# Substitute Decision-Makers & Sexual Expression of People Living with Dementia in Long-Term Care Homes

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A RESOURCE FOR SDMS

Interactive PDF

Created: 2025

## Aim

The aim of this resource is to provide guidance to substitute decision-makers (SDMs) as they navigate sexual expression of people living with dementia in long-term care (LTC).

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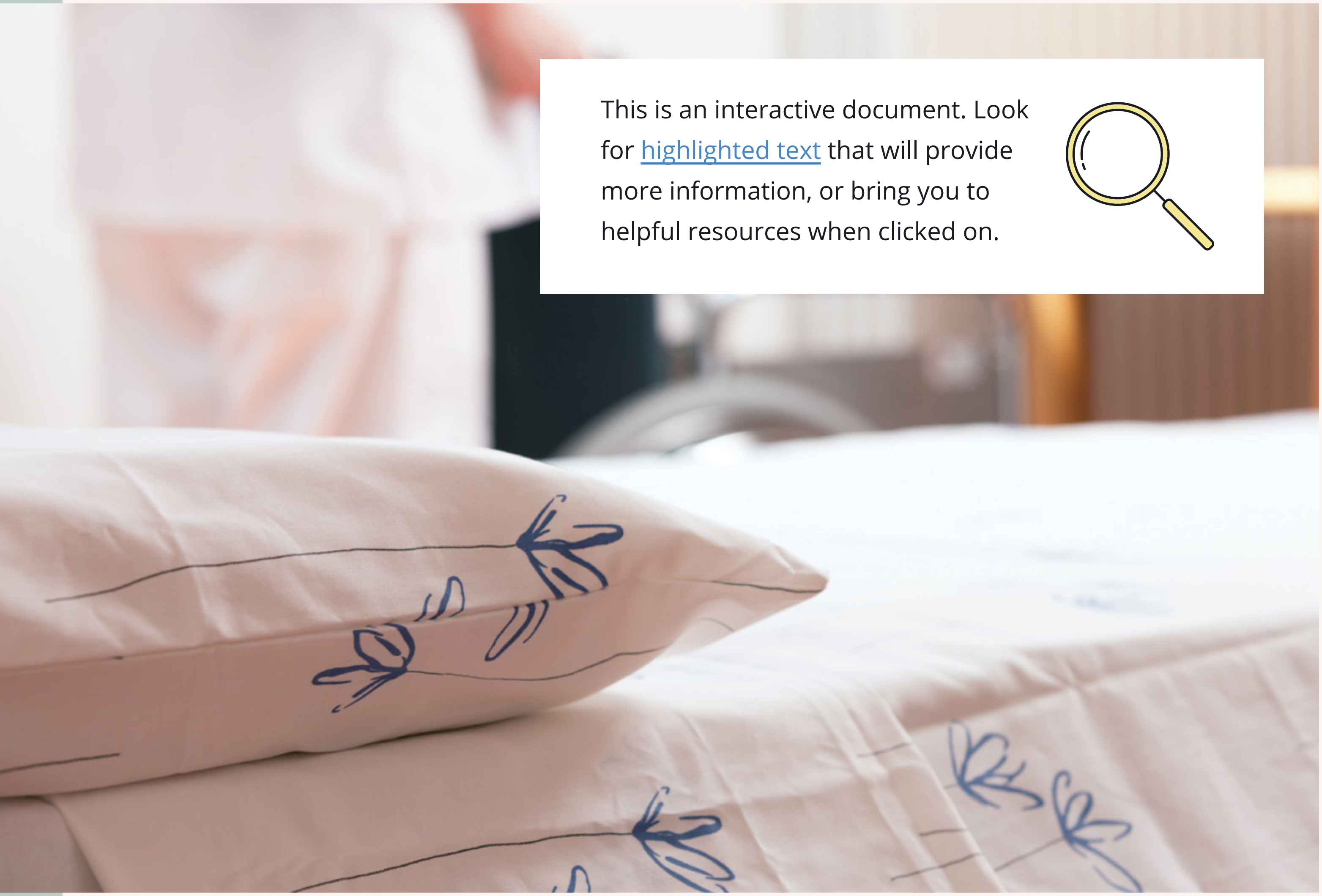

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## Resource:

# Substitute Decision-Makers & Sexual Expression of People Living with Dementia in Long-Term Care Homes

# Introduction

A substitute decision-maker (SDM) makes decisions on behalf of someone who is unable to make those decisions themselves. However, many people are not ready to become an SDM. There are few resources and no training in preparation for this role. Individuals will often find themselves cast into the role of SDM when a family member develops dementia. As an SDM, you will need to make health, safety, and personal care decisions for the person with dementia. This may also include making decisions regarding their sexual expressions.

Sexual expression by residents in long-term care (LTC) homes is complicated by many factors. Physical, social, and interpersonal features that are part of congregate living can have implications for a resident's sexual expression. The presence of dementia adds additional complexity. Sexual expression is sometimes seen as taboo or inappropriate to talk about, and SDMs may not always be comfortable or prepared to discuss it. However, sexual expression (that is free from coercion and does not harm others) is a human right, an element of human flourishing across the lifespan, and remains an important and meaningful aspect of a resident's life.

The aim of this resource is to support SDMs in navigating the sexual expression of residents living with dementia. The resource aims to help SDMs work with LTC home staff in establishing an environment that enables open communication and serves the needs of the resident, while also protecting their safety. As an SDM, you might feel uneasy having conversations with LTC staff about residents' sexual expression. This resource will help you to engage in respectful conversations that put the person you represent at the centre of care.

**This resource will:**

- Explain the complexities surrounding sexual expression of residents living with dementia
- Outline your role and responsibilities as an SDM
- Provide guidance and tips on how to support decisions regarding sexual expression for a resident living with dementia in LTC

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This resource does not provide a "one-size-fits-all" solution. No two cases of sexual expression are the same.

# *What is a Substitute Decision-Maker (SDM)?*

A substitute decision-maker is a designated person who is legally authorized to make decisions for someone who cannot make decisions for themselves. People living with dementia often require an SDM, as their capacity to make decisions may become increasingly impaired. SDMs are sometimes called “surrogate decision-makers” or “proxy decision-makers.”

### SDMs can include:

- Family members (e.g., spouse/partner, child, sibling)
- A trusted friend
- A legally appointed unrelated person (the specifics of this process can vary between jurisdictions)

### As an SDM, your role may include:

- Making healthcare and safety decisions on behalf of the resident, which can sometimes include making decisions about a resident’s sexual expression based on concerns about their healthcare and safety
- Navigating the LTC setting and working with care staff in order to best support the resident
- Familiarizing yourself with the LTC home’s policies and practices
- Developing open communication with nurses, physicians, social workers, and other care staff
- Regularly checking in with the resident to see if their needs are being supported

## *What is Sexual Expression?*

Sexual expression can include a range of identities, practices, acts, and relationships. This can include:

- Hand-holding, hugging, and cuddling
- Kissing
- Bed-sharing
- Fantasies
- Self-presentation (how you present yourself through clothing, make-up, or hair)
- Masturbation (self-pleasure)
- Use of erotica or pornographic materials
- Use of sexual aids (e.g., vibrator)
- Sexual intercourse

When talking about sexual expression, the context is important. Certain actions may be expressions of sexuality in some instances, but they may not be in others. For example, holding your spouse's hand to feel physical intimacy is different than holding your parent's hand to help them stand. The meaning behind similar actions can vary greatly depending on the situation. Therefore, it is always important to assess the context when determining what constitutes sexual expression.

Sexual expression has been associated with physiological, emotional, and psychological benefits for LTC residents. In older adults, sexual expression has been shown to:

- Improve quality and enjoyment of life
- Help with symptoms of depression
- Lower risk of certain cancers and fatal coronary events

Despite these benefits, there are still a number of common myths and misconceptions about sexual expression in care homes. Please see the infographic on the next page for some important myth-busting.

# MYTHS AND MISCONCEPTIONS
## about Sexual Expression in Long-Term Care

**Sexual expression is not often discussed in long-term care homes, but it may still be a part of residents' lives.**

There are a number of common myths and misconceptions that prevent staff, family members, and residents from anticipating these expressions or knowing how to respond to them.

### MYTH #1

*Long-term care residents are not interested in sexual expression.*

### REALITY

Many long-term care residents still desire intimacy or sexuality. Older age, chronic health conditions, or disability do not stop people from expressing themselves and moving into a care home does not mean giving up all other aspects of one's life and identity. Sexual expression can also have physical, mental, and emotional benefits for care home residents.

### MYTH #2

*Sexual expression in long-term care homes is inappropriate. These are congregate, medical settings.*

### REALITY

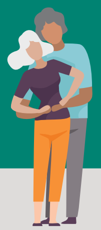
Long-term care homes are workplaces for healthcare staff, but they are also residents' homes. People are entitled to meaningful privacy and self-expression in their own homes. These expressions should not infringe on the comfort and safety of other residents or care staff. In order to ensure this, staff can clearly communicate with residents about when and where they are entitled to such privacy.

### MYTH #3

*If a resident has dementia, they cannot consent to engage in a romantic relationship or any form of sexual expression.*

### REALITY

There is a wide range of ways for people with dementia to express themselves and these expressions may provide comfort, connection, or pleasure. Each individual case requires nuanced assessments for consent and safety. There are some excellent resources available to assist care teams with this work.



**When we do away with these myths and misconceptions, we are all much better prepared to navigate sexual expression in long-term care homes.**

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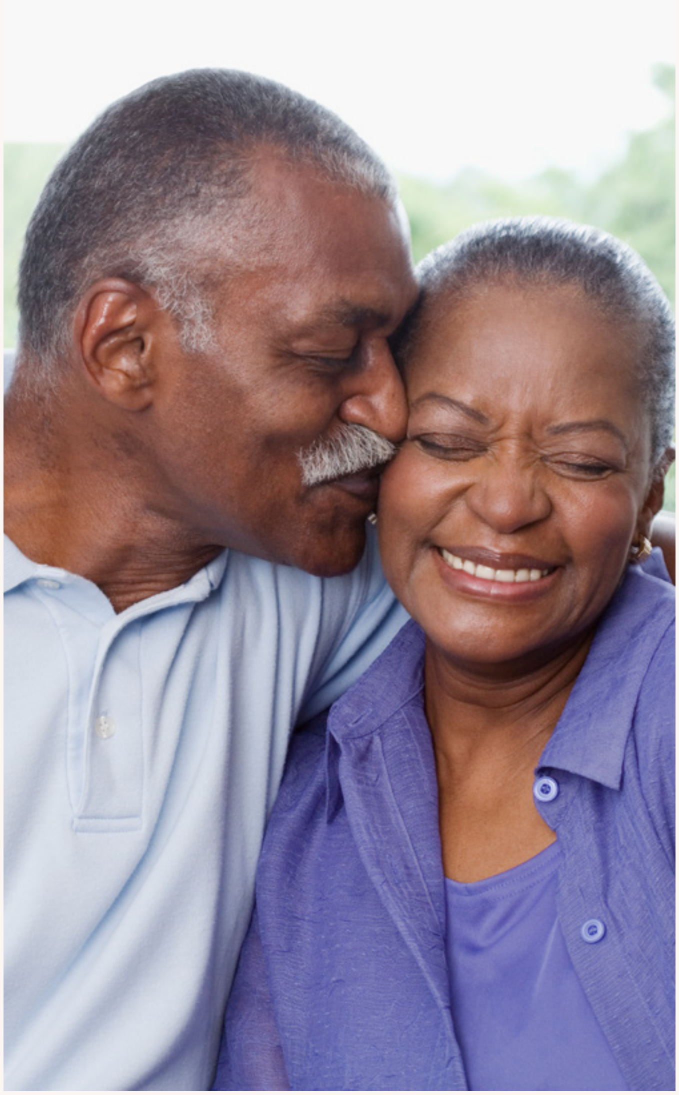
Residents in care homes also have sexual rights that are important to uphold. These rights generally include:

- The preservation of bodily autonomy (i.e., control over one's own body)
- Freedom from interference, coercion, or pressure
- Freedom from discrimination based on gender identity or sexual orientation
- Access to sexual health services and/or information
- Right to privacy
- Freedom of expression
- The preservation of human dignity and freedom from degrading or dehumanizing treatment



As this short video illustrates, LTC home environments add complexity for sexual expression. A congregate living environment involves other people (e.g., care staff or other residents). There will also be different levels of risk associated with different forms of sexual expression. SDMs will have the challenging task of balancing risks and benefits when making decisions for a resident in LTC. As an SDM it will also be important to distinguish between your own values and beliefs and those of the LTC resident for whom you are making decisions. Your relationship to the resident (e.g., as their child, spouse, sibling, etc.) may further complicate this work. We hope that the following content provides some helpful background information and tips to support you and others in substitute decision-making.

## 1

# Substitute Decision-Making in the Relational LTC Context

LTC homes provide a highly relational context. By that we mean that there are many relationships and interactions. Someone living in LTC may regularly interact with other residents, care aides, nurses, physicians, dietary and housekeeping staff, occupational and recreation therapists, spiritual care staff, volunteers, and visiting family members and friends. SDMs will need to collaborate with LTC staff in their decision-making since staff can offer knowledge about the resident based on their interactions with them in their day-to-day life. Because of their role, staff are often best positioned to implement such decisions. As a result of this relational context, a resident's sexual expression (and related decisions) may have implications for many other people.

The nature of the relationship that the SDM has with the person living with dementia can influence their decision-

making with respect to sexual expression. For example, a spouse may be more reluctant to support their partner living with dementia developing a new romantic relationship than their adult child might be. However, a child may have less knowledge about their parent's sexual history and preferences than the person's spouse or sibling and may be more opposed to sexual expression that they feel is inconsistent with monogamous and long-term commitment. The SDM might also have had a complicated relationship with the person living with dementia and/or other family members. They may not have sufficient knowledge of the values and beliefs of the person living with dementia to decide what that person would choose if they were capable of making the decision on their own.

Additionally, SDMs enter this work with their own values and beliefs, which are influenced by culture, religion, education, and other life experiences. SDMs' values and beliefs can include views about appropriate and inappropriate sexual expressions (e.g., modesty and impropriety, disapproval of non-monogamy) and/or prejudice based on age, dis/ability, sexual orientation, and gender identity. These personal beliefs inform their substitute decision-making and may or may not align with the values and beliefs of the person living with dementia. Care staff might have their own beliefs, values, and biases that SDMs may need to contend with as well.

As shown in this short video, both SDMs and LTC staff may not be comfortable engaging in discussion about sexual expression. The parties involved in this relational context may not yet have the skills to navigate differences of opinions about the care of the person living with dementia, although educational programs and courses are being developed to address these gaps.

It is important to be mindful of these potential challenges associated with this work. However, SDMs are well-positioned to be important advocates on behalf of the resident. They are often quite close with the person and know them well. Though making decisions within this context can be complicated, it also offers opportunities to:

- Have meaningful conversations
- Share information and experiences
- Coordinate with others to support safe, healthy, joyful, and dignified forms of sexual expression of residents living with dementia

## 2

# Dementia and Capacity

Before you can engage in decision-making about a resident's sexual expression, it is helpful to know more about dementia and its effects on cognitive capacity and consent.

## *What is Dementia?*

Not all SDMs understand what dementia is and its possible effects on sexual expression. Dementia is not a specific disease, but rather an umbrella term that captures a range of symptoms. The most common type of dementia is Alzheimer's Disease. Living with dementia can impact actions, feelings, and relationships.

Symptoms can include:

- Difficulties with remembering recent or past events and actions
- Difficulties with word-finding and/or understanding language
- Difficulties with reasoning and problem-solving

As a person develops dementia, their sexual feelings, inhibitions, desires, and actions may change. For example, some people who may have been shy or modest with their sexual expression may now express themselves more openly. This can catch SDMs off guard. For more on how to approach changes in sexual expression when your partner has dementia, consult the Alzheimer's Society.

## *What is Decision-Making Capacity?*

"Decision-making capacity" (or "capacity" for short) refers to a person's ability to make decisions. Capacity exists on a spectrum, meaning someone may have more or less of it. Capacity also refers to a person's ability to make decisions with respect to a particular situation. An individual may have the capacity to make one decision but not another. This is especially relevant for people living with dementia, since not all persons with dementia will be equally incapable, and some will be capable of certain decisions, but not others. For example, someone may no longer be able to make decisions about their finances, but can still make decisions about their meal preferences and leisure activities.

Capacity assessments usually include the following four requirements:

**Understanding**
Possession of, and having the ability to comprehend, the relevant information in a particular decision-making context

**Reasoning**
Engaging in rational processes using relevant information to help

**Appreciation**
Insight into what a particular decision means for oneself (i.e., the implications and consequences of a decision or non-decision for one's own circumstances)

**Choice**
The ability to freely express one's choice

A diagnosis of dementia in and of itself does not mean that a person is incapable of making decisions. It would be a mistake to treat an individual's capacity as all-or-none. Instead, a resident living with dementia may be capable of some decisions and not others. Decision-making ability can also fluctuate:

- Over time
- Depending on the setting
- Between activities and situations

This can make it hard for you as the SDM to determine when a resident can help make decisions for themselves and when they cannot. It may be even harder when the decision involves sexual expression.

## 3

# Consent to Sexual Expression

## *What is Sexual Consent?*

Broadly speaking, sexual consent refers to a free, voluntary, and informed agreement between people to participate in a sexual act. Consent must be given without pressure or coercion, and it can be withdrawn at any time, for any reason. Consent must also be given at the time of, and present throughout, the particular sexual activity in question. In the context of sexual expression, consent is personal to the ultimate decision-maker, and so long as there are no concerns about safety and capacity, the authority to provide or withhold consent generally rests with the individual engaging in the sexual act. Discussions about sexual consent have often focused on younger people (e.g., legal age of consent, [in] ability to consent after consuming alcohol or other substances). Our society rarely depicts or discusses the sexual lives of older people or people with disabilities and/or chronic health issues. As a result, we might not know how to anticipate their needs or be well-informed about available supports.

## *How is Consent Assessed in the Context of Long-Term Care?*

Although there are tools for assessing an individual's cognitive capacity, there appear to be no universal standards for assessing consent for sexual expression. There is no such thing as fully informed consent (since we cannot know all possible outcomes), and assessing consent may be complex. Additionally, there are no healthcare providers whose job it is to do these particular assessments. Healthcare providers assess for cognitive capacity but not for consent to sexual expression.

A person living with dementia may not

express their desires in the same way they did in the past, or as others do. But they may still have a strong desire for intimacy and/or longing for physical touch. As an SDM, you want to support activities that the resident clearly desires, finds enjoyable, and that would be beneficial to them. However, it is important to also ensure resident safety and continued consent.

SDMs should be alert to cues that can help inform their decision about whether the activity is consensual. This would include any explicit verbal communication on the part of the resident (e.g., directly saying yes or no). As some scholars have suggested, it is important to also consider and look for assent (i.e., agreement) that is expressed through multiple ways of communicating, including non-verbal expressions. For example:

- simple words of affirmation
- nodding
- smiling
- recurring interest

Looking for assent is important because it respects an individuals' remaining autonomy and provides an opportunity for residents with dementia to still remain involved in the decision-making about their lives. It is valuable to consider this type of embodied self-expression (i.e., non-verbal cues) to help determine if a resident might be rejecting or desiring a particular expression.

## What is Fluctuating Capacity?

People living with dementia may have fluctuating capacity. That is, they may have the capacity to make a particular decision one day but not on another. Fluctuating capacity can make it hard to assess or check for consent.

Since capacity can fluctuate, consent that may have been freely given by a resident in one moment may disappear in the next. This can pose a significant problem for sexual expressions involving another person since the resident could be in and out of lucidity during an intimate interaction. Even if their capacity and consent do not fluctuate that quickly, it is still important to note that consent must be given at the time of, and present throughout, the particular activity in question. Under Canadian law, individuals cannot "pre-consent" to sexual activity, and something that the resident consented to months ago is no longer valid as consent later on, particularly as their capacity changes. As an SDM you must be mindful if the person for whom you make decisions has frequently fluctuating capacity. If so, they may be limited in terms of the activities to which they can genuinely consent. If the capacity fluctuations are more sporadic, it will still be important to regularly re-engage them over time and ensure that there is actual, active consent to the specific sexual expression in question.

# 4

# Making Decisions with and for the Resident

## *When is Co-Decision-Making Appropriate?*

There are many problems with the view that capacity is all-or-nothing– that we either have or lack the capacity for all decision-making. A person living with dementia may no longer be able to make decisions about their finances, but may be able to choose which of two breakfast options they would prefer. This can complicate sexual expression decision-making for LTC residents with dementia. Because capacity is not all-or-none, it may be possible for a person to be capable of consent for some forms of sexual expression (e.g., dancing) but not others (e.g., bed-sharing). A person living with advanced dementia may be incapable of consenting to sex with another person but may still be supported in their desire to cuddle or kiss.

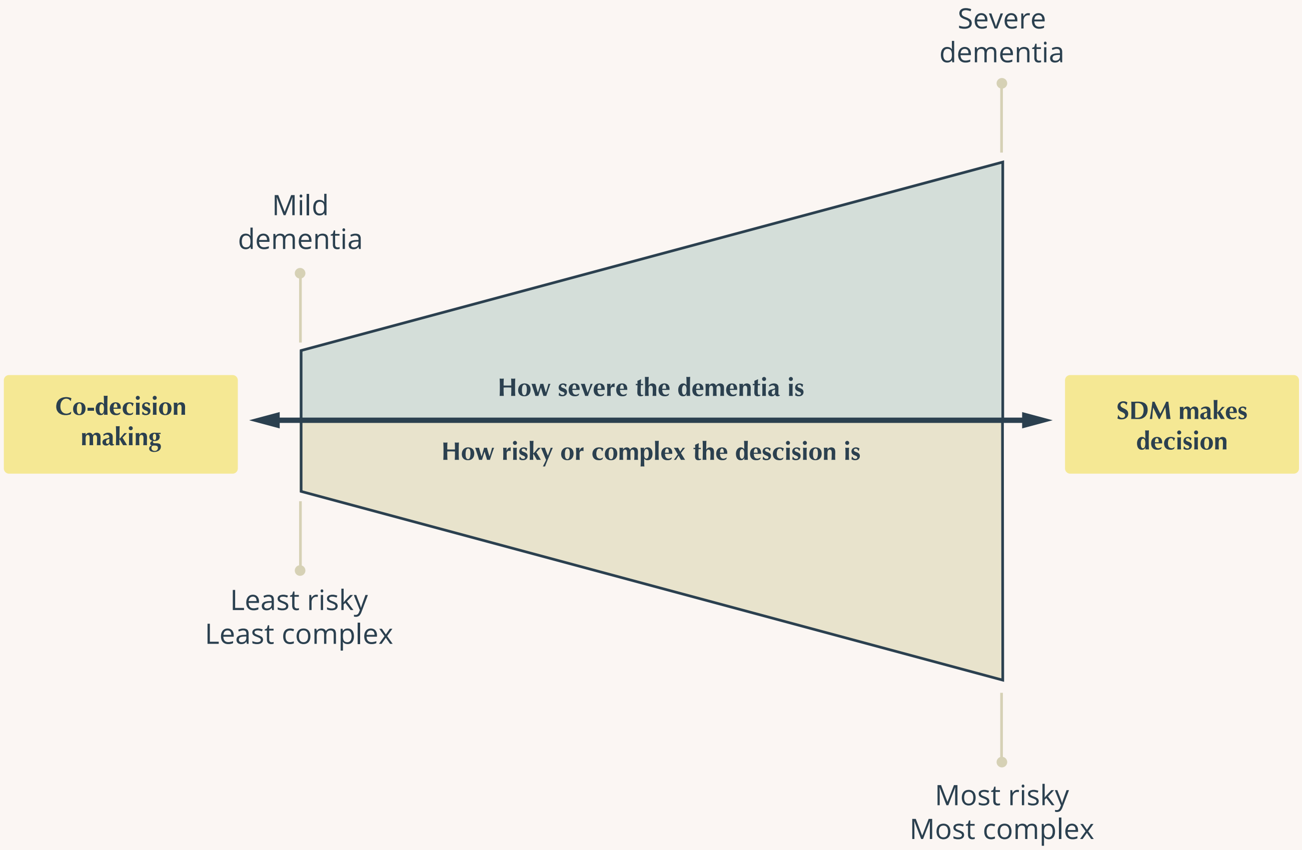
Sexual activities vary in their level of risk and in the kinds of information that must be understood for informed consent. For example, the psychological and physical risks associated with hand-holding are likely much lower than for sexual intercourse. The complexity of the information that must be understood in order to consent to each activity also differs considerably. For example, touching someone's genitals may require being able to understand and appreciate the potential for sexually transmitted infections, whereas handholding does not. The obligation of the SDM to protect the resident may shift depending on the activity.

Additionally, the severity of dementia and the extent to which it compromises capacity can both vary. It may be possible to participate in "co-decision-making," which refers to a collaborative process where decisions are made jointly between the SDM and the person they represent. In some other cases, such as when an individual no longer has capacity or when they may be subject to significant safety or hygiene risks, you may need to make the decision on your own.

Whether or not you engage in co-decision-making will depend on each of these factors:

- The risk of harm associated with the decision/activity
- The complexity of the information associated with the decision/activity
- The severity of the dementia

As an SDM, you must carefully consider the specifics of the scenario and the person whom you represent. In general, the less complex and less risky the activity, the more likely co-decision-making will be appropriate. Similarly, the less severe the impairment to capacity (i.e., the less severe the dementia), the more likely co-decision-making may be appropriate.



## What are the Best Interest and Past Preference Standards and Why Do They Matter?

If the SDM has decided that a more paternalistic approach is warranted, what considerations should be included in the decision-making? In this section, we discuss two different standards that are often included in substitute decision-making.

Policies, laws, and ethical regulations across jurisdictions often promote what is called a “best interest standard.” This standard involves ensuring that any decision made on behalf of a person who lacks capacity must be done in accordance with their best interests, not the interests of the SDM. While there are different ways of defining “best interest,” it generally involves considering:

- The harms and benefits to the person
- The previous and current circumstances of the person
- The values, wishes, and needs of the person

Another common recommendation is for SDMs to use a “past preference standard.” This involves attempting to make decisions for a resident that are in line with the person’s past:

- Wishes
- Values
- Beliefs
- Behaviours

This standard focuses on respecting the person's past autonomous self and honouring what that person may have wanted, based on the way they lived their life. However, there are two important limitations to consider:

### 1. Preferences change over the course of life

People change their preferences over time and in certain moments. People living with dementia may also change their preferences. It is important to recognize that these changes can be authentic expressions even if they are different from the person's past decisions or expressions. Denying these preferences could harm a resident and cause them frustration and anger. To the extent that it is reasonable and safe, SDMs should account for potential changes in preferences.

### 2. SDMs may not be aware of all past preferences

Sexual preferences are not always openly shared. SDMs, especially if they are the children, grandchildren, or friends of the resident, are unlikely to have fully known the resident's previous thoughts and experiences related to sexual expression. As such, they would be left with an incomplete or possibly incorrect perception of the person's past preferences. Some people even keep their sexual fantasies or preferences private from their intimate partners.

In summary, utilizing a past preferences standard can be both useful and limited. It can potentially provide valuable information about a resident's history, but it can also lead SDMs to make decisions that may not necessarily be in the resident's best interest. In short, it is worthwhile to consider both best interests and past preferences, but not to the neglect of the person living with dementia's current expression of their desires.

## 5

# How Do I Make Ethical Decisions About Someone Else's Sexual Expression?

Many people do not expect that they will ever have to make decisions about intimacy and sexuality on someone else's behalf – and these decisions are not always straightforward. You might be wondering:

- How much should SDMs insert themselves into everyday decisions for residents?
- When should LTC home staff consult SDMs about particular decisions?
- What does too much or too little SDM involvement look like?

Currently, Canadian legislation and regulations about SDMs do not specifically address sexual expression. The specific responsibilities of an SDM may be unclear. As a result, most decision-making is done on a case-by-case basis. Ethics can provide guidance in these cases on how to make decisions in ways that are fair and just. In healthcare, there are 4 main ethical principles that help guide decision-making:

- Beneficence (doing good or helping others)
- Non-maleficence (not doing harm to others)
- Autonomy/self-determination (people making their own decisions about their life)
- Justice (fair access to opportunities and resources)

These principles can help guide SDMs when making decisions. Here are some examples of how each principle may guide an SDM's decisions around sexual expression:

| | |
|---|---|
| **Beneficence** might require an SDM to support a resident's sexual expression because it could help their emotional, physical, and mental health. | **Non-maleficence** might require an SDM to question the potential harm that could result from breaking up two people who both have dementia and are benefiting from their relationship. |
| **Autonomy** might lead an SDM to consider supporting the resident to make their own decisions around sexual expression or involving them in decision-making as much as possible. | **Justice** might require an SDM to advocate for their family member to receive equal access to supports they need for sexual expression. |

For adults living in LTC homes, autonomy is already quite limited (e.g., around the timing of daily activities, menu options at meal times, available recreation activities, etc.). It is therefore all the more important to promote resident autonomy wherever possible.

However, autonomy often comes into tension with another concept, paternalism. Paternalism is the interference with the autonomy of a person, against their will, because that interference is understood to be in the person's best interest. We often see this with parents making decisions on behalf of their young children. As an SDM, you will be required to exercise some paternalism. While attempting to carry out ethical decision-making for the resident, you may sometimes experience a tension between your legal role as the decision-maker for someone else and what you personally prefer. For instance, you may not especially like your parent's new partner, or you may feel embarrassed that your spouse has become more sexually expressive than they were before.

When acting in your role as an SDM, it is important to be reflective about both personal values and ethical principles. You may want to ask yourself the following questions (consider printing these questions and writing out your answers):

- What are your values and beliefs about sexual expression?
- What are the values of the resident? How do you know what their values are? How can this knowledge about their values help you to support them?
- What are the gaps in your knowledge about their values and practices? How might these gaps create potential problems for you? How might you seek to fill those gaps? Which values and practices held by the resident differ distinctly from your own values and beliefs? Why might these differences exist?
- How will you navigate a clash in values? Between yours and those of the resident, or those of staff or other family members?  If you believe that the resident's desires should be fully considered as the centre of care, then can you set your own beliefs and values aside? Why or why not?
- How does your decision align with the ethical principles of beneficence, non-maleficence, autonomy, and justice?

A thoughtful SDM can help allow sexual expression in a safe and respectful way that maintains the resident's dignity. And despite the challenges with being an SDM, helping a person living with dementia lead as full a life as possible can be deeply meaningful.

If you have questions about your role as an SDM, do not be afraid to ask for help. You can:

- Speak with LTC home staff
- Contact your provincial or territorial Office of the Public Guardian/Trustee
- Reach out to your LTC home's Clinical Ethics team
- Contact your provincial or territorial health authority's Clinical Ethics Service
- Contact your local Alzheimer Society

## Case examples of SDM involvement in resident sexual expression

Although SDMs are trusted parties who are invested in a resident's well-being, they can unintentionally create challenges for resident sexual expression. This is likely to happen when SDMs are especially *permissive* or especially *restrictive* in their approaches. The following three videos provide examples. While watching these videos, consider how you might handle these scenarios.

### Case Example 1: Too permissive about sexual expression

Consider the following case: A spouse is the SDM and is both seeking and inappropriately granting consent for sexual touching with their partner – a LTC resident. As both the partner and decision-maker there is a clear conflict of interest. Click here to watch the case.

### Case Example 2: Too restrictive about sexual expression

Consider the following case: A resident's adult child does not approve of the parent's sexual expression (a new romantic partner) and wishes to stop the relationship despite no evidence of it causing harm. This denies the resident the benefits of the relationship. Click here to watch the case.

### Case Example 3: A balanced approach to sexual expression

Consider the following case: A new relationship between two residents blossoms. Though one of the resident's SDM has some concerns over the new relationship, these are navigated thoughtfully and the resident is supported. Click here to watch the case.

LTC home staff will often defer to the family's judgements around sexual expression. But some staff may not be familiar with the nuances of the laws in this area and may understandably want to avoid complaints and possible legal liability. As a result, staff may sometimes rely too much on SDMs to make decisions about resident sexual expression.

The boundaries of the SDM role are additionally confusing because the laws vary between provinces and territories, as illustrated in the example in the text box to the right. Current legislation and regulations relating to SDMs are also generally silent on decisions specifically relating to sexual expression. Be sure to consult the guardianship legislation in your jurisdiction and seek qualified legal advice to ensure that your substitute decision-making practices are in adherence with the law. In addition to consulting the legislation, we invite you to engage in further reflection on how this legislation may influence how you approach your role as an SDM regarding sexual expression in LTC. How do you understand this responsibility? It will be your job, with the assistance of others, to figure out how you should be involved in decision-making.

## "Agents" vs. "Representatives"

**Understanding different legal models for SDMs**

Here we review the difference between SDMs in the provinces of Alberta and British Columbia. These provinces have different legislation and the language used in the law can influence the way we think about what it means to be an SDM.

Consider these two different approaches to SDM work and reflect on their benefits and limitations.

In Alberta, an SDM is called an "agent." This language implies that the SDM assumes or takes on the agency of the individual for whom they are making decisions. Following a determination of incapacity in any or all domains, Alberta's Personal Directives Act states that "unless a personal directive provides otherwise, [the] agent has authority to make personal decisions on all personal matters of the maker" (Government of Alberta, 2000, p. 12). Separately, the Adult Guardianship and Trusteeship Act (2008), specifies areas within the purview of the agent. This includes areas such as where the adult lives, with whom they associate, their participation in leisure pursuits, and health care (Government of Alberta, 2008). There is little discussion of involving the individuals with diminished cognitive capacity in the decision-making. SDMs could understandably read this and conclude that they have total decisional authority.

By contrast, in British Columbia, SDMs are referred to as "representatives." This language implies that their role is to represent the interests of the individual. The Representation Agreement Act (1996) stipulates that a "representative" shall not take the place of the individual. Rather, they must act as an intermediary to help third parties (such as care home staff) understand and interact with the resident. As Stainton (2016) observed, this legislation's central strength is the representatives' imperative to support self-determination and participation in decision-making and to discern the individual's wishes based on knowledge of the person, how they communicate (traditional and non-traditional forms), and their socio-cultural context. This approach reflects more of a co-decision-making model that enables residents to retain as much agency as possible.

# 6

## Summarized Tips

Here are some tips summarizing the content above that can help you to be an ethical representative for someone living with dementia in LTC:

- Remember that capacity is not all-or-nothing. The resident may be capable of consenting to some forms of sexual expression, even if they cannot consent to others.
- Consider when co-decision-making or paternalism is more appropriate. When making this decision, remember to account for the:
    - Level of risk
    - Complexity of information
    - Severity of dementia
- Pay attention to the person's verbal and non-verbal signs. Be attentive to all forms of communication.
- Consider the person's past preferences but remember that preferences can and do change over time.
- Try to include the person in decision-making about their life to the greatest extent possible.
- Check in with the person often and ensure they can still consent.

# Conclusion

Being a decision-maker for someone else is an important role with profound responsibility. This resource provides you with lots to consider. There are not always straightforward answers. However, we hope that this resource has provided you with valuable information to guide and inform decisions you may need to make as an SDM. Simply by seeking out supports and information (through resources such as this one), you are demonstrating a commitment to doing this work with integrity and care.

Here are some additional online resources to help support SDMs:

**The Alzheimer Society:**
Decision-Making and Respecting Independence

**Ontario Health at Home:**
Substitute Decision-Makers

**Advanced Care Planning Ontario:**
Who is My Substitute Decision-Maker (SDM)?

**Alberta Health Services:**
Continuing Care Practice Resources: Decision-Making Capacity Assessment

# Resource: Substitute Decision-Makers & Sexual Expression of People Living with Dementia in Long-Term Care Homes

**A RESOURCE FOR SDMS**

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