



SUPPORTING SEXUAL HEALTH AND INTIMACY IN LONG TERM CARE HOMES: A Pocket Reference Guide

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This Pocket Guide is based on the original guidelines which are both available at vch.ca/Documents/Facilities-licensing-supporting-sexual-health-and-intimacy-in-care-facilities.pdf

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SECTION 1: Introduction

Sexual health and intimacy are essential components of overall health and healthy living. Moving into a long term care home should not, in and of itself, equate to losing the opportunity to engage in intimate and sexual behaviors. Long term care homes have ethical and legal obligations to recognize, respect, and support individuals’ sexual lives.

The values and beliefs of long term care homes and care providers may be challenged in situations where ethics and sexual health intersect. These “real life” situations range from persons wanting to share the same room, to a person needing assistance with sexual expression, to people with questionable consent capability engaging in sexual activity together.

Supporting Values

The following value statements underpin the clinical recommendations and responsibilities found within this document.

- Sexuality is an integral part of the lives of all people and is a normal part of the lives of people living in long term care homes.
- All persons are sexual beings and should be treated with respect, in regard to sexual health and sexual expression, irrespective of their age, sex, race or ethnic origin, disability, cognitive capacity, marital or family status, beliefs, sexual orientation, gender identity and expression, or socioeconomic status.
- Feelings and capacity for sexual expression may continue with the most significantly impaired persons.
- People require a safe environment for sexual activity.
- People have the right to make choices, as circumscribed by law and ethics, which caregivers may not agree with, or feel willing or able to support.

- Dealing with people who live in long term care homes' sexual expression should be respectful and caring and should not include revulsion, disdain, contempt, mockery or punishment towards the person.
- Individual freedoms are preserved, as much as possible, in care settings.

What is the Pocket Guide?

This Pocket Guide offers approaches to these “real life” sexual health situations which may occur in long term care. These approaches will assist you to recognize, respect and support the sexual lives of people living in long term care homes, while acknowledging the complexities of addressing this area of health.

The Pocket Guide is written for health care clinicians and other care providers who support adults, age nineteen and above, living in long term care homes in British Columbia.

It is a short, practical, guide based on the document “Supporting Sexual Health and Intimacy in Long Term Care: Guidelines for Supporting Adults Living in Long Term Care and Group Homes in British Columbia, Canada” (Vancouver Coastal Health Authority; July 15, 2009) ⁽¹⁾. The original 2009 document contains the ethical, clinical, and legal reasoning (including extensive references) underpinning the material in this Pocket Guide. The development of the 2009 document was funded by the Public Health Agency of Canada, the British Columbia Ministry of Health (Healthy Children, Women and Seniors, Population Health and Wellness), and Vancouver Coastal Health, British Columbia, Canada.

Sections 1 through 6 of the Pocket Guide focus on six common questions that may arise in scenarios involving sexual health and intimacy in long term care homes:

- Is there risk of harm in these sexual activities?
- Is the person(s) capable of making choices about sexual activities? If not, who should make decisions about the activities?
- Should others (e.g. the health care team/care providers) intervene in the activities? If so, when, and how?
- Should care providers assist in facilitating these sexual activities?
- Who should make the decisions about assisting?
- If there is assistance, when and how should it occur?

Long term care homes have ethical and legal obligations to recognize, respect, and support persons living in cares' sexual lives.

SECTION 2:

How do I assess risk of harm to a person where sexual activity is concerned?

Care providers owe a reasonable standard of care to the people who live in their long term care homes. This also includes a legal duty to prevent foreseeable risk of harm to anyone in their long term care home, in particular, to any person in care and to any person who is vulnerable because of a mental and/or physical disability.

People who are capable of sexual consent are allowed to engage in sexual activity that is not illegal ⁽²⁾ and does not pose harm that is imminent, serious, and virtually certain. Detailed information about intervening is provided in Section 5.

People, who have been deemed incapable of making their own sexual decisions, are ethically entitled to engage in sexual activity provided it: (1) does not involve unreasonable risk of harm and (2) is deemed to be in their best interests. ⁽³⁾ Detailed information about capability for sexual consent is provided in Section 3.

Reasonableness of harm depends on:

- the degree of probability that harm will result,
- the seriousness of the harm,
- the availability of less risky alternatives, and
- the importance of the activity to the person.

Ideally, the reasonableness of the level of harm will be determined by an experienced group of interdisciplinary care providers, in consultation with the person living in care, and if the person is not capable of giving sexual consent, their substitute decision-maker(s)/significant others. More information about intervening when risk is present follows in Section 5.

Risk of harm must be “real” harm, which, in this context, means primarily physical harm, including justifiable fear of anticipated physical harm, but may also include emotional harm.

Simply being offended because one disapproves of the behaviour involved does not constitute harm.

“Best interests” is determined by considering the physical, psychological, and emotional harms and benefits of sexual activity; the persons’ previous and current circumstances, values, wishes, and needs, and, whether on balance of harms and benefits, sexual activity should be supported.

No one has the right to stop behaviour that is legally protected (e.g. same-sex sexual activities), or that is not legally prohibited (e.g. extra-marital relationships), solely on the basis of disapproval or personal offense.

Ensure that assumptions about sexuality (e.g. men as sexual aggressors and females as vulnerable and in need of protection) are not affecting the decision-making process when evaluating the potential for harm.

SECTION 3:

How do I determine whether a person is capable of making the decision to engage in sexual activity?

Unless determined otherwise, adults in British Columbia, Canada, including people living in long term care homes, are presumed to be capable of making choices for themselves, including making decisions about sexual activity. If there is some question about a person's ability to make a decision regarding their sexual health and/or sexual activity, then sexual consent capability must be determined.

It is proposed that for individuals to have sexual consent capability and the right to engage in sexual activity with another with no third party intervention (e.g. from care providers), they must meet the following five criteria: ⁽⁴⁾

1. Have basic knowledge such as knowledge of sexual anatomy & function, and knowledge of the nature of sexual activity.
2. Understand the possible consequences, including risks, of the sexual activity to themselves and their partners.
3. Have the ability to understand appropriate and inappropriate locations and times for sexual activity.
4. Possess the ability to express a personal choice and to resist coercion. (Expression does not need to be verbal. It may include expressions of agreement such as smiling, nodding head, or holding out a hand, or expressions of refusal such as grimacing, shutting eyes, pushing away, or using a loud voice. This assessment should be carried out by persons who are familiar with the person resident and knowledgeable about non-verbal communication.)
5. Possess the ability to recognize distress or refusal in a partner and stop the activity.

When an individual does not meet the above criteria, an ethical case can be made for allowing the person to engage in sexual activity, provided any associated risk of harm can be reduced to a reasonable level and the activity is deemed to be in their best interests.

These criteria are not intended to prohibit sexual activity between individuals where one or more parties do not meet them. They are intended solely as a benchmark to indicate when others (e.g. the health care team) may ethically intervene, perhaps temporarily to allow planning time, to reduce foreseeable harm to a reasonable level. Any intervention will require assessment of the unique circumstances of the person with a view to developing a person-centered plan. More details about intervening are included in Section 5.

Criteria 2-4 above also apply to individuals engaging in solitary sexual activity (e.g. unsafe masturbation that causes genital abrasions). Again, the criteria are not intended to restrict solitary sexual activity but to ethically "allow" others to reduce risk of harm to a reasonable level.

This pocket guide will assist you to recognize, respect and support the sexual lives of people living in long term care homes, while acknowledging the complexities involved.

SECTION 4:

How do I determine the decision-maker if a person is not capable of making the decision about sexual activity?

If a person is not capable of making their own sexual decisions, a legally appointed substitute decision maker may be appointed by the Court or may have been appointed by the person when they were capable.

1. The Court can appoint a Committee of Person ⁽⁵⁾ to make these decisions.
2. The person, while capable, can appoint a Representative ⁽⁶⁾ and specify that they can make sexual decisions.

In the absence of a legally appointed substitute decision-maker, it is proposed that the long term care home and the person or persons' (substitute decision-maker(s)/significant others) who generally make health care decisions for the person living in a long term care home should make the determination as to what ought to be done regarding sexual activity. The long term care home has a role in the decision as it has a duty of care to the person and an ethical duty to strive to improve quality of life for all people in the long term care home. Substitute decision-maker(s)/significant others may have knowledge of the person's values. For more information about issues to consider in making a decision, see Section 5.

No one has the right to stop behaviour that is legally protected (e.g. same-sex sexual activities), or that is not legally prohibited (e.g. extra-marital relationships), solely on the basis of disapproval or personal offense.

SECTION 5:

When and how to intervene in choices of individual when there is a risk of harm?

The appropriateness of intervening in peoples' sexual activity depends on whether:

- the individual is capable of sexual consent,
- the risk of harm is reasonable, and
- the activity is in the best interests of the incapable individuals.

If the person is capable of making decisions about sexual activity and the person does not require assistance from care providers, the person should be offered information and education about reducing foreseeable risk of harm to self. The capable person may choose to use this information or not.

The only circumstance when care providers would intervene with a capable, independent person is if the sexual activity would result in harm that is imminent, serious, and virtually certain. Intervening in this circumstance should be for the purpose of creating reasonable time to have a qualified clinician assess if the person is making an informed decision.

If the person is not capable, the long term care home and substitute decision-maker(s)/significant others jointly decide whether or not to permit sexual activity. In a consensus building process, they would consider the physical, psychological, and emotional harms and benefits of sexual activity; the person's previous and current circumstances, values, wishes, and needs; and, whether on balance of harms and benefits, sexual activity is in the best interests of the person. The person should be included in the decision-making process as much as possible.

Joint decision-making and coming to consensus is important because the process of decision-making may be complex. For example, it is not straightforward whether to prohibit the current extra-marital sexual activity of an individual who has had a life-long monogamous relationship. Substitute decision-maker(s)/significant others can speak to the person's past values and convictions and care providers can speak to current wishes, the benefits of intimacy given current circumstances, and the ways that foreseeable harm can be reduced to a reasonable level.

If intervention is required to reduce risk of harm to a reasonable level, the intervention must meet the following five conditions:

1. The intervention must be effective (i.e. must decrease the risk of harm).
2. The intervention must be the least intrusive.
3. The intervention must not create harms greater than those it seeks to prevent.
4. The intervention must not be discriminatory.
5. The intervention must be thought justifiable, if at all possible, to those on whom it is imposed.

Even if a consensus cannot be reached, a course of action must be chosen by the decision-makers in order to address the given situation. Each case needs to be considered individually and there may be times when the long term care team goes along with a family decision they do not agree with if it is the least stressful for the person involved. Options such as transfer to another long term care home may also be considered.

SECTION 6:

What should I do when assistance is needed by a person/persons to engage in sexual activity?

When individuals are unable to engage in sexual activity on their own, the long term care home has an ethical obligation to reduce foreseeable harm to a reasonable level and then ensure that assistance is provided. Whether the person(s) are capable or incapable of sexual consent, assistance should be provided only if the foreseeable risks can be reduced to a reasonable level. As well, when a person is not capable of sexual consent, the sexual activity must be determined to be in their best interests.

Before any form of assistance with sexual activity is provided, the care provider needs to clarify the nature and extent of the assistance. It is the responsibility of care providers to maintain their professional codes of ethics and act within professional boundaries and standards of practice. It must be clear to all parties that the assistance is provided in a care-giving capacity and not as a "friend" or "participant."

Three broad categories of assistance commonly exist, each having unique guidelines for providing assistance.

Assisting with sexual activity

The first category is care providers helping with preparation for, and clean up after, sexual activity. If foreseeable harm can be reduced to a reasonable level for both capable and incapable people, and if the sexual activity is in the best interests of incapable person(s), care providers should assist with preparation and clean up using universal precautions and treating body fluids from sexual activity as they would any other body fluid. However, care providers should not participate in or be present during the activity itself.

Obtaining sexually explicit materials

The second category is care providers obtaining sexually explicit materials or aids such as adult magazines, videos, vibrators, etc.

Although long term care homes are encouraged to provide this support for people who are unable to do it on their own (or do not have family or friends who could assist them), it remains questionable if a care provider is obliged to carry out this request. Although there is nothing illegal about obtaining such material or aids, care providers should seek guidance from their long term care home's administration.

Supporting people in long term care homes to access paid sex workers

The third category is when residents request assistance from care providers to access paid sex workers. This usually involves a request to contact a paid sex worker. It is not possible to say with certainty that there could be no legal problems if a health care worker contacts a paid sex worker on behalf of a person living in a long term care home. It is therefore recommended that care providers decline to contact sex workers. Care providers may inform people in their care of where they can find public information about these services (e.g. websites) and, if appropriate, encourage the person to find a family member or friend to provide assistance in accessing this service.

If a care provider finds a person in the company of a sex worker on the premises of the long term care home, there is no legal duty to intervene in the situation except to ensure that foreseeable harms are reduced to a reasonable level for incapable people and to ensure that this particular activity is in the incapable person's best interests. It is not illegal for this activity to be occurring on the premises. It is recommended that decisions about this type of concern be addressed to site administration or by obtaining specific legal advice about a particular situation.

Sexual consent capability is based on:

- *having basic sexual knowledge;*
 - *understanding possible consequences;*
 - *appreciating appropriate and inappropriate location and times;*
 - *possessing the ability to express choice and resist coercion, and*
 - *recognizing distress in a partner.*
-

SECTION 7:

CASE EXAMPLES

CASE EXAMPLE A: Sid and Jean

“Determining Consent Capability”

Sid, who has a mild form of dementia, lives in a long term care home. He is attracted to Jean, who also lives in the long term care home, is physically quite able, and has moderate Alzheimer’s dementia. Jean’s communication is compromised but she can consistently and reliably indicate likes or dislikes. She does this by either nodding her head “yes,” smiling and reaching out, or shaking her head “no,” closing her eyes tightly, and crossing her arms. Jean is married to a man who lives in another city and who has minimal contact with her. They have one adult daughter who is very involved and is named as Jean’s Representative. Jean and Sid are discovered in Sid’s room, undressed on his bed.

CASE COMMENT

The long term care home has a duty of care towards all people in their care. The long term care home (in consultation with the person or substitute decision-maker(s)/ significant others) therefore has an obligation to assess the possible risk of harms of an intimate relationship to both Sid and Jean. These may include physical, emotional, or psychological harm. The long term care home must then determine what risks are reasonable for Sid and Jean. Care must be taken 1) to be clear in identifying the possible harms and, 2) in this case, not to bring personal values about extra-marital relationships and male-female roles into the decision.

Once the possible risks of harm are identified, the long term care home has a duty to determine whether both Sid and Jean are capable to make decisions about engaging in intimate and sexual activities. A person may be incapable in other areas, (e.g. managing their finances) but capable

to give sexual consent. If either of the parties is found to be incapable of sexual consent, it is necessary to intervene (possibly only to assess risk of harm) to reduce foreseeable harm to a reasonable level. Sid or Jean need only have one unmet sexual consent capability criterion to indicate the need for intervention to reduce foreseeable harms to a reasonable level. Information regarding sexual consent capability is in Section 3.

Sid has basic sexual knowledge and good general social skills. He has not been known to take risks or cause harm to others in the long term care home. He has been appropriately private in his daily living and he has been able to make his needs known to care providers and take “no” for an answer from others. Therefore Sid meets the criteria and is capable of sexual consent.

Jean does not initiate activities of daily living in any organized manner. She is physically able but requires prompting and/or assistance to wash, dress, toilet, eat and rest. She is unable to clearly give more than “yes” or “no” answers. Jean is able to respond and indicate likes and dislikes, but she may not be strong enough to resist physical or emotional coercion. She has sometimes responded to the word “no” by stopping what she is doing, but it is unclear if she truly understands the word. As per the criteria, Jean is not capable of sexual consent.

Sid is capable of sexual consent and therefore his significant others may be consulted only with his permission. Jean is not capable of sexual consent and therefore her substitute decision-maker/ significant others must be consulted. Although Jean’s Representation Agreement does not include specific instructions about sexual activity, her daughter is the appropriate substitute decision-maker because she makes all her mother’s health care decisions and is well-informed about Jean’s past values and lifestyle.

Sid should be offered information and support, but no other intervention is required. The priority is to ensure Sid understands the possible consequences Jean may experience as a result of sexual activity. Sid should be offered information about issues such as possible risk of emotional harm (e.g. loneliness and confusion should the relationship end) and physical risk (e.g. joint pain, or sexually transmitted infection). Sid should confirm that he is willing and able to provide support to Jean to mitigate these risks. Care providers should follow up on a regular basis.

Given Jean has been determined to be incapable of sexual consent, she requires support to reduce foreseeable harms to a reasonable level. Care providers should check with Jean each time she wants to be with Sid to ensure that she is in agreement with any possible sexual activity. Further, care providers should ask Sid to agree to stop any activity if Jean resists or appears at all physically, emotionally or psychologically uncomfortable. As the persons' dementias progress, interventions will likely need to change. However, at this time, the proposed interventions of education, reminders, and follow-up meet the five conditions of intervention. These conditions are defined in Section 5.

The long term care home has a duty of care to lead a well-informed decision-making process on Sid and Jean's behalf. Sensitive involvement early and often, with both families (if Sid consents to his family's involvement), for education, support and decision-making will promote a positive collaborative process. Time must be spent to explain to Sid the need for Jean's family's involvement. Whenever possible, Jean should be included. If a consensus is not reached, the long term care home makes the decision. The option of changing long term care home is available.

CASE EXAMPLE B: Dylan

“Assessing Risk”

Dylan is a twenty-year-old man with cerebral palsy. He has significant cognitive impairment and lives in a group home. Dylan can express and say “yes” and “no” and uses a basic communication board for other communication. Formal IQ testing has not been possible but it is thought that he functions at approximately an eight year old level. Dylan is able to move his arms and legs around and grab onto objects although his movements are quite spastic and he cannot always control their direction. Dylan's mother comes to see him every two weeks. She takes part in major health care decisions; however, she is not his Committee of Person or Representative. Recently it is discovered that Dylan engages in repetitive genital stimulation by rubbing his penis on the carpet or other rough materials. This has caused severe genital abrasions.

CASE COMMENT

Dylan is not capable of making his own decisions about sexual activity. He does not understand the consequences of his behaviour or the risks of his genital abrasions. Because Dylan is not capable, it is appropriate to intervene to determine if the risks of his rubbing behaviour can be reduced to a reasonable level and if the activity is in his best interests. Dylan's reasons for rubbing his genitals to this extent should be assessed in order to rule out other reasons such as an infection or boredom. The benefits and risks of allowing masturbation should then be analyzed and weighed up. In Dylan's case, harms can likely be reduced to a reasonable level. For example, harms can be reduced by having a trained sexual health clinician teach Dylan to use his hands, possibly with a lubricant, versus a carpet to self-stimulate, or provide him with a properly lined vibrator. Care providers can also be instructed on how to safely support this activity.

Intervening to entirely stop Dylan's masturbation will not meet the five conditions of intervention. This is because trying to stop masturbation is unlikely to be effective as there will always be some place and time where Dylan can engage in the activity (e.g. in bed, in the shower). Restraining Dylan so that he cannot masturbate will likely cause physical, psychological, and emotional harms and it is discriminatory not to allow him this form of sexual activity. How to best intervene in a person's choices is described in Section 5.

Therefore, Dylan should be supported to reduce the harm to a reasonable level so that he is able to carry out this sexual activity safely and privately.

CASE EXAMPLE C: Chloe and Sarah "Assistance with sexual expression"

Chloe is a forty-year-old woman with multiple sclerosis who lives in a long term care home. She and another person living in the home, Sarah, who has ALS, are attracted to each other. Both have significant physical disabilities but are cognitively intact. They want to engage in physically intimate behaviours and, in order to do so, need assistance to undress and re-dress, to lie close to each other, and assistance with positioning. The couple also ask care providers to rent adult movies for them.

CASE COMMENT

When people who are capable of sexual consent choose to independently engage in activities that may harm themselves, the long term care home has a duty to offer professional advice about how these potential harms may be reduced to a reasonable level. Capable people may choose to heed or ignore this advice. However, when a person asks for assistance to carry out an activity that poses risk to themselves or another person, assistance can be denied if the risk cannot be reduced to a reasonable level. When to intervene when there is a risk of harm is described in Section 5.

In this case, both people are capable so can choose to take risks. However, before agreeing to assist, care providers must decide if there are potential risks of harm and if so, if these can be reduced to a reasonable level. With Chloe and Sarah, it appears that the nature of foreseeable risk of harm may be physical harm, (e.g., increased risk of falls if they attempt sexual activity without assistance). Hence there is no reason not to assist these individuals with sexual activity and good reasons to do so. Chloe, Sarah, and the team members who need to know in order to provide care, should discuss their needs and decide upon a plan to meet them. This care plan will outline

the type and frequency of assistance that will be provided. The fact that the relationship between Chloe and Sarah is same sex has no bearing on whether assistance is provided.

Chloe and Sarah should be provided with the assistance they need to undress, re-dress, and position themselves. Whatever method to call for assistance is usual for them (e.g. call bell) should be used. Care providers should leave the room after set up is complete and prior to any sexual activity commencing. Care providers are encouraged to obtain legal sexual materials/aids for the couple if they are unable to do so and help them set up to use them. Care providers should not watch videos with either/both person(s).

SECTION 8: Footnotes

- 1) “Supporting Sexual Health and Intimacy in Long Term Care: Guidelines for Supporting Adults Living in Long Term Care and Group Homes in British Columbia, Canada.” Vancouver Coastal Health Authority; July 15, 2009. Available at: vch.ca/Documents/Facilities-licensing-supporting-sexual-health-and-intimacy-in-care-facilities.pdf
- 2) In a recent decision, *R. v. J.A.*, 2011 SCC 28, [2011] 2 S.C.R. 440, involving two capable adults in a long-term relationship, the Supreme Court of Canada decided that it is not possible for a person to give advance consent to a sexual act that takes place while that person is unconscious. To prevent sexual exploitation the law requires a conscious, capable mind throughout so that a person can change their mind.
- 3) Everett, B. (2008). Supporting Sexual Activity in Long-Term Care. *Nursing Ethics*. 15(1):78-87.
- 4) Kennedy, C.H. (2003). Legal and Psychological Implications in the Assessment of Sexual Consent in the Cognitively Impaired Population. *Assessment*. 10(4): 352-358.
Kennedy, C.H. and Niederbuhl, J. (2001). Establishing Criteria for Sexual Consent Capability. *American Journal on Mental Retardation*. 106(6): 503-510.
- 5) Patients Property Act [RSBC 1996] Chapter 349.
- 6) Representation Agreement Act [RSBC 1996] Chapter 405.

SECTION 9:

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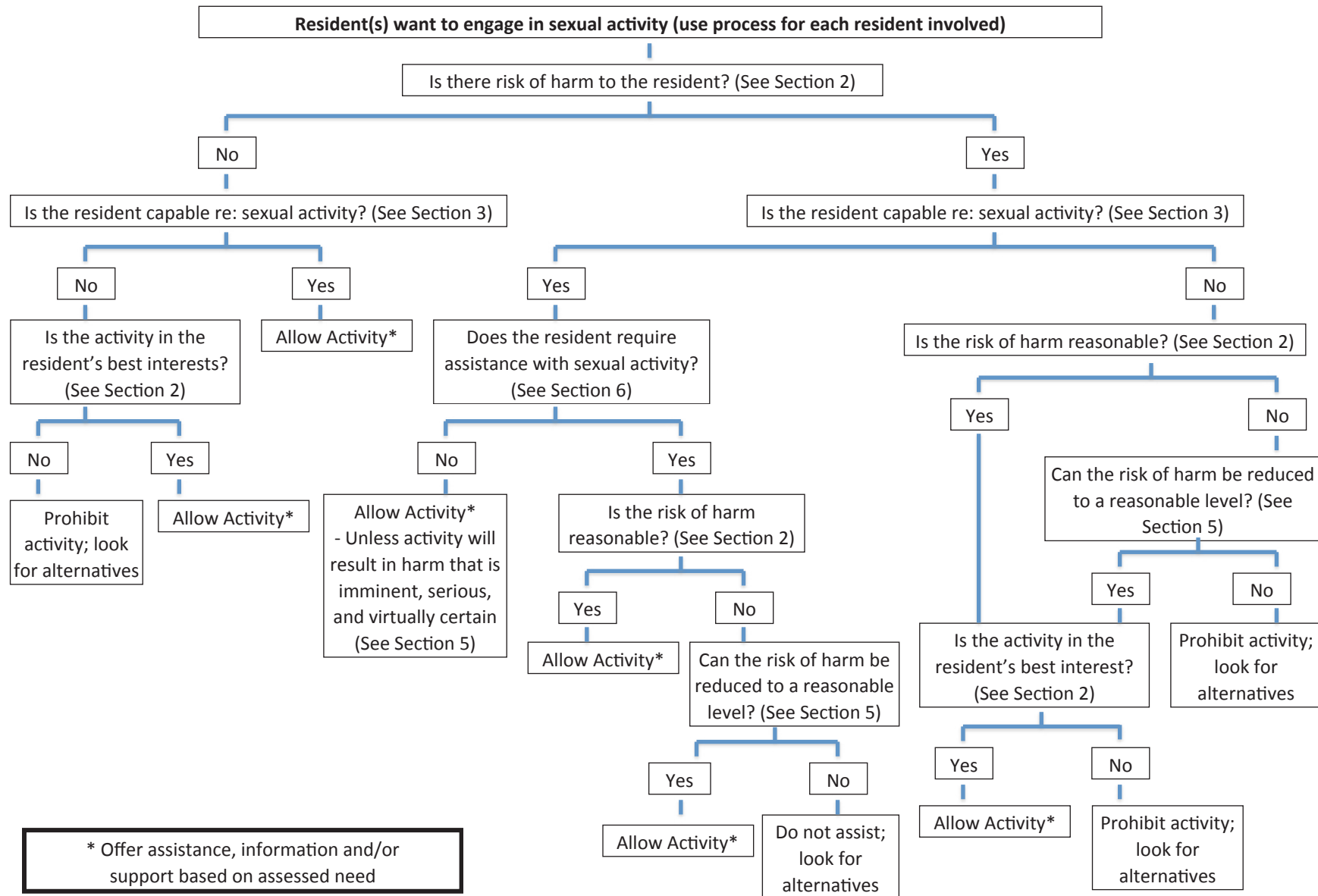
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APPENDIX: Decision-Making Flow Chart

To be used only in conjunction with the "Pocket Guide"



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