doctors and they don't always get the information they need about their health. The following questions can be used as a guide for preparing for a doctor's appointment and getting the most out of your time.

GETTING READY

What are the main reasons why I am going to see the doctor

- ☐ a check up
- ☐ I have started feeling sick
- ☐ I am being treated for a medical condition or illness



If you have been using the Health Log on page 49, you can take it with you to the appointment.

Who can help me prepare to see my doctor?

Who would I like to have with me during my appointment?

What information from this appointment do I want to share with my social worker/foster parent/group home staff?

I can decide not to share some information. Is there any information about my health that I want to ask my doctor not to share with my social worker/foster parent/group home staff?

Why? _____

GIVING INFORMATION TO THE DOCTOR

If I have just started feeling sick, which symptoms have I been feeling (for example, pain, fever, sneezing, hard time sleeping, low energy, or other symptoms)?

If I am already being treated for a long-term medical condition or illness, how have I been feeling since the last time I saw the doctor? Have there been any changes in my condition?



Health Log,
page 49.

Have I been feeling any side effects (for example, things that are not part of my medical condition but may be caused by the treatment)?



Health Log,
page 49.

GETTING INFORMATION FROM THE DOCTOR

What does the doctor say about my general health?

Is the doctor is suggesting a new treatment or a change in treatment?

Is this a short term or a long term change?

What would I do to get ready for the treatment?

How is the treatment done?

What are the risks?

What side effects or problems could happen as a result of the treatment?

How could this treatment affect me?

Do I have to change my lifestyle?

Do I have to stop doing something or start doing something because of this treatment?

What other types of treatment are available and might also work for me?

What other questions do I have for the doctor?

If a decision was made for medical treatment, who gave consent for this treatment:



Check out the Making a Health Decision worksheet on page 19 in the Decision Making section of this guide. It will give you a quick reminder of all the things you will want to consider when you are making a decision.



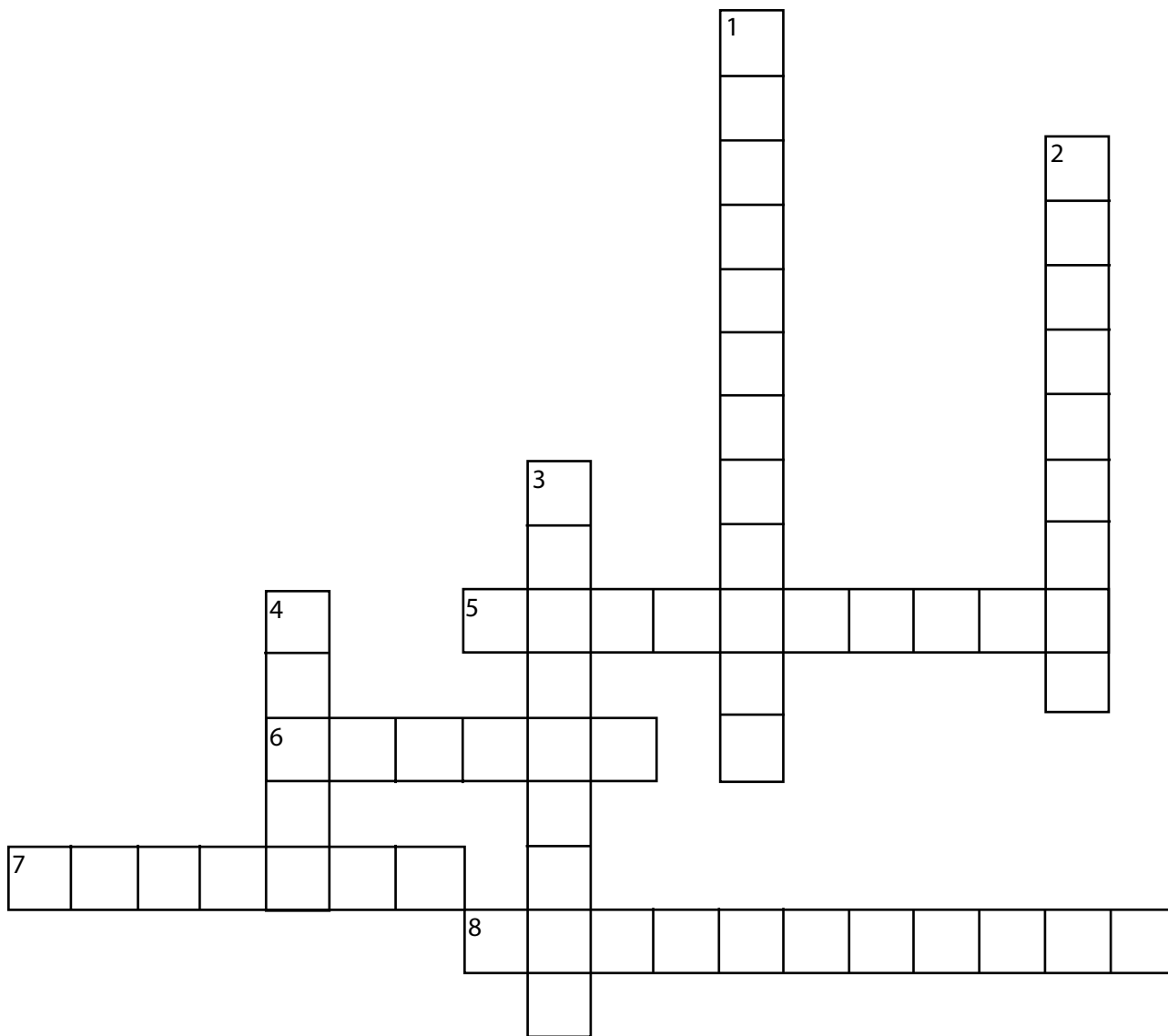
MAKING A DECISION

Remember that someone must give consent for any treatment. If you can understand the treatment information and what might happen if you take or don't take the treatment, you can make your own decision. If the doctor believes that you can't understand the treatment information and what might happen if you take or don't take the treatment, then your Substitute Decision Maker can make the decision. See the section **When You Can't Make a Decision** for more information. Even if you can make the decision yourself, you don't have to make it alone. You can ask other people for their ideas or include other people in making the decision if you want to.

INFORMED CONSENT CROSSWORD PUZZLE



Read each clue and fill in the missing word, starting with the box with the same number as the clue.



Words going across:

5. Consent means that you give someone _____ to do something.
6. The Health Care Consent Act is the law that gives you information about your _____.
7. "Permission" is another word that can be used for _____.
8. You must be given all of the _____ about the treatment.

Words going down:

1. Have a _____ with your doctor so that you understand everything about the treatment.
2. The law says that you need to have the _____ explained to you in a way that makes sense to you.
3. Ask _____ about the treatment.
4. When making health decisions, no one can _____ or trick you into making decisions.

See page 25 for puzzle solution





"NOT BEING ABLE TO MAKE MY OWN DECISIONS MEANS TO ME THAT MY VOICE AND OPINION ISN'T BEING HEARD. NOT BEING ABLE TO MAKE MY OWN DECISIONS CAN MAKE A PERSON FEEL SMALL AND INVISIBLE. THIS COULD MAKE PEOPLE FEEL INSECURE BECAUSE NO ONE LISTENS TO THEIR OPINIONS, IDEAS AND DECISIONS."

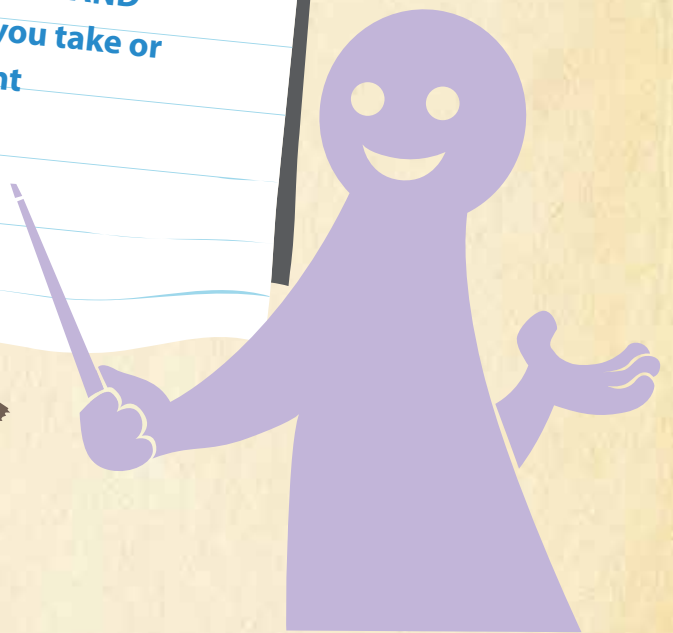
- YOUNG PERSON

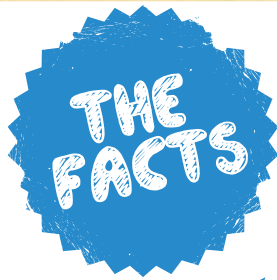
DECISION MAKING

KEY POINTS

For every medical treatment, someone must make the decision and give or refuse consent

- There is **no age of consent** in Ontario
- You can make your own decision if you can understand
 - **the treatment information AND**
 - **what might happen if you take or don't take the treatment**
- You can **change your mind**





DECISION MAKING

CAN I MAKE MY OWN HEALTH DECISIONS

In Ontario, the law (Health Care Consent Act) is that everyone, even people younger than age 12, can make their own decisions about their health, including choosing “alternative treatments,” traditional medicines, and culturally appropriate treatment. The only way this is not true is if your doctor, after speaking with you in a way that you understand, feels that you are not able to understand the information about the treatment or what might happen if you take, or don’t take, the treatment (“not capable”). Then, your doctor can ask your parents or guardian for permission to treat you.

Nobody should assume that you can’t make decisions just because of age, gender, language, disability, race/ethnicity, place of origin, gender identity, sexual orientation, etc.

Doctors can treat someone without consent if it is an emergency (like if someone is unconscious) and no one is able to give permission. Doctors cannot treat someone in an emergency if they know that the person said they did not want the treatment when they were able to understand the information and say what they wanted.

“EVERY DECISION HAS TO BE EXPLAINED, INCLUDING ALL OPTIONS AND IF THEY DO UNDERSTAND THEY SHOULD BE ABLE TO HAVE A DIALOGUE WITH THE HEALTH PROFESSIONAL.”

- YOUNG PERSON

SOME THINGS TO KEEP IN MIND

- The law says that social workers, Children's Aid Society workers, parents/guardians, group home staff, and Youth Service Officers cannot decide that you are not able to make your own health decisions
- Only a **doctor or other health care professional** can decide whether or not you can make a health decision
- Just because you say yes once does not mean that you have said yes forever—every time your doctor wants to give you a new treatment, or change the treatment, or do the treatment longer than you agreed to, they need to ask for permission again
- You can change your mind! If you can understand the information and what might happen if you take or don't take the treatment, you can decide that you no longer want treatment
- Each decision is separate. You might be able to make the decision for one kind of treatment but not another. Or you might not be able to make a decision today, but can make it in the future



ROLE OF DOCTOR (OR OTHER HEALTH CARE PROFESSIONAL)

- use language young person can understand
- explain treatment process, effects, risks, and side effects
- explain any other options for treatment
- answer questions
- explain right to a second opinion
- explain right to withdraw consent
- ensure young person knows consent is for each treatment / treatment plan (no blanket consents)

Young person gets more information about options, explores risks and benefits, asks more questions, may ask for support from others

- begins with assumption young person is capable
- can consider a disability, but just having disability does not make young person incapable
- not necessary for young person to agree with the diagnosis; may be enough that young person recognizes they are affected by a condition or symptoms
- maturity is based on the individual person, not on age
- can consider the complexity of the decision as one factor
- cannot consider "reasonableness" (young person can make a decision others consider unwise)
- cannot rely on doctor's personal values, priorities, or their own view of the young person's best interests

- doctor tells young person that a Substitute Decision Maker (SDM) will make this decision
- could be professional misconduct if doctor fails to tell young person they have been found incapable
- could be criminally charged if doctor treats without consent a patient who was capable and would have refused

TREATMENT CONSENT PROCESS

Doctor or other health care professional (HCP) proposes a treatment

Has young person been given all information about the proposed treatment? Have the young person's questions been answered?



Doctor determines if the young person has capacity

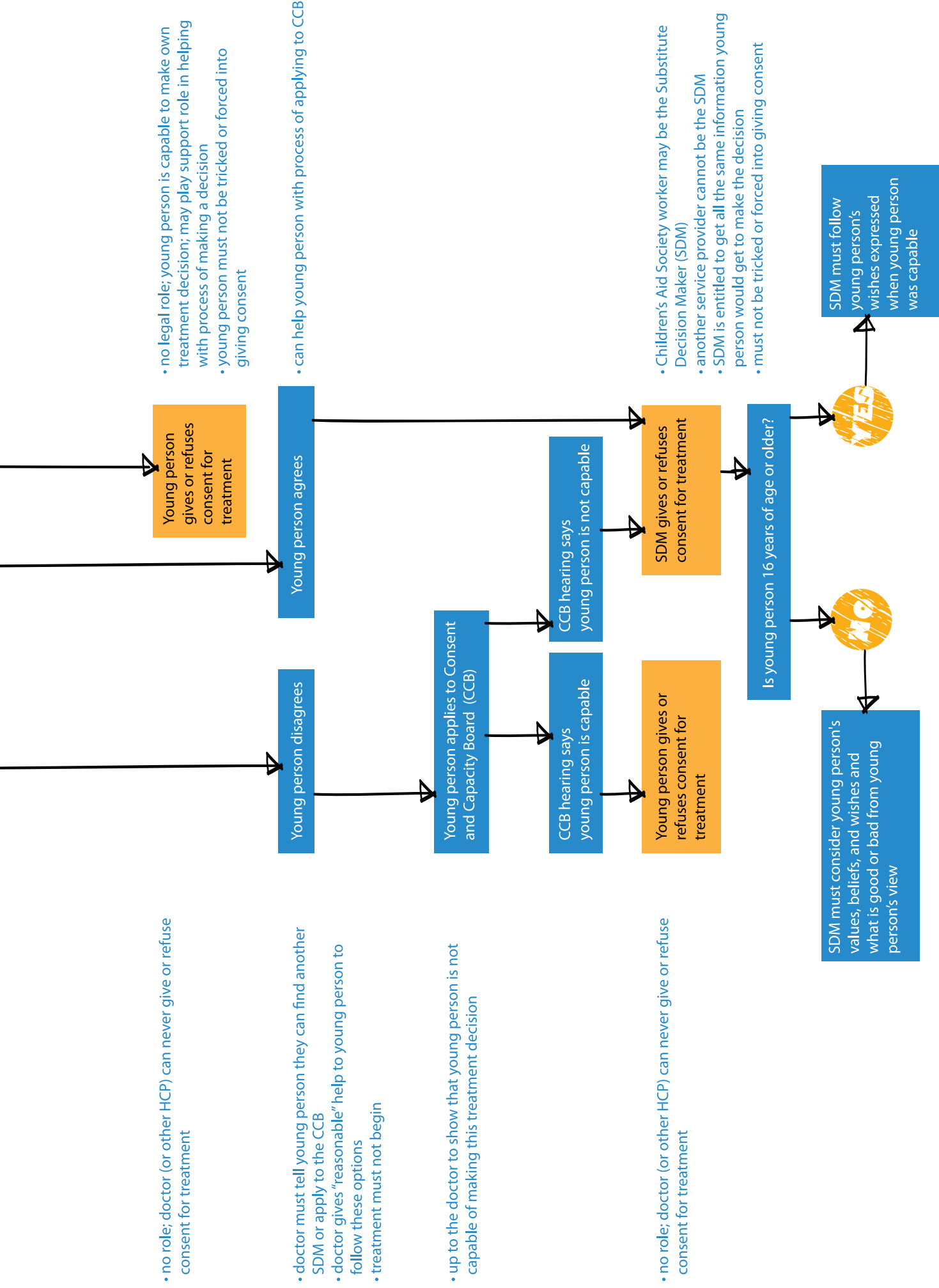
- understands the treatment information
- applies the information to self and current circumstances
- understands what might happen if they take or do not take the treatment



Doctor tells young person they are "incapable" and cannot make this treatment decision at this time

ROLE OF CHILD WELFARE WORKER AND OTHER SERVICE PROVIDERS

- ensure young person receives information they can understand
- ensure information is full and comprehensive
- assist young person to ask questions
- good practice to offer assistance to young person to make decision
- make sure young person has all information
- weigh benefits and risks of each option
- understand young person's values and what is most important
- who does young person want to support them?
- no role; service providers can never decide young person's capacity



MAKING A HEALTH DECISION ¹

STEP 1 — BEING CLEAR

What is the decision I am trying to make?

Why am I making it?

When do I need to make it?

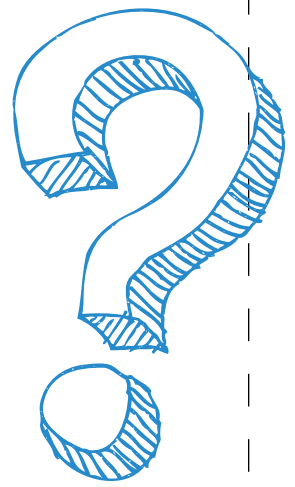
How close am I to making the decision?

- | | |
|---|---|
| <input type="checkbox"/> Have not thought about the options | <input type="checkbox"/> Close to making a decision |
| <input type="checkbox"/> Thinking about the options | <input type="checkbox"/> Already made a decision |

¹ Based on the Ottawa Personal Decision Guide © 2012 O'Connor, Stacey, Jacobsen. Ottawa Hospital Research Institute & University of Ottawa, Canada. See Patient Decision Aids in the Contacts and Links section of this book, under General Information about Health and Health Rights of Young People, if you want to get the original form.

”MAKING DECISIONS. THIS WOULD CHANGE FOR ME BECAUSE IT WOULD MAKE ME FEEL MORE RESPONSIBLE FOR MY OWN DECISIONS.”

- YOUNG PERSON















STEP 2 — THINKING ABOUT THE DECISION

WHAT ARE MY OPTIONS FOR MAKING A DECISION? WHAT DO I KNOW ABOUT EACH OPTION?













For each of the next two charts, write in each possible treatment under the *Options* column.

In the second column of each chart, fill in the reasons why you might **CHOOSE** or **AVOID** this option.

In the last column of each chart, circle one face to show how much each benefit or risk matters to you. Ask yourself: how does each option fit with my values? Does it include the benefits and advantages that are most important to me? Does it include risks or disadvantages that I can live with, or are they ones that I most want to avoid?

OPTIONS	REASONS TO CHOOSE OPTION Benefits/advantages for now and for the future (These can include medical effects and effects on my everyday life)	HOW MUCH DOES EACH BENEFIT/ADVANTAGE MATTER TO ME?
OPTION 1		<div> <div>NOT AT ALL</div> <div>A LOT</div> <div>  </div> </div>
		<div>  </div>
		<div>  </div>
		<div>  </div>
OPTION 2		<div>  </div>
		<div>  </div>
		<div>  </div>
		<div>  </div>
OPTION 3		<div>  </div>
		<div>  </div>
		<div>  </div>
		<div>  </div>

OPTIONS	REASONS TO AVOID OPTION Risks/disadvantages for now and for the future (These can include medical effects and effects on my everyday life)	HOW MUCH DOES EACH RISK/ DISADVANTAGE MATTER TO ME?
----------------	--	--

OPTION 1		<div> <div>NOT AT ALL</div> <div>A LOT</div> </div> 
		
		
		
OPTION 2		
		
		
		
OPTION 3		
		
		
		



WHAT SUPPORT AM I GETTING TO MAKE THE DECISION?

WHO ELSE IS INVOLVED?	WHAT OPTION DO THEY LIKE?	ARE THEY PRESSURING ME?
		<input type="checkbox"/> YES <input type="checkbox"/> NO
		<input type="checkbox"/> YES <input type="checkbox"/> NO
		<input type="checkbox"/> YES <input type="checkbox"/> NO

How do I want to make the decision?

- ☐ I decide myself after talking to _____ and hearing their point of view
- ☐ I talk to _____ and we decide together
- ☐ I ask someone else to decide for me

HOW SURE AM I ABOUT MAKING THIS DECISION?

After thinking about the benefits and risks of each option and how much they matter to me, I am leaning toward:

- ☐ OPTION 1 ☐ OPTION 2 ☐ OPTION 3 ☐ Not ready to decide

STEP 3 — FIGURING OUT WHAT MORE I NEED IN ORDER TO MAKE A DECISION

Do I **know** the benefits and risks of each option? ☐ YES ☐ NO

Am I clear about how they fit my **values**? Which benefits and risks matter most to me? ☐ YES ☐ NO

Do I have enough **support** and the right people supporting me to make a decision? ☐ YES ☐ NO

Am I choosing without pressure from others? ☐ YES ☐ NO

Do I feel **sure** about what the best option is for me? ☐ YES ☐ NO

[Adapted from the SURE Test © 2008 O'Connor, Légaré.]



People who answer no to one or more of these questions are more likely to put off their decision, change their mind, feel sorry about their choice later, or blame other people if things don't turn out well. It is important to plan what else you need to do in order to feel sure about making a decision and then go through the steps again until you ARE sure.

STEP 4: PLANNING WHAT ELSE I NEED

Knowing – What else do I need to know about the options and the benefits and risks? What questions do I have, who can I ask and where can I go for answers?

Values – Have I looked at the charts to see what matters most to me?

Have I done the Wishes, Beliefs, and Values worksheet? [page 46].

Can I talk to or read about other people who have made the decision?

Can I talk to someone to be clear about what matters most to me?



Support – Who else do I trust to talk to about the options? Do I need practical help (for example, transportation)?

If I am feeling pressure from someone else to pick a specific option, I would like to try:

☐ focusing on the opinions of people who matter most to me

Who? _____

☐ showing this worksheet to other people

Who? _____

☐ asking someone else to do this worksheet too

Who? _____

☐ finding a neutral person to help with the decision

Who? _____

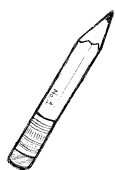
Anything else?



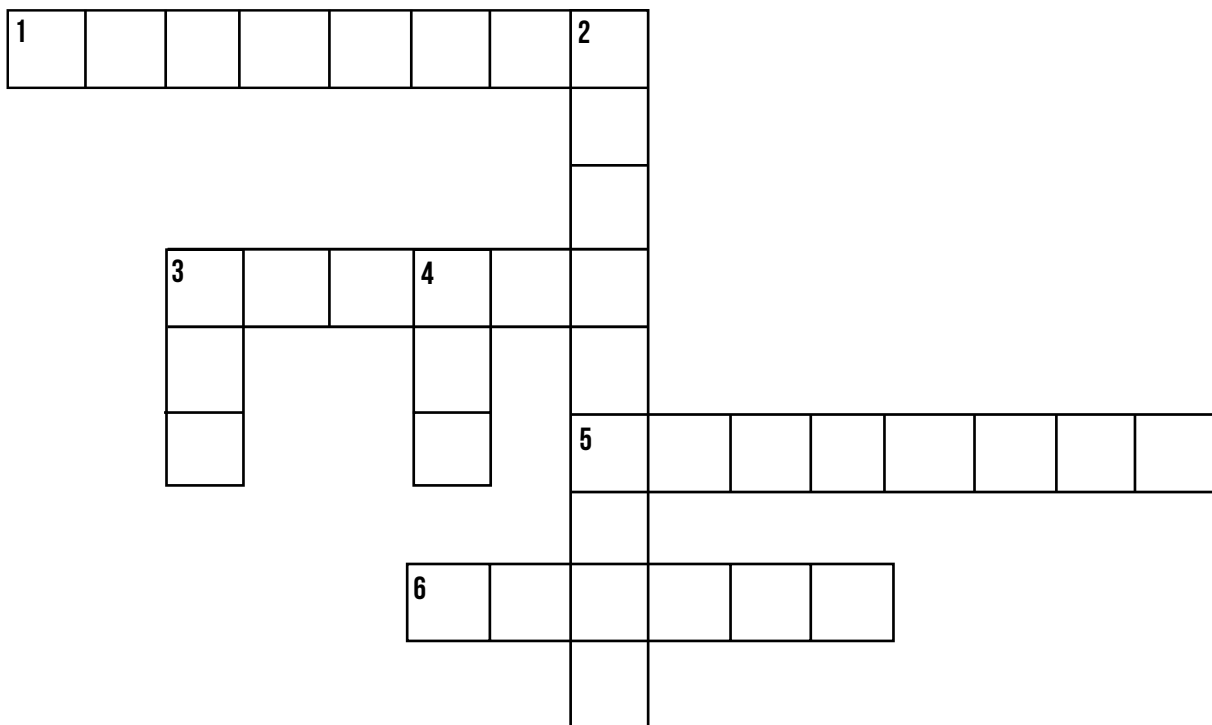
When you have everything else you need, you can go back to the beginning and work through each step again until you are sure of your decision.

What option do I prefer? _____

DECISION MAKING CROSSWORD PUZZLE



Read each clue and fill in the missing word, starting with the box with the same number as the clue.



Words going across:

1. Each decision is _____. You might be able to make a decision for one kind of treatment but not another.
3. If a doctor says you can't make a decision, you can get a _____ to speak for you at the Consent and Capacity Board.
5. The law says that _____, even people younger than 12, can make their own decisions about their health.
6. Only your _____ can decide if you are "capable" or "not capable" of making a health decision.

Words going down:

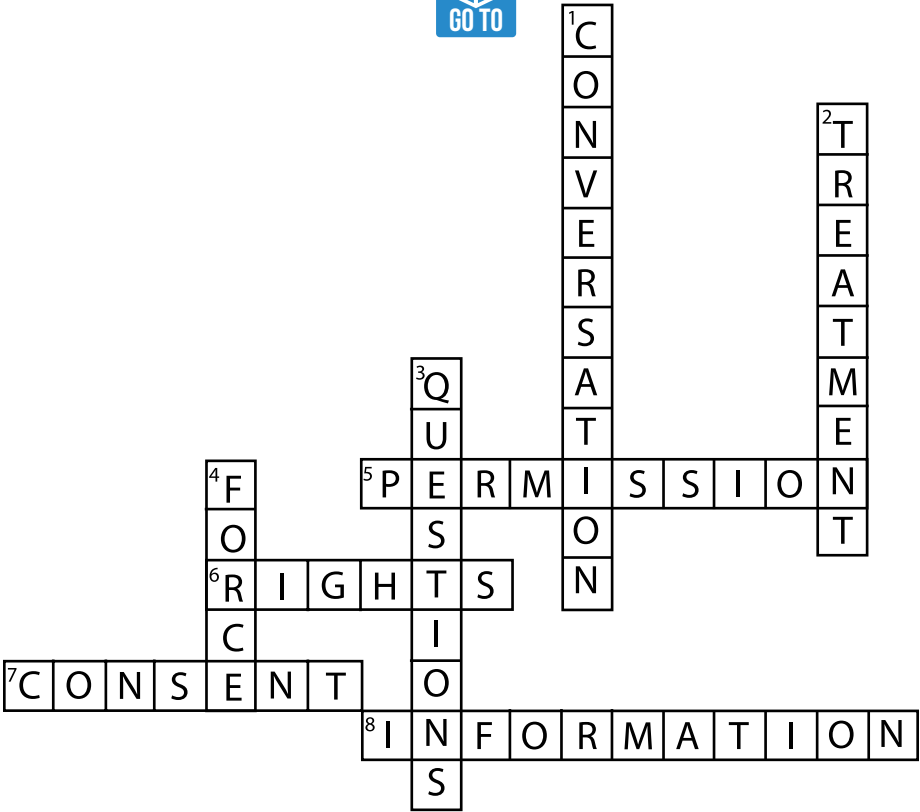
2. Doctors can treat someone without consent if it is an _____.
3. The _____ says that social workers, CAS workers, parents/guardians, group home staff, and Youth Service Officers cannot decide if you are capable of making your own health decisions.
4. Just because you say _____ to a treatment does not mean that you have said it forever.

See page 25 for puzzle solution

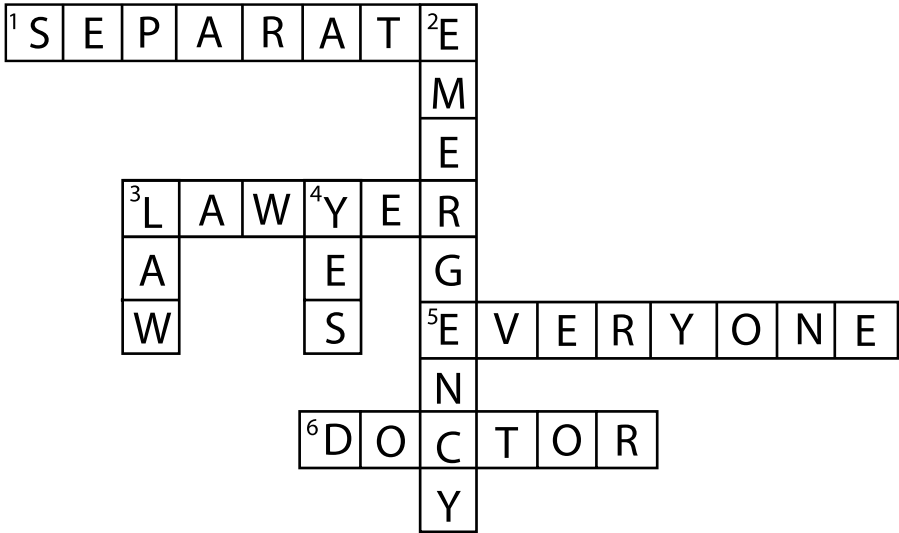


PUZZLE SOLUTIONS

Informed consent crossword (see page 12)



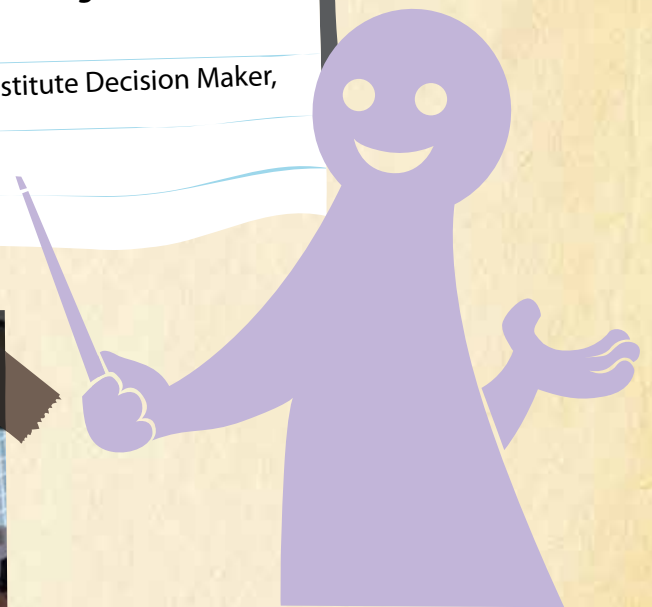
Decision making crossword (see page 24)



WHEN YOU CANT MAKE A DECISION

KEY POINTS

- **Someone must give consent** for each medical treatment
 - Only a doctor or other health care professional can decide that you are not able to make the decision
- If you can't make the decision, a Substitute Decision Maker will give consent
 - this is usually your parent(s) or guardian
- If you are 16 or older, a Substitute Decision Maker **must** follow your wishes that were said when you were able to make your own decisions
- If a Substitute Decision Maker does not know your wishes or you were younger than 16 when you said it, they should think about your **values and beliefs, other wishes**, and what is **good and bad** from your point of view
- If you want a **different person** to be your Substitute Decision Maker, you can ask the Consent and Capacity Board



THE FACTS

WHEN YOU CAN'T MAKE A DECISION

WHAT IF I CAN'T MAKE MY OWN HEALTH DECISIONS?

All treatment information should be given to you in a way that you understand. If, after speaking with you, a doctor feels that you are “not capable” (meaning, you are not able to understand all the information about the treatment or you are not able to understand what might happen if you take or don't take the treatment), then your doctor can ask your parents or guardian for permission to treat you. The parent/guardian would be called a **Substitute Decision Maker (SDM)**.

“IF YOU CAN'T MAKE DECISIONS, THEY SHOULD THINK WHAT WOULD BENEFIT IN YOUR BEST INTEREST

- YOUNG PERSON



SDM

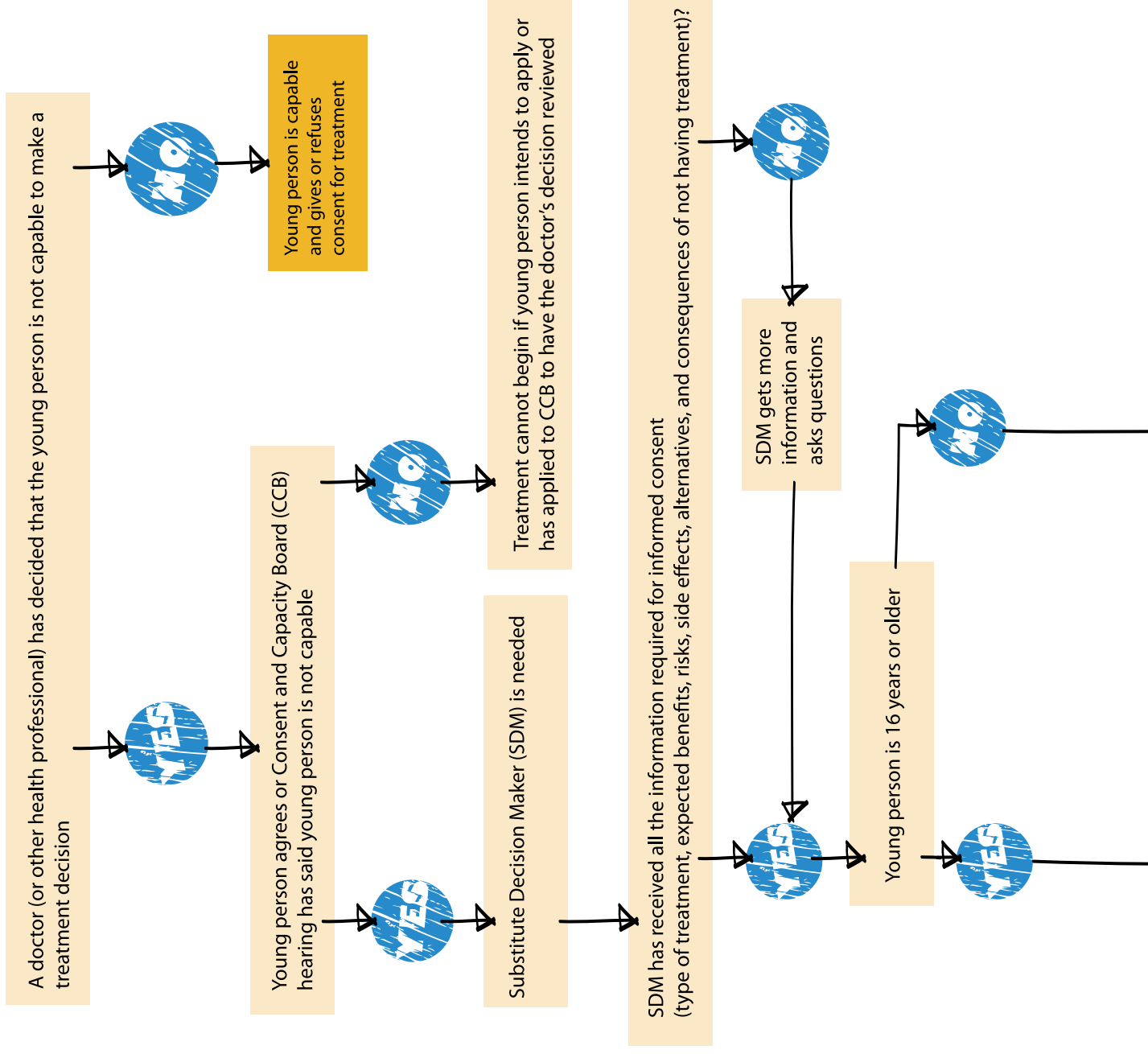
If there is another adult that you feel understands you better than your Substitute Decision Maker, you can ask the Consent and Capacity Board to make that person your SDM or that adult can ask the Consent and Capacity Board to be your SDM. The person who you want and who wants to be your SDM would have to be older than 16 and able to understand the information themselves. The Consent and Capacity Board cannot appoint an adult to be your SDM if you don't agree, even if that adult has said they want to do this.

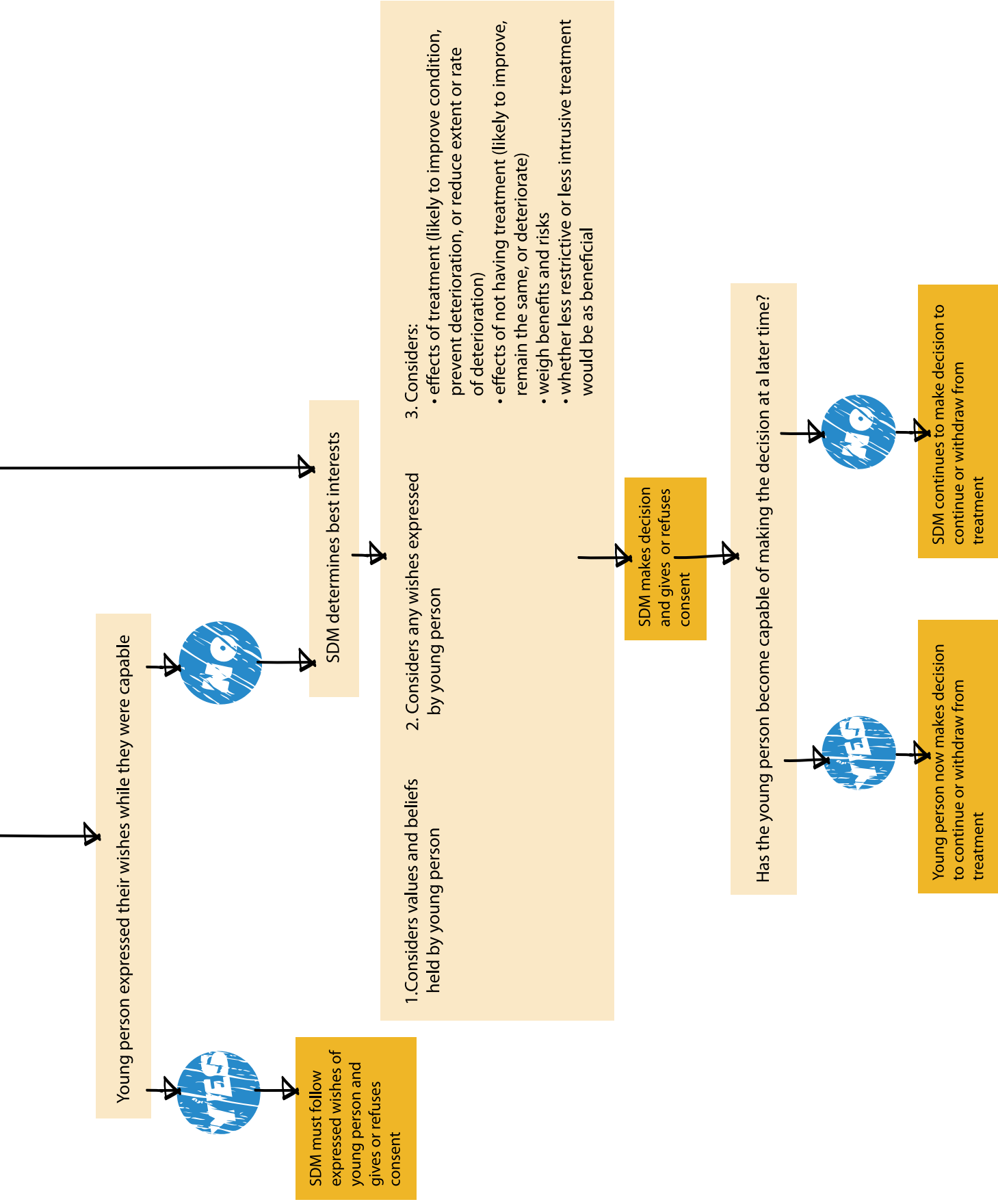
RULES FOR SDMS

There are rules for Substitute Decision Makers. **If you are older than 16, the SDM must follow your wishes that were said when you were able to make your own decisions**, even if you did not write them down in a special document, or anywhere, as long as someone knew how you felt about the treatment. If you have said different things over time, they should follow what you have said most recently. If a doctor knows that you did not want treatment when you were able to understand the information, they cannot give you treatment even if the SDM asks for it and not even in an emergency.

If the SDM does not know your wishes about a treatment, or you were younger than 16 when you said it, or it is impossible to follow your wish, they should think about your values and beliefs and other wishes that you have had in your life. They should also think about what is **good and bad about a treatment from your perspective or point of view!**

MAKING A TREATMENT DECISION FOR SUBSTITUTE DECISION MAKERS





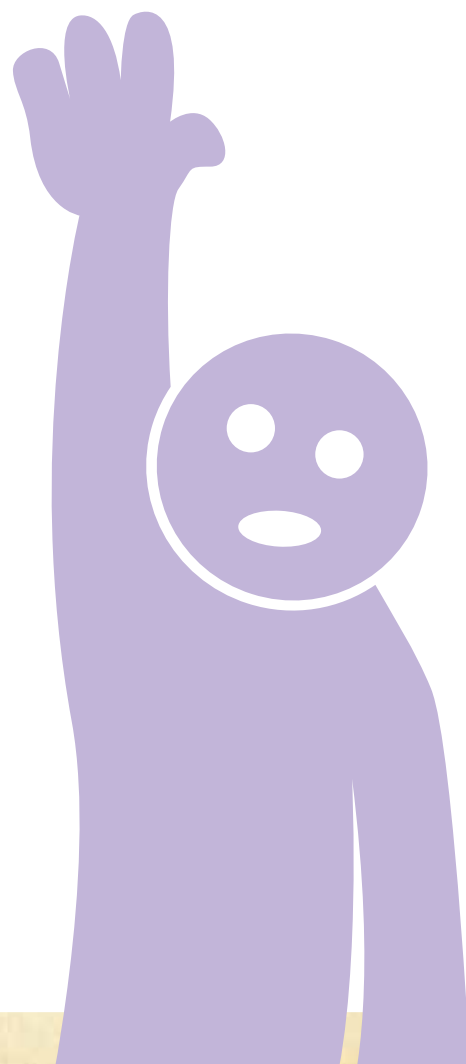
HAVING A SUBSTITUTE DECISION MAKER

Before anyone has any kind of medical treatment, **someone must give consent**. (The only time this is not true is in an emergency if the person is unconscious or there is another reason why they can't say their consent and they would be seriously harmed if doctors waited to get consent.) Most of the time, the person who has the medical treatment gives their own consent. Sometimes, a doctor or other health care professional will decide that the person is not capable of making their own decision. When this happens, **someone** must still make the decision. Sometimes this is done informally, by the doctor asking someone other than you to make the decision. However, you must still be asked if you agree to someone else making the decision for you. This person is called your Substitute Decision Maker.

The law gives a specific list of eight types of people who can be a Substitute Decision Maker (SDM). The person in your life who ranks **highest** on this list will be your SDM.

“EVEN THOUGH
CHILDREN/YOUTH
DO NOT MAKE
DECISIONS,
THEY SHOULD
BE ASKED TO
ENGAGE IN
DIALOGUE.”

- YOUNG PERSON



LIST OF PERSONS WHO MAY GIVE OR REFUSE CONSENT ¹

If a person is incapable with respect to a treatment, consent may be given or refused on his or her behalf by a person described in one of the following paragraphs:

1. The incapable person's guardian of the person,² if the guardian has authority to give or refuse consent to the treatment.
2. The incapable person's attorney for personal care,³ if the power of attorney confers authority to give or refuse consent to the treatment.
3. The incapable person's representative appointed by the Consent and Capacity Board under section 33, if the representative has authority to give or refuse consent to the treatment.
4. The incapable person's spouse or partner.
5. A child or parent of the incapable person, or a children's aid society or other person who is lawfully entitled to give or refuse consent to the treatment in the place of the parent. This paragraph does not include a parent who has only a right of access. If a children's aid society or other person is lawfully entitled to give or refuse consent to the treatment in the place of the parent, this paragraph does not include the parent.
6. A parent of the incapable person who has only a right of access.
7. A brother or sister of the incapable person.
8. Any other relative of the incapable person.

¹From the Health Care Consent Act, 1996, c. 2, sched. A, s. 20 (1).

²Guardian of the person is a legal term and is not the same as legal guardian. Someone has to apply to a court to become a guardian of the person, after the person has become incapable.

³Power of attorney for personal care does not require a court process. A person must be 16 years old or older and appoint an attorney for personal care while they are capable. See page 36 for more information.



MY SUBSTITUTE DECISION MAKER



Everyone has a Substitute Decision Maker (SDM) if they need one. Look on the list on the previous page and find the person in your life highest on the list. For most young people, that will be their parent or, if they are in care, the Children's Aid Society.

Who would be my Substitute Decision Maker if I could not make my own medical decision?

Who do I want to talk to about important medical decisions?

Have I told my Substitute Decision Maker the things that are important to me about my health? How have I done this?

☐ Written them down. Where did I write them?

☐ Conversation

☐ Plan of Care meeting

☐ Other:

REMEMBER!

People who are not on the list include group home staff, foster parents, doctors, and other medical professionals. None of these people can make a medical treatment decision for you. However, you can still **include** anyone you want in figuring out what decision you want to make or what information you want to give to your SDM. For example, you may live with foster parents who know you very well and you might feel very comfortable talking with them about your health.

RULES FOR SUBSTITUTE DECISION MAKERS

☐ I am age 16 or older

My SDM **must** follow any wishes I said when I was **able to make my own decisions** and I was **at least 16** when I said my wishes

☐ I am younger than 16

My SDM has to consider my values and beliefs and any wishes I have said. Also, my SDM has to consider

- whether the treatment would improve things for me or keep them from getting worse
- whether I could get better, stay the same, or get worse without the treatment
- how any improvements from treatment compare to the risks
- whether there is another treatment that could work that I would rather have.

TRACKING HEALTH DECISIONS BY SUBSTITUTE DECISION MAKERS

HEALTH DECISION MADE	WHO WAS THE SDM	HOW THEY FOLLOWED OR CONSIDERED MY WISHES, VALUES, AND BELIEFS	WAS I HAPPY WITH THE DECISION?	WHAT COULD MAKE THE DECISION BETTER?

CHANGING SUBSTITUTE DECISION MAKERS

If your SDM can no longer act for you for any reason or you don't think they are following the rules, including your wishes, you can ask the Consent and Capacity Board (CCB) to appoint someone else. The CCB can appoint that person only if that person agrees to act for you. Someone else who wants to replace your SDM can also apply to the CCB and may be appointed to decide for you, but only if you agree.

See page 35 for a step-by-step guide to contacting the Consent and Capacity Board.



GOING TO THE CONSENT AND CAPACITY BOARD



When you call the Consent and Capacity Board (CCB), they need to know why you are calling so they can send you the right type of application. You can ask someone to help you fill in the application if you would like. Once the CCB receives your application, the CCB must schedule a hearing within seven days unless all of the people involved agree to making the hearing later.

Three reasons for contacting the CCB:

- ☐ 1. I am being locked in a hospital for mental health reasons and I don't agree with being locked in (you can ask your Rights Advisor to help you with this one) See page 42.
- ☐ 2. My doctor (or other medical professional) has said that I am not able to make my own health decision and I disagree
- ☐ 3. I want a different person to be my Substitute Decision Maker (I must be at least 16 years old)



You do not have to give information about your health or your treatment when you call the CCB. They do need to know how to get the correct form to you.

Address, fax number, or e-mail address where you would like the CCB to send your form

Will the form come directly to you or to another person? Name of the person receiving the form

If you want, you can ask someone you trust to call the CCB and get the right form for you to begin the process. You still have to sign the form yourself.

Name of person contacting the CCB for me

Who could help me if I have any problems explaining why I am calling and what I want?

It is important to contact the CCB as soon as you can. When phoning the CCB, you just have to give one of the three reasons for your call.

The CCB's phone number is **1-866-777-7391** and fax number is **1-866-777-7273**. These numbers are free to call from anywhere in Ontario.

You can get information sheets, application forms, and more information about the CCB by contacting the CCB by telephone or go on the CCB website at <http://www.ccboard.on.ca/>

POWER OF ATTORNEY FOR PERSONAL CARE



Another option for choosing a Substitute Decision Maker is to appoint a person to act as your attorney for personal care. If you are told that you are not able to make your own treatment decision, this person would then become your Substitute Decision Maker. An attorney for personal care is higher on the list of decision makers than a family member or CAS worker. Even though the word “attorney” appears in the title, this person **DOES NOT HAVE TO BE A LAWYER.** It should be someone you know well and trust to make decisions according to your wishes, values, and beliefs.

TO GIVE A POWER OF ATTORNEY, YOU MUST

- Be age 16 or older
- Be capable of making your own decisions at the time you choose someone as your attorney for personal care
- Write down that you want a specific person to act as your attorney for personal care if you are ever incapable
- Sign and date it
- Have two witnesses sign it, showing that they saw you sign it



You do not have to use a special form, but if you want to, you can get the form made by the OFFICE OF THE PUBLIC GUARDIAN AND TRUSTEE

Telephone: 416-314-2800 (Toronto only) or 1-800-366-0335 (toll-free)

Internet: <http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poakit.asp>

You do not have to go to a lawyer, but you might find it very helpful to have a lawyer explain exactly what powers you are giving to your attorney for personal care and to answer your questions.

You can cancel a power of attorney by writing down that you are “revoking” it. Again, you must sign and date it and have two witnesses sign it, showing that they saw you sign.



MENTAL HEALTH

We have added a fourth rights section because so many young people in the care systems have asked about health rights in mental health treatment. The three rights sections earlier in this guide all apply to mental health treatment, as well. This section is specifically for young people who are locked in for mental health reasons.

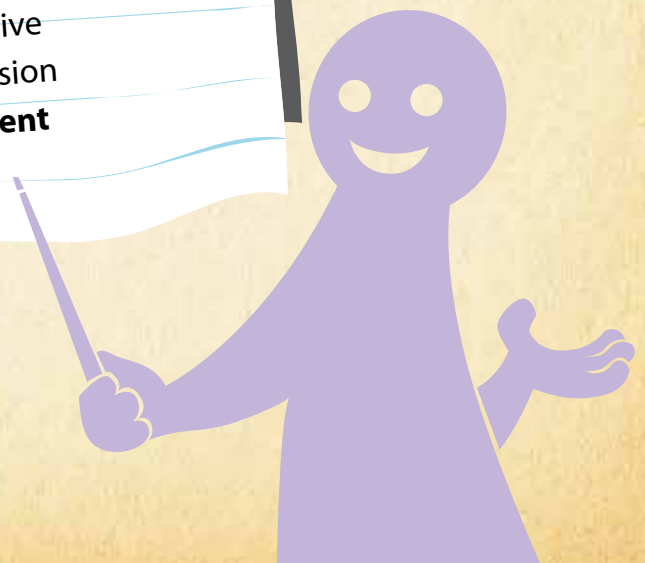
Young people can be locked in for mental health reasons, but only for specific reasons, including being a danger to themselves or someone else. If you are locked in, there are certain steps that have to be followed. These steps are slightly different if you are locked in a children's residence or in a hospital. This section will help you to keep track of those steps.

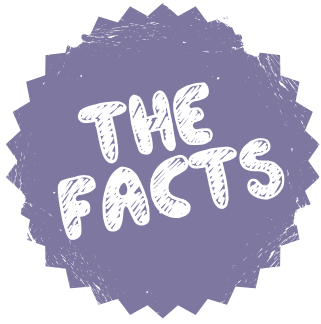
LOCKED IN

FOR MENTAL HEALTH REASONS

KEY POINTS

- Only two types of places can lock you in for mental health reasons:
 1. Some **children's residences**
(currently: Youthdale, Roberts/Smart, and Kinark-Syl Apps)
 2. Some **hospitals**
- You should know **why** you are locked in
- You have the right to get **advice about your rights**
- You can dispute it if you **don't agree** with being locked in
 - An outside organization will take another look at why you are locked in
- Being locked in does not mean you receive treatment—you or your Substitute Decision Maker still get to **decide about treatment**





LOCKED IN A CHILDREN'S RESIDENCE FOR MENTAL HEALTH REASONS

IF I AM HAVING MENTAL HEALTH PROBLEMS, CAN I BE LOCKED IN A CHILDREN'S RESIDENCE OR FACILITY EVEN IF I DON'T AGREE?

Yes, you can be locked in, but only under very special circumstances. **The law** (The Child and Family Services Act) gives lists of reasons why a person can be locked in, and the person who runs the children's residence/facility must believe that you are showing *all* of those reasons. **You should be told the reasons why you are being locked in.** One of the reasons has to be that you have a mental disorder.

Only some children's residences can lock you in. They have to be specially allowed by the government to lock in children and youth. The only children's residences in Ontario that can lock in children and youth for mental health reasons are Youthdale Treatment Centres, Acute Support Unit in Toronto; Roberts/Smart Centre, Secure Treatment Unit in Ottawa; and Kinark Child and Family Services–Syl Apps Youth and Secure Treatment Centre in Oakville.

You can be locked in one of these places for up to 30 days. This is called *emergency secure treatment*.

- You must be given **information about your rights** from an advocate from the Office of the Provincial Advocate for Children and Youth.
- If you **don't agree** with being locked in, the advocate will arrange for a lawyer to meet you.
- The lawyer can help you to apply to the Child and Family Services Review Board to **take another look at the decision to lock you in.**
- The Board will hold a **hearing** to discuss your situation.
- The Board can say either that you should stay or that you must be let out.

You can also be locked in a children's residence when someone thinks that you have mental health problems that have been going on for a long time. In this case, it is called *secure treatment* and can be up to 6 months at a time. The only places in Ontario for secure treatment are Kinark–Syl Apps in Oakville and Roberts/Smart in Ottawa.

- Someone must make an application to Family Court and explain all the reasons why you should be locked in.
- You have the right to have a lawyer work with you, help you present your case, or speak for you.
- The Family Court has a hearing and the Judge makes the final decision about whether or not you can be locked in. The Judge must be sure that you have met all of the reasons for being locked in.

Even when you have been locked in a facility, you still have the same rights to make decisions about your medical treatment or to have a Substitute Decision Maker make decisions (if you are not able to understand the treatment information or what might happen if you take or don't take the treatment). **Being locked in does not automatically mean that someone else makes decisions for you about treatment.**

LOCKED IN A CHILDREN'S RESIDENCE

EMERGENCY SECURE TREATMENT

1. Only three children's residences in Ontario are allowed to lock you in. Which one are you in?

☐ Youthdale in Toronto

☐ Kinark-Syl Apps in Oakville

☐ Roberts/Smart in Ottawa

2. An advocate from the Office of the Provincial Advocate for Children and Youth must come to see you or have a telephone conversation with you and explain your rights. The advocate must speak to you within 24 to 48 hours (one to two days) from the time you arrive the residence.

Name of advocate: _____

Telephone number: _____ or 1-800-263-2841

Date the advocate explained my rights: _____

☐ I understand the reasons for being in a locked mental health residence (you don't have to agree, but you should know why people thought you should be locked in)

☐ The possible treatment while in the residence was explained so I know what to expect and why (again, you don't have to agree but you should be told, so you know)

3. If you do not agree with being locked in, the advocate will arrange for a lawyer from the Office of the Children's Lawyer to come see you. The lawyer must see you and do all the necessary paper work within five days from the day you arrived at the residence.

☐ I asked for a lawyer to see me

Name of lawyer: _____

Telephone number: _____ Date the lawyer came to see me: _____



4. Your lawyer will write an application for an outside organization (called the Child and Family Services Review Board) to take another look at why you are locked in. This must happen within five days of when they receive your application.

Date of meeting: _____

- I decided ☐ to attend the meeting
☐ not to attend the meeting and have my lawyer speak for me
☐ to change my mind and not ask for another look at why I am locked in

Why did I change my mind? _____

Did I call my advocate to talk about changing my mind? ☐ Yes ☐ No

5. The Child and Family Services Review Board will say whether you should stay locked up or whether you should be let out.

- Decision ☐ I stay
☐ I leave

6. In any case, you can stay locked up for a maximum of 30 days. (If you come back a second time, you will go through the same process, with the same visit from an advocate. Each stay can be up to 30 days.)



REMEMBER!

During this time, staff at the children's residence and other people in your life should be working on where you will live and what help you will need after you leave the locked residence. You can attend a Plan of Care meeting to talk about the plans or talk to the residence staff and your Children's Aid Society worker individually about your ideas. You can also ask your advocate to attend a Plan of Care meeting to help you give your ideas.

The purpose of these meetings is to help develop a good plan for when you leave the residence. The plan should include things like:

- where you will live when you leave
- your treatment or programs you will attend for your mental health disorder
- any medications or other treatment
- strategies that help others work with you
- things that may trigger you or have been identified as part of your disorder
- what other things should be looked at to get a better understanding of you and your disorder, such as tests or assessments to be done

THE FACTS

LOCKED IN A HOSPITAL FOR MENTAL HEALTH REASONS

IF I AM HAVING MENTAL HEALTH PROBLEMS, CAN I BE LOCKED IN A HOSPITAL, EVEN IF I DON'T AGREE?

Most people who are in a hospital agree to be there. If you have agreed to stay in a hospital, you are a voluntary patient. This means you can change your mind later and leave.

Yes, you can be locked in, but only under very special circumstances. The **law** (Mental Health Act) gives a list of reasons why a person can be locked in and a doctor must believe that you are showing those reasons. This is called being an *involuntary patient*. You must be told the reasons why you are being locked in.

If you are locked in a hospital:

- A doctor can decide to have you stay for up to three days in order to figure out if they think you have a mental disorder. During that time, you must stay. The doctor must sign a paper called a **Form 1**, giving the reasons for keeping you.
- After that, you can be kept in the hospital but a doctor must see you and continue to fill in new forms. **A Form 3 (Certificate of Involuntary Admission)** lasts for up to two weeks.
- After that, a doctor must continue to see you, and give reasons why you should stay in the hospital, and fill out a **Form 4 (Certificate of Renewal)**.
- Each time a doctor fills out a new form, the hospital must arrange for a **Rights Advisor** to come and see you. You must be given information about your rights from an outside, independent Rights Advisor, usually from a place called the Psychiatric Patient Advocate Office, according to the times written in the law. See "Form 1, Form 3, Form 4" in Words to Know section on page 3 for the exact times.



If you don't agree with being locked in:

- You can speak with the doctor. The doctor can decide at any time to release you.
- If the doctor wants you to stay and you don't agree with being locked in, the Rights Advisor can help you to apply to the Consent and Capacity Board (CCB) to take another look at the doctor's decision.
- The CCB will hold a hearing (meeting) to discuss your situation.
- You can have a lawyer work with you, help you present your case, or speak for you at this hearing. The Rights Advisor can help you find a good lawyer who has helped a lot of people in your situation. The CCB can appoint a lawyer for you or you can choose and hire your own lawyer. Legal Aid will pay the lawyer so it's free for you.
- The CCB can either agree with the doctor and say that you should stay or make you a voluntary patient so that you can leave if you want.
- If you have to stay in the hospital at this time, you must continue to get rights advice and a review of your situation. Every time there is a new Form signed, you can have a new hearing by the CCB.

Even when you are locked in a hospital, you still have the same rights to make your own decisions about your medical treatment or to have a Substitute Decision Maker make decisions (if you are not able to understand the treatment information or what might happen if you take or don't take the treatment). **Being locked in does not automatically mean that someone else makes decisions for you about treatment.**

LOCKED IN A HOSPITAL

1. A hospital can lock in someone of any age. If they are trying to understand what the problem is (called an assessment), they can lock you in for up to three days on a **Form 1**.
2. After the three days, they have to either let you leave or put you on a **Form 3** because they have decided that you are a danger to yourself or someone else or that you are unable to take care of yourself properly. This means you can be kept locked in the hospital for up to two weeks, to keep you safe. A Rights Advisor must come to see you. Often that person will be from the Psychiatric Patient Advocate Office.

Name of Rights Advisor: _____

Rights Advisor's organization: _____

Telephone number: _____ Date the Rights Advisor explained my rights: _____

3. If you do not agree with being locked in, the Rights Advisor will explain how you can have an outside organization take another look at why you are locked in. You can also ask your Rights Advisor for help to arrange for a lawyer to speak for you. It is very important to find a lawyer who has experience with mental health and consent problems. The lawyer will not cost you anything and will not contact your parents or anyone else without your consent. Anything you tell your own lawyer is completely private and confidential.

☐ I asked for another look at why I am locked in ☐ I asked for a lawyer

Name of lawyer: _____ Telephone number: _____

Date the lawyer came to see me: _____

4. If you ask for another look at why you are locked in, the organization that will do this is called the Consent and Capacity Board. They should have a meeting (called a hearing) about you within seven days of when you ask for it, unless both you and the doctor agree to make it at a later time.

Date of meeting: _____

5. The Consent and Capacity Board will say whether you should stay locked up by the hospital or whether you should be let out, but will not say where you should go if you leave.

Decision: ☐ I stay ☐ I leave

6. In any case, each time a doctor signs a new Form saying that you have to stay locked in the hospital, you have to be given rights advice and you can choose to ask that the Consent and Capacity Board look again at why you are locked in and whether you should still be locked in. See Words to Know on page 3 for definitions of Form 1, 3, and 4.



ADVOCATES IN HOSPITALS

Some hospitals have their own advocates who work for the hospital. They may have other titles like Patient Relations, Patient Care, or Hospital Ombudsperson. They may hear about problems with care from patients and try to get answers within the hospital. Their work is different from a Rights Advisor and they do not have the same legal responsibility to make sure that your mental health rights are explained or to help connect you with the Consent and Capacity Board if you want to have a hearing.

UNDERSTANDING MY OWN HEALTH

WORKSHEETS

- Words to Describe Me
- My Wishes, Beliefs, and Values About My Health
- Health Log



WORDS TO DESCRIBE ME



This list of words gives you a chance to think about how you would describe yourself. Sometimes it is easier to describe problems, so this list asks you to circle your positive qualities. If you would like, you can copy this list and ask someone else to fill it out also and compare your choices

HOW AM I WITH OTHER PEOPLE?

funny
good listener
understanding
loving
delightful
considerate
charming
polite
friendly
kind
cheerful

WHAT IS MY ENERGY LIKE?

easygoing
eager
outgoing
energetic
spirited
enthusiastic
calm
steady
active
balanced

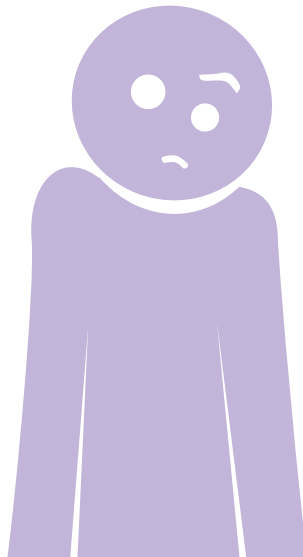
HOW DO I THINK?

curious
practical
logical
clever
alert
thoughtful
perceptive

HOW DO I ACT?

responsible
loyal
dependable
trustworthy
determined
honest
daring
respectful
independent
patient
confident
persuasive
cooperative

WHO I AM?



HOW DO I FEEL?

sensitive
brave
modest
fair
sentimental
careful
tough
outspoken
passionate
generous

WHAT SKILLS DO I HAVE?

artistic
organized
hardworking
creative
coordinated
speak well
solve problems

WHAT ACTIVITIES AM I GOOD AT?

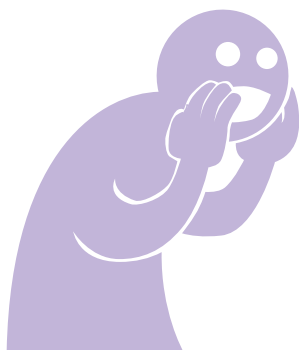
cooking
reading
schoolwork
sports
music
computers
art

WHAT OTHER WORDS DESCRIBE ME?

other: _____

MY WISHES, BELIEFS, AND VALUES ABOUT MY HEALTH

In thinking about your wishes for your health, it is also important to think about your beliefs and values. Your values are the things that are important to your life and, in this case, to your health. Values often stay much the same, but they can also change over your life as you change. When the things that you do and the decisions you make match your values, you tend to feel good and happy. When you or others act against your values, things usually feel wrong.



The list below is a way for you to think about your own beliefs and values about your health, so you can be clear about your wishes. You will find that you agree more with some statements than others and that some will be more important to you than others. This can help you sort out what is most important to you. There are no right or wrong answers. You are the only person who knows what mix is right for you. You may also have other beliefs and values that are not on the list that you want to add for yourself.

IT IS IMPORTANT TO ME THAT:

- ☐ I have as little pain as possible
- ☐ my thinking is always clear, even if this means having some pain
- ☐ I have the best chance of getting better, even if this means having some pain
- ☐ my behaviour is under my control so I am not upsetting myself or other people
- ☐ my thoughts and feelings are not upsetting to me (for example, hearing voices or feeling very anxious)

- ☐ I have clear thinking and more energy, even if that means having more thoughts and feelings like hearing voices or feeling very anxious
- ☐ I do things for myself
- ☐ things get done, even if someone else has to do them for me
- ☐ I have enough concentration to do regular activities like school and recreation
- ☐ I have enough energy to do sports or other activities I enjoy
- ☐ I have the best possible chance of getting better, even if the treatment has higher risks or side effects
- ☐ the treatment I have has lower risks or side effects
- ☐ I try other things to help my health (for example, exercise, relaxation, vitamins, massage, acupuncture, or many others):

Other:

WHAT DO I THINK OF DIFFERENT TYPES OF TREATMENT?

Medication in pills or liquids

Medication by needles

Having an operation

Having physiotherapy

Having counselling

Other:

REMEMBER!

Communicating your wishes for the future is not the same as giving consent. Even if you have said your wishes, no one can use that to say you have given consent in advance to a treatment that might be suggested in the future. You (if capable) or your SDM (if you are not capable) must still give consent for a treatment at the time it is suggested.

What treatment would I choose first?

Which treatment(s) would be okay with me to make me more comfortable?

Which treatment(s) would be okay with me to cure an illness?

Which treatment(s) would be okay with me to keep me from dying?

Which treatment(s) would be okay with me if it is for a short time only?

Which treatment(s) would be okay with me if it would be going on for a long time?

What are my most important wishes about my health and what treatment I want to have?

SAYING YOUR WISHES

You might find it helpful to think through these questions and to bring your wishes for your health and medical treatment to your next Plan of Care meeting. However, you are not required to use this form or to discuss your wishes at your Plan of Care meeting. You can let people know your wishes in other ways too, such as saying them out loud or writing them in a journal. If you have strong wishes about your medical treatment, it is important that you let your Substitute Decision Maker know what they are so your SDM can follow or consider your wishes if at any time you cannot make your own decision. Also, if your wishes change over time, your SDM must follow or consider your most recent wishes.

HEALTH LOG

GENERAL HEALTH AND WELL-BEING

How do I feel in general? This includes physical (my body), mental (my thoughts and feelings), and social (my involvement with other people and activities):

What do I do to stay in good health?

What could make my health and well-being better?

SHORT SICKNESSES

These are things I have that last a short time. These may get better on their own or by taking care of myself, or I may need medical treatment. They include things like colds, flus, or chicken pox.

What sicknesses have I had? _____

Do I get any sicknesses often? _____

Do I have any sickness now? _____

What I am doing to take care of myself?

What medical treatment I am taking?

LONGER HEALTH CONDITIONS OR ILLNESSES

These are things I have that are expected to go on for some time. I may have some treatments to make them better or keep them from getting worse. They include things like asthma, depression, or diabetes.

☐ No health conditions/illnesses. (I am done this worksheet! I can skip to the next section)

Names of any health conditions:

What does it look like and feel like to me?

These are often called symptoms. Common symptoms for many different health problems could include cough, feeling worried all the time, fever, finding it hard to breathe, finding it hard to pay attention, pain, sore throat, hearing voices, or throwing up.

My symptoms:

TRACKING MY HEALTH

Taking Care of Myself

What are some things I do that help this condition get better? These will depend on what condition I have, but might include things like getting more sleep, exercising, having a regular schedule, or relaxation exercises.

Medical Treatment

What treatments are given by a doctor, nurse, or other medical professional? These might include medications, operations, an inhaler, or physiotherapy.

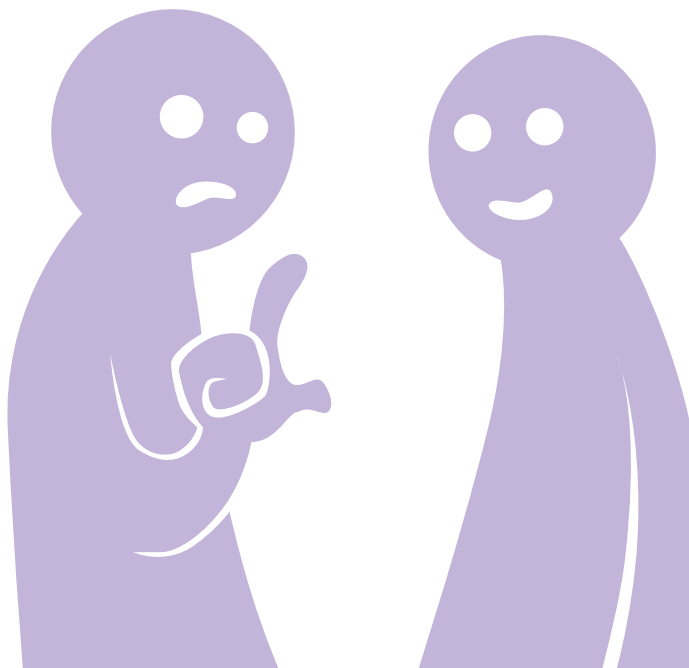
WHAT ARE THEY?

Sometimes a treatment will cause something besides what it is supposed to do. This is a side effect. Often they are small and don't bother you, but sometimes they do, and that might make you not want to take the treatment. Some side effects happen before you start to feel the helpful parts of the treatment.

Common side effects could be dry mouth, upset stomach, or skin rash. Each medication comes with a list of possible side effects, but they can affect each person differently. Treatments other than medication can also have side effects. Some side effects are temporary when you begin a new treatment and others may last the entire time you are on a treatment. It might help to track your own side effects so you can understand them and try to make them affect you as little as possible.



You can use the worksheet on page 55.



What side effects can I expect from this treatment?

Are there any side effects that could be dangerous? _____

If yes, what should I do if I get these dangerous side effects?

Is there anything I should **not** do while taking this treatment?

Are there any tests I need to have while taking this treatment (for example, blood tests, X rays, or other tests)?

What could happen if I stopped taking the treatment suddenly?

Positive Effects of Treatment

What can I expect to happen to make my condition better?

When are these positive effects likely to happen?

Effects On Other Parts Of My Life

Is the treatment affecting my daily routine? If so, how?

Is the treatment affecting my school or other activities? If so, how?



TRACKING MY SYMPTOMS

1. DAY/DATE	2. WHAT I FEEL	3. HOW I RATE IT (CIRCLE ONE)	4. WHAT ELSE IS GOING ON / WHAT AM I DOING?

Using This Chart

Column 1

Write down the day, date, time, or anything else that will help you to keep track of the symptoms

Column 2

Write down the symptom and try to be as specific as possible. For example, write "kept gagging, felt like I was going to throw up" instead of just "felt bad" because it gives more information.

Column 3

How do you feel about this symptom? How much or how often does it bother you? See icons below.

Column 4

Keeping track of what else is happening or what you are doing at the time when you rate your symptom could help you see patterns in your health. For example, if you see that you have less pain after you walk home from school, you might decide to try short walks more often.



Really hard for me, bothering me a huge amount



Not great, bothering me somewhat



Hard for me, bothering me a big amount











































Okay, bothering me a small amount



Fine, bothering me a tiny amount

TRACKING MY SIDE EFFECTS

1. DAY/DATE	2. WHAT I FEEL	3. HOW I RATE IT (CIRCLE ONE)	4. WHAT ELSE IS GOING ON / WHAT AM I DOING?
		    	
		    	
		    	
		    	
		    	
		    	
		    	
		    	

Using This Chart

Column 1

Write down the day, date, time, or anything else that will help you to keep track of your side effects.

Column 2

Write down the side effect and try to be as specific as possible. For example, write "very sleepy in English class, eyes kept closing" instead of just "tired."

Column 3

How do you feel about this side effect? How much or how often does it bother you? See icons below.

Column 4

Keeping track of what else is happening or what you are doing at the time when you rate your side effect could help you see patterns in your health. For example, if you notice that you always feel really sleepy an hour after you take your medication, you could talk to your doctor about the best time to take it so it affects you as little as possible.



Really hard for me, bothering me a huge amount



Not great, bothering me somewhat



Hard for me, bothering me a big amount











































Okay, bothering me a small amount



Fine, bothering me a tiny amount

TRACKING MY POSITIVE EFFECTS

1. DAY/DATE	2. WHAT I FEEL	3. HOW I RATE IT (CIRCLE ONE)	4. WHAT ELSE IS GOING ON / WHAT AM I DOING?
		    	
		    	
		    	
		    	
		    	
		    	
		    	
		    	

Using This Chart

Column 1

Write down the day, date, time, or anything else that will help you to keep track of the positive effects.

Column 2

Write down the positive effect and try to be as specific as possible. For example, write "can walk 20 minutes without pain" instead of just "felt better."

Column 3

How much or how often is this treatment helping you? See icons below.

Column 4

Keeping track of what else is happening or what you are doing at the time when you rate your positive effects could help you see patterns in your health.



No improvement or worse, not helping any of the time



Some improvement, sometimes



A very small improvement, a bit of the time



A big improvement, most of the time



A huge improvement, all of the time



"COMMUNICATION IS IMPORTANT TO ME BECAUSE THEY NEED TO KNOW MY OPINION AND MY CHOICES. THEY CAN'T GUESS FOR ME, ESPECIALLY WHEN IT COMES TO HEALTH DECISIONS AND TREATMENT. NOT DISMISSING MY QUESTIONS OR COMMENTS WOULD MAKE THINGS EASIER BECAUSE WE CAN ALL WORK THINGS OUT. RESPECTING MY DECISIONS IS CRUCIAL AND IMPORTANT AND BECAUSE IT IS MY RIGHT TO REFUSE AND CHOOSE."

- YOUNG PERSON

THE PLAN OF CARE

"The plan of care section will change how workers, clients, and health professionals work together and communicate. The plan of care will become something that actually benefits the client instead of others ... I think there would be less miscommunications and less tension between adults / authority figures and others for the youth."

—Melissa,
**Guide•Participate•Support Youth
Advisory Group member**

"What will the Plan of Care section change? I will have the whole information and get a clear understanding and it can help me get prepared so that adults can take me seriously. As a young person, I will feel good because it's for my own good and for a good future. It is important for adults so that they can understand us and help us better."

—King, **Guide•Participate•Support
Youth Advisory Group member**

"Using this section is useful for a young person to use because it has wonderful information and it could give you more knowledge about yourself, your life, and how your time in care is going."

— Jeremy,
**Guide•Participate•Support
Youth Advisory Group
member**

THE PLAN OF CARE

PLAN OF CARE CYCLE

Often people living and working within the care systems think of a Plan of Care as a meeting. Young people tell us that we need to stop thinking about planning care as a meeting and begin to think about it as a process that is always going on.

PLANNING

- what has been happening since the last meeting
- think about what is going well and what is not
- get more information
- come up with other options

MAKING DECISIONS (THE PLAN OF CARE MEETING)

- talk with other people about everything you looked at in the planning phase
- get other points of view
- set goals
- make the decision
- will someone I trust help with the decision if I can't make it?
- decide who will do what

CARRYING OUT DECISIONS

- each person does what they agreed to do
- each person keeps track of any problems they had
- they try to solve problems so the plan can go ahead

PLANNING THE PLAN OF CARE

Young people tell us what a Plan of Care looks and feels like when it does not go well. Here is what they say:

- No general discussion about health
- Very little time spent on health—often less than five minutes
- Health portion focused on listing appointments (for example, with whom or outcome)
- No real conversation
- Feels like an interrogation rather than a conversation, with adults asking a series of questions and young person answering
- Worker not paying attention to young person
- Worker focusing on taking notes
- Four or more adults present, so young person feels overwhelmed and outnumbered
- When the young person asks questions, adults talk together, rather than talk to the young person
- Adults talk and make plans about the young person when the young person is not in the room
- Adults talk in front of the young person about forcing them to take medication
- Adults use a different tone of voice when discussing the young person's wanted behaviour (soft, encouraging) and unwanted behaviour (harsh, accusing)
- Lack of privacy: meeting rooms are often not soundproof, so those outside the room can overhear private information
- Too much health information is shared unnecessarily with family members and too much information about other parts of their lives is shared with doctors and other medical professionals

Some young people also have a helpful Plan of Care. They tell us how a Plan of Care process can go well for them:

Planning (Before the Plan of Care)

- Have conversations before the Plan of Care meeting (this can be in person, but youth recognize that conversations might be by telephone, text, or e-mail because of distances)
- Listen and try to understand the young person's point of view
- Refer back to the previous Plan of Care for continuity
- Check to see if the young person has questions or concerns
- Some young people may want to write all or part of their own Plan of Care
- Ask about any behaviours observed by others and their relationship to health or impact on health
- Make sure to talk about positives



Making decisions (during this Plan of Care meeting)

General

- Have a specific time within the Plan of Care meeting to focus on health
- Review the last Plan of Care, so each builds on the previous one
- Review health rights each time
- Interpretation for language and culture available as needed

Place

- Meeting happens in a private place where other people cannot see or hear and where the young person feels comfortable
- Young person decides where to sit and is able to sit next to an adult they find supportive

Taking the Lead

- Young person takes the lead in talking about their own health throughout the meeting
- For the meeting, the young person can identify who they would like to assist them to talk about each topic

Talking and Listening

- Decide together how much time is needed to talk and comment on health
- Young person gets to say how they are experiencing own health
- Adults try to understand how the young person is feeling
- Adults ask questions about:
 - health choices
 - young person's understanding of consequences of treatment or choosing no treatment
 - young person's understanding of any side effects of treatment
 - how treatment (including medications) might affect other parts of the young person's life
- Adults are respectful and patient, giving the young person time and support to say their thoughts
- Adults and young person listen to each other and the young person is able to say what would be most helpful to them
- Young person is asked about their preferences, values, opinions, and perspectives
- Workers do not talk among themselves without the young person

Decisions

- Adults ask young person what they want for own health
- Clear statement of who makes the health decision and who would be the Substitute Decision Maker, if necessary
- Primary worker is present, not a temporary or substitute worker
- Make goals that make sense for the young person and the service providers
- Try to find areas of agreement
- No surprises, no attacking, no ganging up, and no pressuring
- Adults offer assistance (for example, booking appointments)
- Adults ask young person who they would like to attend appointments with them, if anyone
- Adults offer help with the process of making a decision: getting more facts, understanding values, increasing support. See Making a Health Decision on page 19.
- Adults do not tell the young person which decision to make



Sharing information

- Talk about what health information will be shared, for what purpose, and with whom

Carrying out decisions (after the Plan of Care meeting)

- Each person who has activities to do carries them out
- Check back to see if the young person is having any problems carrying out the goals
- Adults let the young person know if they are having any problems carrying out the goals
- Recognize that any person has the right to change their mind about a medical treatment—a decision is not a binding contract and can be changed

ANYTHING TO ADD?

For my own Plan of Care, I would also find these things helpful:





PLAN OF CARE



This worksheet is meant to be used by young people and adults together. It can be used before a meeting to get ready and as a guide during a Plan of Care meeting.

REVIEW

Review of the key health rights

- ☐ informed consent (see page 7)
- ☐ making a decision (see page 15)
- ☐ if young person can't make a decision (see page 27)
- ☐ if necessary: locked in for mental health reasons (see page 38)



Who will talk about topic?

Who will talk about topic?

Substitute Decision Maker (SDM)



You can bring information from the Wishes, Beliefs, and Values worksheet on page 46.

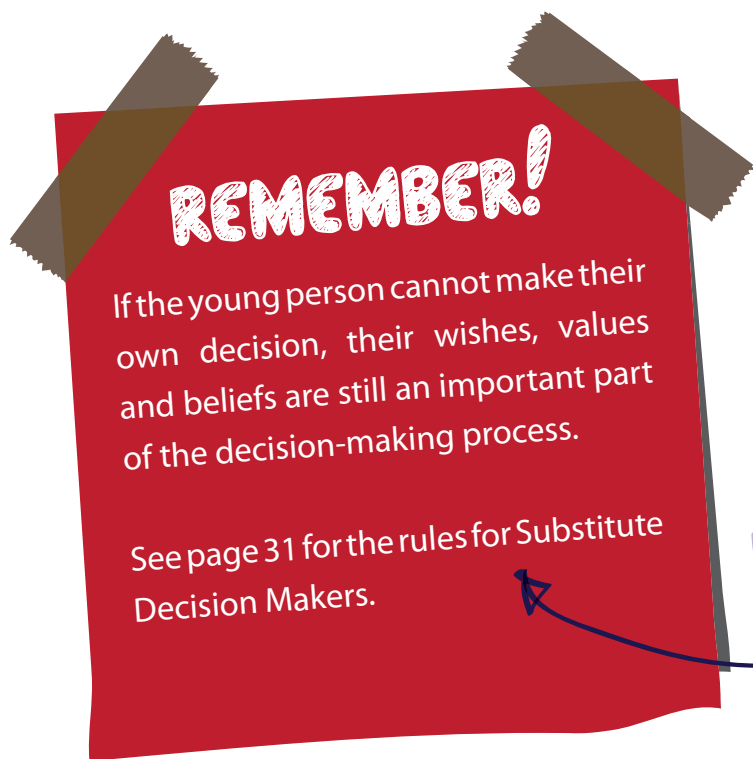
Who would be the SDM if the young person could not make a health decision?



What do other people need to know to make the best decision for the young person (likes/dislikes, important activities, people/things I am scared about, etc.)?

What are young person's wishes, values, and beliefs about their own health and treatment?

- ☐ Young person is 16 or older: the SDM must follow any wishes made when they were capable
- ☐ Young person is younger than 16: the SDM must consider their wishes, values, and beliefs



Age 16 or older: what are young person's instructions to **be followed** by the SDM?

Younger than age 16: what are the young person's wishes, beliefs, and values **to be considered** by the SDM?

CARRYING OUT DECISIONS (AFTER LAST PLAN OF CARE MEETING)

Who will talk about topic?

Since last Plan of Care meeting, what was carried out?

Who agreed to do it?

1. _____
2. _____
3. _____

What was planned but could not be carried out?

Who agreed to do it?

1. _____
2. _____
3. _____

How did the person solve the problem? If it wasn't solved, can it be solved now?

1. _____
2. _____
3. _____



PLANNING (FOR THIS PLAN OF CARE)

Who will talk about topic?



You can bring information from the Health Log on page 49 and the Appointment worksheet on page 9.



General health

Short sickness

Longer health conditions or illnesses

Treatment

What medical treatment am I having now?

What is going well with treatment? _____

What is not going well? _____

- ☐ I want to keep the treatment the same.
- ☐ I want to make changes to the treatment: _____
- ☐ I want to stop the treatment.



Discuss together how the young person could make it known if they were unhappy with the treatment and wanted to change or stop the treatment. Talk about how adults would know if the young person were worried or scared or had changed their mind. Adults can ask the young person what the adults could do or how the team could support the young person by reading the cues provided. Who would the young person go to? Planning ahead of time for how to talk about making changes might make it easier for a young person to work through any problems they are having about their current treatment.

Appointments coming up or to be made

Questions

MAKING DECISIONS (DURING THIS PLAN OF CARE MEETING)

Who will talk about topic?



The young person and team can use the Making a Health Decision worksheet on page 19

What do we want to accomplish (goals) for general health, illness, and health conditions?



1.

2.

3.



Goal #1

What will be done? Be specific (for example, make an appointment with Dr. X, walk 20 minutes each day, track side effects every day for a week, get more information about a possible treatment).

Who will do it?

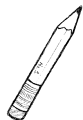
When will it be done?

What support does that person need to do it?

What else do you need to make a decision?

If a treatment decision was made, who gave consent for this?

If the young person did not make the decision, how were they included in the decision-making process?

Goal #2

What will be done? Be specific (for example, make an appointment with Dr. X, walk 20 minutes each day, track side effects every day for a week, get more information about a possible treatment).

Who will do it?

When will it be done?

What support does that person need to do it?

What else do you need to make a decision?

If a treatment decision was made, who gave consent for this?

If the young person did not make the decision, how were they included in the decision-making process?

Goal #3 _____



What will be done? Be specific (for example, make an appointment with Dr. X, walk 20 minutes each day, track side effects every day for a week, get more information about a possible treatment).

Who will do it? _____

When will it be done? _____

What support does that person need to do it?

What else do you need to make a decision?

If a treatment decision was made, who gave consent for this?

If the young person did not make the decision, how were they included in the decision-making process?

SHARING INFORMATION

Who will talk about topic?

What information about my health do I want to share or not want to share with family members?

What information about my life aside from my health do I want to share or not want to share with the doctor (or other health professional)?

What information about my health do I want to share or not want to share with another person?

Who? _____

IMPORTANT RESOURCES

- Health Care Professions List
- Contacts and Links



IMPORTANT RESOURCES

Only people who work in the health professions on this list (from Regulated Health Professions Act, 1991) can decide whether or not you can understand the information and make a decision. The decision has to relate to a treatment that the health professional is suggesting that they give you. For example, a dentist can decide if you can make a decision about getting a filling for one of your teeth. The dentist could not say whether or not you could make a decision about getting eyeglasses.

HEALTH CARE PROFESSIONS LIST



Overall Health

Medicine (doctors)
Nursing



Breathing

Respiratory therapy



Ears

Audiology and Speech-Language
Pathology



Eyes

Opticianry
Optometry



Feet

Chiropody



Food

Dietetics



Having Babies

Midwifery



Medication

Pharmacy
Traditional Chinese medicine



Moving

Kinesiology
Occupational therapy
Physiotherapy



Muscles and Bones

Chiropractic
Massage therapy



Lab Tests

Medical laboratory technology



Teeth

Dental hygiene
Dental technology
Dentistry
Denturism



Thoughts and Feelings

Psychology

To be added at a later date:

Homeopathy
Naturopathy
Psychotherapy



GOVERNMENT AND COMMUNITY RESOURCES

We are providing a list of offices that might help you if you want to know more or if you think your health rights are not being followed. Each of these offices does a different job in health rights. For each office, we suggest how they might be helpful to you.

Child and Family Services Review Board

Phone: 416-327-4673 or 1-888-728-8823 (toll-free)

Website: www.cfsrb.ca

Your lawyer will contact them for you if you are locked in a children's residence for mental health reasons and don't agree with being locked in.

College of Physicians and Surgeons of Ontario

Phone: Public Advisory Department at 416-967-2603 or 1-800-268-7096, extension 603

Website: www.cpso.on.ca

Contact them if

- you have questions or concerns about how your doctor communicated with you, the information they kept or shared with others, the treatment you received, or how consent was given for treatment

Consent and Capacity Board

Phone: 416-327-4142 or 1-866-777-7391 (toll-free)

Website: www.ccboard.on.ca

Contact them if

- your doctor has said you are not able to make a treatment decision and you disagree
- you are locked in a hospital for mental health reasons and don't agree with being locked in
- you are at least 16 years old and want a different person to be your Substitute Decision Maker

Justice for Children and Youth

Phone: 416-920-1633 or 1-866-999-5329 (toll-free)

Blog: <http://jfcy1.blogspot.ca/>

Website: www.jfcy.org

Contact them if

- you want information or legal advice
- you are looking for a lawyer to represent you

Legal Aid Ontario

Phone: 416-979-1446 (Toronto only) or 1-800-668-8258 (toll-free)

Website: www.legalaid.on.ca

Contact them if

- you want to hire your own lawyer for mental health hearings (consent and capacity) and want to apply to Legal Aid to pay for your lawyer

The Office of the Children's Lawyer

Phone: 416-314-8000

Website: <http://www.attorneygeneral.jus.gov.on.ca/english/family/ocl/> (English) or
<http://www.attorneygeneral.jus.gov.on.ca/french/family/ocl/default.asp> (français)

Your advocate will contact them for you if you are locked in a children's residence for mental health reasons and don't agree with being locked in.

Office of the Provincial Advocate for Children and Youth

Phone: 416-325-5669 or 1-800-263-2841 (toll-free)

Website: www.provincialadvocate.on.ca

The children's residence will contact them for you if you are locked in a children's residence for mental health reasons.

Contact them if

- you have questions about health rights
- you feel that someone is not following your health rights correctly

Psychiatric Patient Advocate Office

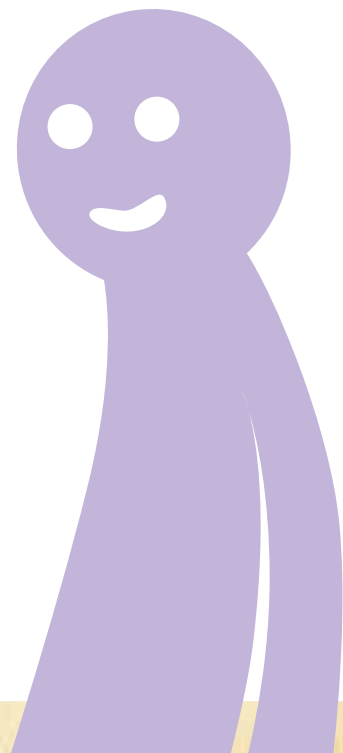
Phone: 416-327-7000 or 1-800-578-2343 (toll-free)

Website: www.ppao.gov.on.ca

The hospital will contact them for you if you are locked in a hospital for mental health reasons.

Contact them if

- you are in a hospital for mental health reasons, disagree with being there, and have not yet had anyone explain your rights
- have questions about mental health rights



GENERAL INFORMATION ABOUT HEALTH AND HEALTH RIGHTS OF YOUNG PEOPLE

Health Care Consent Act, 1996, Legislation (http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_e.htm)

Standards of Care for the Administration of Psychotropic Medications to Children and Youth Living in Licensed Residential Settings: Summary of Recommendations of the Ontario Expert Panel (www.children.gov.on.ca/htdocs/english/documents/topics/specialneeds/residential/summary_report.pdf)

UN Convention on the Rights of the Child in Child-Friendly Language (http://www.unicef.org/southafrica/SAF_resources_crcchildfriendly.pdf)

Recommendations for Canada from the UN Committee on the Rights of the Child in Youth-Friendly Language (http://www.provincialadvocate.on.ca/documents/en/concluding_observations_in_youth_friendly_language_EN.pdf)

Patient Decision Aids (<http://decisionaid.ohri.ca/>)

Patient decision aids are tools that help people make decisions by being clear about what the decision is, giving information about treatment options and what the effects could be, and by thinking through the person's own values. They are meant to be used along with conversations with a doctor. This is the original version of the Making a Health Decision worksheet on page 19.



"I WAS AFRAID TO ASK FOR ANY HELP, IN ANY WAY. ANYTHING MEDICAL WAS DECIDED IN ANOTHER ROOM, WITHOUT ME, AND THE RESULT WAS USUALLY AGGRESSIVELY TOLD TO ME IN A CROWD OF PEOPLE I DIDN'T KNOW."

- YOUNG PERSON

ACKNOWLEDGEMENTS AND THANKS

We would like to thank the following organizations and individuals for playing a role in the I Do Care Project. Roles included meeting with the team, reviewing our information, organizing an interactive group, writing a guest blog, organizing a presentation, and providing information. Each contribution was much appreciated.

Across Boundaries

Anita Szigeti

ARCH Disability Law Centre

Canadian Hearing Society

Children's Aid Society of London and Middlesex

Children's Aid Society of the District of Nipissing and Parry Sound

Children's Aid Society of the Districts of Sudbury and Manitoulin

Children's Aid Society of Toronto

Council of Canadians with Disabilities

Empowerment Council

Centre for Addiction and Mental Health

Children's Mental Health Ontario

Consent and Capacity Board

Guide•Participate•Support I Do Care Project Youth Advisory Group

Justice for Children and Youth

Kinark Child and Family Services

Nidus Personal Planning Resource Centre

Northern Youth Services

Office of the Children's Lawyer

Ontario Association of Children's Aid Societies

Ontario Association of Residences Treating Youth

Ontario Human Rights Commission

Psychiatric Patient Advocate Office

Sound Times

The New Mentality

Youth Services Bureau



Young People Rights

Capacity Knowledge Exchange
I DO CARE PROJECT

Have Your Say Law

Office of the Provincial Advocate for Children and Youth

Admissions INFORM DECIDE CONSENT Doctor Questions
Age Treatment Health Permission



Facebook: /idocareproject





Twitter: @projectIDC



Blog: idocareproject.wordpress.com



 Facebook: /idocareproject

 Twitter: @projectIDC

 Blog: idocareproject.wordpress.com

www.provincialadvocate.on.ca

Provincial Advocate *for* Children & Youth

401 Bay St Suite 2200
Toronto ON M7A 0A6
Canada

435 Balmoral Street
Thunder Bay ON P7C 5N4
Canada

Tel: (416) 325-5669

Toll Free: 1-800-263-2841

TTY: (416) 325-2648

Fax: (416) 325-5681

ooVoo: provincial-advocate.on.ca

twitter: @ontarioadvocate