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**INCAPACITY AND SEXUAL RELATIONSHIPS
IN THE ELDERLY
Balancing Autonomy and Protection**

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I Introduction

Older people enjoy the same freedom as other adults to enter into relationships, including sexual relationships. However, this exercise of autonomy and self-determination can be regarded as problematic when an older person is perceived to have lost the capacity to make decisions about sexual relations. While the law adopts an approach that is designed to support incompetent adults to continue to make decisions to the greatest extent possible,¹ carers and family members can become concerned about an incapacitated older person having sexual relations.² This may be because of fears of abuse or exploitation, or because of social or familial stigma about sex. Where the older person lives in an aged residential care facility (“resthome”³), carers or family may complain about sexual relationships, or even ask staff to prevent sexual contact from occurring.

Anecdotally, resthomes struggle with the vexed question of sex and incompetent adults. Resthomes have a number of legal and professional obligations to protect residents from harm,⁴ and a legal duty to uphold residents’ rights to be treated with respect, to have their privacy respected, and to provide services in a manner that recognises dignity and independence.⁵ It is not difficult to see how the tension between carers’ responsibilities and individual autonomy could result in the erosion of the right to self-determination.

With this tension in mind, this paper discusses consent for sexual relations and the law on determining capacity to give such consent. It argues that the context in which decisions about sexual relations and capacity assessments are made is relevant to determining capacity. Then, with a particular focus on those elderly with questionable or fluctuating capacity, it explores how expressed wishes about sexual relations might establish the necessary consent to sex while also balancing the need to protect those in need of protection. A proposed model of statutory supported decision-making and the existing framework for substituted decision-making are canvassed, and advocated as lawful

¹ Protection of Personal and Property Rights Act 1988, s 8(b).

² “Incapacitated” and “incompetent” are used interchangeably in this paper.

³ Resthome is used here to refer to aged residential care facilities that provide 24 hour caregiver care to residents, and facilities that provide 24 hour hospital level care.

⁴ See for example the legal duty to protect vulnerable adults from risk of sexual assault: Crimes Act 1961, s 195A (an offence punishable by a term of imprisonment not exceeding 10 years).

⁵ Health and Disability Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulations 1996, Right 1 and 3.

mechanisms to uphold expressed wishes while also allowing for risk assessment and protection. It then suggests that more can and should be done to address questions about sexual relationships in the elderly. Advance directives are encouraged as a means to express how a person wants to live once incapacitated, and to influence decisions made after incapacity. Finally, it is recommended that resthomes should develop industry agreed guidelines on sexual relations in resthomes to expressly guide staff, individuals and families about sex in that setting, and to address the difficult questions that can arise when adults who are perceived to lack capacity enter sexual relationships.

II Consent and Sexual Relations

It is a well-accepted principle that all adults of sound mind have a right to determine what should be done with their own body.⁶ Thus, subject to the bounds of the law, competent adults have the freedom to choose how and with whom they might enter into sexual relations.⁷ Consent, and therefore the capacity to make a decision to have sex, is an essential legal requirement for sexual relations. In the absence of consent, sexual connection is a criminal offence.⁸

Importantly, the criminal law deems consent to be absent in circumstances where a person is “affected by an intellectual, mental, or physical condition or impairment of such a nature and degree that he or she cannot consent or refuse to consent to the activity.”⁹ Commentary to the Crimes Act 1961 suggests that “prior consent or an implication of consent derived from the nature and history of the relationship and the surrounding circumstances is not relevant.”¹⁰ This indicates that a mutually consensual sexual relationship prior to incapacity will not operate as a defence.

It is also a criminal offence to have “exploitative sexual connection with a person with a significant impairment”,¹¹ being a condition that significantly impairs the capacity to understand the nature or to foresee the consequences of sexual conduct.¹² In a judgment

⁶ *Schloendorff v Society of New York Hospitals* 211 NY 125, 105 NE 92 (1914) at 130, 93.

⁷ The bounds of the law is reference to the fact that some sexual acts are criminal acts, including incest and sexual connection with minors.

⁸ Crimes Act 1961, s 128.

⁹ Crimes Act 1961, s 128A(5).

¹⁰ Bruce Robertson (ed.) *Adams on Criminal Law* (online looseleaf ed, Brookers) at [CA128A.05].

¹¹ Crimes Act 1961, s 138.

¹² Crimes Act 1961, s 138(6).

on a similar provision in United Kingdom (UK) law,¹³ the criminal jurisdiction of the House of Lords made it clear that capacity to consent relates to the specific act of sexual touching.¹⁴ However, not all sexual relations are (or should be) viewed through the lens of the criminal law, which is concerned with specific alleged acts at a past point in time.

III The Law on Capacity to Consent to Sexual Relations

In New Zealand, the Protection of Personal and Property Rights Act 1988 (PPPRA) provides a legal framework for protecting and promoting the personal rights of those not able to manage their own affairs. It creates a presumption of competence to make decisions until the contrary is proven.¹⁵ Rebutting the presumption requires a determination that a person is not capable of understanding the nature, or foreseeing the consequences, of their decisions.¹⁶ In general terms, assessing capacity under the PPPRA involves consideration of an individual's ability to communicate his or her choice; to understand relevant information; to "appreciate the situation and its consequences"; and to manipulate information.¹⁷

Applying the statutory test to sexual relations would likely involve an assessment of a person's understanding of the sex act itself, the risks of sexually transmitted infection and pregnancy, and the ability to communicate the choice (including the choice to say no). For the older adult, it is arguable that the understanding of the sex act may exist through prior experience, and for older women the risk and implications of pregnancy is removed by menopause. Understanding the risk of sexually transmitted diseases would, however, remain a relevant matter.¹⁸

¹³ Sexual Offences Act 2003 (UK), s 30.

¹⁴ *R v C* [2009] UKHL 42, at [26], [2009] 4 All ER 1033.

¹⁵ PPPRA, s 5.

¹⁶ PPPRA, s 5.

¹⁷ Sylvia Bell and Professor Warren Brookbanks "Decision-Making and the Protection of Personal and Property Rights Act 1988" in Kate Diesfeld and Ian McIntosh (eds.) *Elder Law in New Zealand* (Thomson Reuters, Wellington 2014) 79 at 89, citing *KR v MR* [2004] 2 NZLR 847 (HC).

¹⁸ There is evidence of an increasing prevalence in sexually transmitted infections in the elderly. See for example Roberta Bilenchi, Sara Poggiali, Chiara Pisani, Mariele De Paola, Rosanna Sculco, Lucia Anna De Padova and Michele Fimiana "Sexually Transmitted Diseases in Elderly People: An Epidemiological Study in Italy" (2009) 57(5) *J Am Geriatr Soc* 938.

As to understanding the “situation and its consequences”, some guidance may be taken from case law considering the question of capacity to enter into marriage.¹⁹ The test for capacity for marriage involves more than a functional assessment of the nature of the act:²⁰

...a person can be perfectly well aware of the nature of marriage and what it involves, yet lack the intellectual capacity to decide whether or not to marry a particular person or to resist a decision to marry that person.

There are, however, limitations with a comparative analysis between consent to sex and consent to marriage. Importantly, marriage is not solely concerned with sexual relations and, unlike most sexual relationships, it involves a potentially long-lasting legal relationship with implications for property and inheritance rights. That said, if New Zealand courts adopt a similar approach as with consent to marriage, capacity for sexual relations would require both a functional understanding of sex *and* an understanding of circumstances in which the sexual act may occur, including the identity of the sexual partner.

In the UK, this so-called “situation specific” capacity to consent is applied in the criminal jurisdiction, where the leading decision puts it this way:²¹

...it is difficult to think of an activity which is more person and situation specific than sexual relations. One does not consent to sex in general. One consents to this act of sex with this person at this time and in this place. Autonomy entails the freedom and the capacity to make a choice of whether or not to do so.

In contrast, the UK Court of Appeal has confirmed that an “issue specific, rather than person or event specific”²² assessment applies to sexual relations in the context of the Mental Capacity Act 2005 (MCA), which relates to adults who lack capacity and which provides a framework for protecting vulnerable adults from abuse, coercion and

¹⁹ For the purpose of this paper, marriage may be read as including civil unions.

²⁰ *X v X* (2000) 19 FRNZ 544, at [28]. The Court held, at [76], that “Mr X’s disease, in all the surrounding circumstances including his increasing dependence on Mrs X and his increasing isolation from his own family, had robbed him of the ability to make the reasoned and informed decisions which were a necessary prerequisite of an agreement to marry Mrs X”.

²¹ *Anove n 14*, at [27].

²² *IM v LM* [2014] EWCA Civ. 37, at [79].

exploitation.²³ Thus, it is sufficient to “understand the rudiments of the sexual act, [and to have] a basic understanding of issues of contraception and the risks of sexually transmitted disease.”²⁴ In reaching this view, the Court of Appeal endorsed the need for pragmatic limits on “what needs to be envisaged as ‘reasonably foreseeable consequences’”, noting that:²⁵

...the information typically, and we stress typically, regarded by persons of full capacity as relevant to the decision whether to consent to sexual relations is relatively limited. The temptation to expand that field of information in an attempt to simulate more widely informed decision-making is likely to lead to...both paternalism and a derogation from personal autonomy.

Accordingly, the UK Court of Appeal purports to uphold autonomy by judging an otherwise incompetent adult’s capacity for sexual relations against the relatively limited questions competent adults may ask themselves about sexual relations. Put another way, the threshold is not so high as to require adults who lack capacity in other respects to demonstrate an analysis of sexual relations that would not be required of competent others. As one UK court described it, the protective purpose of the MCA is not to wrap a person in “forensic cotton wool” but to allow them as far as possible to make the same mistakes that others “are at liberty to make and not infrequently do”.²⁶

This “desire to avoid paternalism, while supporting autonomy” has been criticised for overlooking the fact that there is limited, if any, evidence about what considerations are relevant to a competent person’s decision about sexual relations, and the extent to which this is different for a person who is under some disability.²⁷ The low threshold has also been criticised for interpreting autonomy as simply allowing incompetent adults to have sex, without proper regard to the need to protect those who are at risk of abuse.²⁸ In particular, a suggestion from the UK courts that vetting sexual partners would be unworkable has been condemned as inconsistent with a protective role,²⁹ and because it

²³ Above n 22.

²⁴ Above n 22, at [18], citing the decision of the Court of Protection, which was upheld.

²⁵ Above n 22 at [79] and [82].

²⁶ Above n 22, at [81] citing *A NHS Trust v P* [2013] EWHC 2322 (COP).

²⁷ Robin Mackenzie and John Watts “Capacity to Consent to Sex Reframed: IM, TZ (no2), the need for an evidence-based model of sexual decision-making and socio-sexual competence” (2015) 40 *Int J Law Psychiat* 50, at 52-53.

²⁸ Jonathan Herring and Jesse Wall “Capacity to Consent to Sex” (2014) 22(4) *Med Law Rev.* 620 at 629.

²⁹ Above n 28 at 629.

risks “privileging administrative convenience over the need for a test which is sensitive to...the vulnerabilities of those...whose capacity is in question.”³⁰

Against this, it is arguable that setting comprehensive (and more sensitive) criteria for assessing capacity has a number of possible drawbacks, including the risk of placing people with certain diagnoses (e.g. dementia) into a category that is effectively deemed incapable of consenting to sexual relations. Strict ‘person and event’ assessments may also be inadequate to recognise that capacity can fluctuate, and that people with varying degrees of incapacity may retain the ability to make genuine choices about entering into sexual relations.

As can be seen, debate as to the appropriate measure of capacity is complex, lacking in empirical evidence, and strongly influenced by the differing perspectives of individual autonomy and protective interests. While setting a low (i.e. functional understanding) threshold for capacity may endorse sexual freedom, it also creates a risk of at least some incidents of non-consensual sex. Conversely, although a high threshold may provide a greater degree of protection by potentially excluding more individuals from sexual relations, it also risks being a paternalistic intrusion into self-determination, even in the absence of vulnerability.

To attempt to balance autonomy and protection, it is suggested that any assessment of capacity for sexual relations must be conscious of the need to protect those “whose limited capacity prevents them from appreciating the risks,”³¹ while not interfering with decisions unless protection is objectively necessary. However, resthomes’ (and other carers’) legal obligations may favour protective outcomes that prevent “detached and objective” capacity assessments.³² Although protection will be appropriate in some cases, to avoid unnecessary limits on autonomy it is important for those raising questions about capacity to be required to give consideration to the whole context in which decisions about sexual relations, and capacity assessments, are made.

³⁰ Above n 28.

³¹ *Re R M S [PPPR]* (1993) 10 FRNZ 387, at 392.

³² *A Local Authority v TZ* (No.2) [2014] EWHC 973 (COP), at [28].

IV Capacity Assessments in Context

The starting point is that loss of capacity is not a normal part of ageing, and therefore ‘old age’ (however defined) is insufficient to establish incapacity, or even vulnerability.³³ That said, dementia is a “disease of the ageing”³⁴ that impacts on memory, reasoning and language skills.³⁵ While dementia alone should not be enough to establish incapacity, a diagnosis of dementia, including the rate of cognitive decline and behavioural changes over the course of the disease, must be relevant to determining capacity. In addition, the extent to which dementia is coupled with disinhibited sexual behaviour, either in inappropriate settings or towards unwilling participants, will also be relevant.³⁶ That is, observable changes in attitude or desire for sex that can be attributed to dementia may be relevant to the genuineness of a person’s choice, their vulnerability, and the risk they pose to themselves or others.³⁷

More broadly, it is clearly arguable that a person’s capacity to consent to sexual relations is “affected by relationships with sexual partners.”³⁸ Therefore, assessing capacity must logically involve consideration of the sexual relationship in question. This could be particularly relevant in resthomes, where residents may have long-term relationships that remain important despite cognitive decline, or where residents simply seek comfort and

³³ For this reason alone, imposing an upper limit for the age of consent to sexual relations must be rejected. See for example Stephanie L. Tang “When “Yes” Might Mean “No”: Standardizing State Criteria to Evaluate the Capacity to Consent to Sexual Activity for Elderly with Neurocognitive Disorders” (2015) 22 *Elder L.J* 449, at 478.

³⁴ Michael Boyd, Chris Perkins and Rod Perkins “Older Adult Health Issues: The Emerging Implications in New Zealand” in Kate Diesfeld and Ian McIntosh (eds.) *Elder Law in New Zealand* (Thomson Reuters, Wellington 2014) 59 at 65.

³⁵ Ministry of Health “Dementia” <www.health.govt.nz/your-health/conditions-and-treatments/mental-health/dementia> accessed 18 March 2016.

³⁶ See Gabriele Cipriani, Martina Ulivi, Sabrina Danti, Claudio Lucetti and Angelo Nuti “Sexual Disinhibitions and Dementia” (2016) 16 *Psychogeriatrics* 145.

³⁷ See for example *A Report by the Health and Disability Commissioner (Case 04HDC07008)* <<http://www.hdc.org.nz/decisions--case-notes/commissioner's-decisions/2006/04hdc07008>> highlighting the risks faced by vulnerable resthome residents to incidents of inappropriate sexual behaviour by a resident with dementia. Accessed 24 February 2016.

³⁸ Lucy Series “Relationships, Autonomy and Legal Capacity: Mental Capacity and Support Paradigms” (2015) 40 *Int J Law Psychiat* 80 at 82.

intimacy in what has become their ‘home’ environment. In other words, it must be recognised that healthy relationships can be integral to a person’s wellbeing:³⁹

There’s nothing about being cognitively impaired that means that you wouldn’t necessarily appreciate being connected with other people through both nonsexual means and sexual means.

Consideration of the relational context should not be understood as requiring a person to be (or intending to be) in a stable or long-term relationship in order to have sexual relations. Instead, it is suggested that for an accurate picture of capacity for sexual relations consideration should be given to all the factors that may influence capacity, including the sexual partner. While scrutinising (intended) sexual partners may be regarded by some as an intrusion into a person’s right to privacy, such an inquiry is not necessarily an anathema to autonomy. It is equally arguable that making an assessment of relational factors actually supports autonomous decision-making, while also allowing for a proper assessment of vulnerability and risk.⁴⁰ In resthomes, asking residents about sexual relationships is a reasonable part of discharging the obligation to protect them from harm. It also goes some way to supporting a person’s ability to have sexual relationships in a safe and supportive environment.

Relationships with others can also provide an otherwise incapacitated person with support and guidance for decision-making. Autonomy has “social and relational dimensions” that may influence capacity, and therefore examining how an incompetent person utilises others to assist with decision-making is important.⁴¹ In addition, it must be acknowledged that the identity of the person who undertakes the assessment may influence its outcome, whether for lack of trust on one hand or lack of knowledge about the person concerned on the other. Likewise, capacity assessments should have regard to the factors that may

³⁹ See “Former Iowa legislator Henry Royhons, 78, found not guilty of sexually abusing wife with alzheimers” (23 April 2015) The Washington Post < www.washingtonpost.com/news/morning-mix/wp/2015/04/23/former-iowa-legislator-henry-rayhons-78-found-not-guilty-of-sexually-abusing-wife-with-alzheimers> accessed 24 February 2016.

⁴⁰ It is notable, for example, that in *IM v LM* the initial application had been made by a male friend of the incapacitated woman who wished to have sex with her (and the order allowing contact had been appealed by the woman’s mother).

⁴¹ Above n 38, at 81.

temporarily affect capacity, such as tiredness, stress or medication, and should expressly recognise that capacity may fluctuate for these reasons.⁴²

While the courts exercising powers under the PPPRA will very likely consider the context for the decision, a clear statutory requirement to do so would provide greater clarity for individuals and resthomes about how capacity will be assessed. Therefore, it is suggested that rebutting the presumption of competence should expressly require consideration of all the circumstances relevant to the capacity to make the decision. This could be achieved by amending the PPPRA to read that: “...every person shall be presumed, until in all the circumstances relevant to the decision the contrary is proved, to have the capacity...” (addition underlined). It is noted that such a requirement could well signal that mere functional understanding of sex is an insufficient basis for capacity. In other words, an individual’s failure to appreciate the significance or implications of a particular sexual relationship could be fatal to his or her perceived understanding of the nature and consequences of their decision. That said, contextual matters are equally relevant to consideration of how expressed wishes for sexual relations might be facilitated.

V Making Decisions about Sexual Relations

It is recognised that incapacity can create significant vulnerability and expose people to exploitation. For some incompetent adults there will be no basis on which expressed wishes for sexual relations can be upheld. However, between obvious competence and complete incapacity is a grey area of questionable (or fluctuating) capacity. This section is concerned with upholding, where possible, the rights of those older adults who retain some degree of capacity for making personal choices. As noted by the former Health and Disability Commissioner (HDC):⁴³

...it does not necessarily follow from the fact that consumers require care and support in some areas of their life that they are not capable of participating in a sexual relationship, or making decisions about their sexuality. To make this

⁴² See for example Mental Capacity Act 2005, s 3(3): “The fact that a person is able to retain the information relevant to a decision for a short period only does not prevent him from being regarded as able to make the decision.”

⁴³ Ron Paterson “Relationships and Rights – The Application of the Code of Rights to Consumers with Intellectual Disability” (2009) <www.hdc.org.nz/education/presentations/relationships-and-rights--the-application-of-the-code-of-rights-to-consumers-with-intellectual-disability> accessed 21 March 2016. While the article relates to adults with intellectual disabilities, the comments are equally applicable to elderly with impaired capacity.

assumption where it is not appropriate places unnecessary limits on a consumer's independence.

Studies suggest that sex can remain an important part of an elderly person's life, and that even with cognitive decline individuals may derive "emotional pleasure...life satisfaction, confidence and overall psychological health" from sexual relations.⁴⁴ Those adults with impaired capacity should not, therefore, automatically be deprived of the opportunity to maintain or enter into sexual relations.

However, despite the existence of legislation intended to promote and protect the rights of incompetent adults, New Zealand courts have not yet been asked to consider an otherwise incompetent person's capacity to consent to sexual relations. That said, New Zealand law does not expressly recognise a 'right' to sex. The New Zealand Bill of Rights Act 1990 (NZBORA) confirms the right to association and freedom from discrimination,⁴⁵ meaning that individuals enjoy the freedom to choose whom they associate with (including the nature of such relationships⁴⁶), and freedom not to be discriminated against by virtue of their age or disability.⁴⁷ On the face of it, these rights could possibly extend to sexual relationships, although this has not been tested.

The NZBORA also affirms that it does not limit any "existing right or freedom."⁴⁸ Therefore, rights existing at common law and international law may be relevant to sexual 'rights'. The International Covenant on Civil and Political Rights requires signatories (including New Zealand) to recognise the right to marry and found a family.⁴⁹ Similarly, the European Convention on Human Rights recognises the right to respect for private and family life, and to marry and found a family.⁵⁰ At international law, these rights have been interpreted as including the freedom to engage in sexual activity "largely free from state interference."⁵¹ However, while New Zealand courts have previously expressed a view that protection of private and family life is an important *value* in New Zealand law,

⁴⁴ Above n 33 at 460.

⁴⁵ Sections 17 and 19.

⁴⁶ Provided they are not for a criminal purpose. See *Kerr v Attorney-General* [1996] DCR 951, at 958.

⁴⁷ Human Rights Act 1993, s 21(1)(h) and (i).

⁴⁸ Section 28.

⁴⁹ International Covenant on Civil and Political Rights, Article 23. Article 17 recognises that "No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence...".

⁵⁰ European Convention on Human Rights, Article 8 and 12.

⁵¹ Richard Griffith and Cassam Tengnah "Assessing Capacity to Consent to Sexual Relations: A Guide For Nurses" (2013) 18(4) BR J Community Nurs. 198.

it is not strictly recognised as a justiciable common law right in itself.⁵² Nevertheless, in the absence of direct consideration of sexual rights in New Zealand, international law may still provide an important basis for any purported ‘right’ to sexual relations.

Another source of rights is the Code of Health and Disability Services Consumers’ Rights (Code of Rights). The Code of Rights applies to the provision of health and disability services, including resthome care. It creates rights to respect, privacy and services that recognise dignity and independence.⁵³ Where a resthome is regarded as a person’s ‘home’, these rights could be interpreted as including the necessary privacy for intimate contact, or at least the opportunity for intimacy, largely free from intrusion. While there is scope for these rights to be relevant to sexual relationships, there are no HDC cases that provide examples of individuals seeking to advocate these rights as including sexual relations.⁵⁴

Whether sexual relations can be translated into a ‘right’ that is deserving of promotion or protection is unclear. However, if it is accepted that sexual relations can be an important aspect of a person’s relationships, wellbeing or way of life, and that such decisions are also intrinsically linked to privacy and independent choice, then it is arguable that sex is a matter that is worthy of careful consideration and possibly protection, even when there are questions about capacity. While the ‘rights’ focus of the PPPRA is intended to facilitate and support the subject person,⁵⁵ it is evident that protection of those with limited capacity is also an important aspect of the PPPRA jurisdiction.⁵⁶ With this in mind, the way in which a person who is perceived to lack capacity might be supported to give valid consent for sexual relations, and whether such decisions can be made on his or her behalf, is explored below.

A Supported Decision-Making

Social supports can influence capacity and assist decision-making, and therefore supported decision-making can offer those with diminished or declining capacity an opportunity to retain some control over their personal choices. Currently, the only

⁵² See for example *Helu v Immigration and Protection Tribunal* [2015] NZSC 28, at [76], [2016] 1 NZLR 298.

⁵³ Health and Disability Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulations 1996, Right 1 and 3.

⁵⁴ The Health and Disability Commissioner may investigate alleged breaches of the Code of Rights and publish opinions as to whether or not a breach has occurred.

⁵⁵ *T-E v B [Contact]* [2009] NZFLR 844 (HC), at [18].

⁵⁶ Above n 31.

statutory model for ‘supported decision-making’ in New Zealand is the requirement under the PPPRA for welfare guardians and those acting under an enduring power of attorney (EPA) to consult with and encourage an incompetent individual to act on their own behalf.⁵⁷ However, those appointed decision-makers also have a responsibility to protect that person’s welfare, and their decision will ultimately override the wishes of the person concerned.⁵⁸ Similarly, in exercising jurisdiction under the PPPRA a court must “enable or encourage” the exercise of capacity, but it can still make decisions in that person’s place.⁵⁹ Thus, these ‘supported decisions’ are simply a precursor to, or relevant consideration for, substituted decisions.

In contrast, in other jurisdictions there are legal frameworks for supported decision-making where there is no corresponding power of substituted decision-making. To illustrate, since 2000 Sweden has had a system of personal ombudsmen, a user controlled service focused on client (not relative or authority) priorities, whereby skilled individuals provide independent support for an incompetent client’s wishes in a variety of matters, including sexuality.⁶⁰ In Canada, supported decision-making has been expressly included in legislation to give “trusted friends and relatives” legal status as “associate decision-makers” to participate in discussions when an impaired adult is making decisions.⁶¹ Decisions are made with the assistance of the associate, but not *by* the associate, and decisions made or communicated with such assistance are binding except to the extent that fraud, misrepresentation or undue influence exist.⁶² Supported decision-making agreements may be entered into if a person understands the nature and the effect of the agreement, which suggests that a person with partial capacity may agree to support for identified types of decisions.⁶³ Those decisions could reasonably include relationships with others.

Closer to home, between 2010-2012 South Australia piloted a non-statutory ‘supported decision-making’ project in which incompetent adults entered support agreements for

⁵⁷ PPPRA, ss 18(4), 98A(3) and 99A(1)(a).

⁵⁸ PPPRA, ss 18(3), 98A(2).

⁵⁹ PPPRA, ss 8(b) and 10.

⁶⁰ Maths Jespersion “The Personal Ombudsman System in Sweden” (Presentation at Ler Seminario Internacional sobre Discapacidad, Salud Mental y Cuidado Facultad de Medicina, Universidad de Chile, Santiago, Chile, 28 March 2015). Note that the personal ombudsman system developed out of psychiatric reforms in 1995, and generally applies to individuals with mental health issues.

⁶¹ Decision Making, Support and Protection to Adults Act 2003 (Yukon, Canada), ss 4 and 8.

⁶² Above n 61, s 11.

⁶³ Above n 61, s 4.

assistance from friends or family for decisions about various life choices.⁶⁴ The project focused on minimising substituted decision-making by using less restrictive ‘support’ options for cognitively impaired individuals. Overall, it demonstrated the viability of supported decision-making, but highlighted the requirement for training and guidance for supporters; the need for monitoring and oversight of support agreements to ensure they work as intended; the lack of legal protection with informal support agreements; and the absence of clarity about the “boundaries and intersections” between supported decision-making and guardianship.⁶⁵

It is unclear whether supported decision-making has been used to assist with decisions about entering sexual relationships. While the Swedish personal ombudsman system has been used to assist with questions about sexuality, it is unclear whether sexuality is used to mean sexual identity and orientation, or sexual relationships, or both. However, the evaluation of the South Australia pilot found that the majority of participants wanted to have support to make decisions about relationships (although not expressly sexual relationships).⁶⁶ Although discussions about sexual relations might be regarded as intrusive or embarrassing, this assumption can be an obstacle to addressing questions of sexual health and wellbeing in the elderly.⁶⁷ In the context of medical care, research shows that older individuals want to be asked about sexual function as a way of providing an opportunity to discuss concerns.⁶⁸ On this basis, with the right supporter in place, a collaborative and companion based supported decision-making process may actually lend itself to decisions about personal matters, including sex. In particular, a trusted supporter could be well placed to discuss the benefits, risks, and relationship(s) in question and the relevant options for reaching a decision.

An amendment to the PPPRA that creates responsibilities and standing for supporters to participate in decision-making processes would provide legal recognition for the

⁶⁴ The pilot was run by the South Australian Office of the Public Advocate through a committee appointed under the Guardianship and Administration Act 1993, which allowed the Public Advocate to set up committees for advice on areas relevant to its functions.

⁶⁵ Mary-Ann De Mestre “Supported Decision Making as an Alternative to Guardianship Orders: The South Australian Trial” (2014) 8 Elder L. Rev. 1, at 3.

⁶⁶ Margaret Wallace *Evaluation of the Supported Decision-Making Project* (South Australian Office of the Public Advocate, Report, November 2012) at 30.

⁶⁷ Sharon Hinchcliff and Merryn Gott “Seeking Medical Help for Sexual Concerns in Mid and Later Life: A Review of the Literature” (2011) 48 Journal of Sex Research 106, at 112.

⁶⁸ Above n 67, at 114.

important role of social relationships to decision-making capacity.⁶⁹ Moreover, a statutory framework could ensure that appropriate and enforceable safeguards were in place. For example, there might be restrictions on who could be appointed;⁷⁰ a requirement to consult with or have a supporter present for specific decisions; express reference to invalidating decisions made under duress; and a complaints process that is accessible to the supported adult and others interested in that person's welfare. The Canadian requirement for supported decisions to be tried or "carefully considered"⁷¹ before guardianship orders are made would emphasise the value of supported decision-making in a hierarchy of decision-making. Such a direction might also provide clarity as to the relationship between supported decision-making and substituted decision-making, and underscore the fact that supported decisions are made and communicated with assistance, but are not the decision of the supporter.

To balance the need for protection, where required, statutory provisions could permit a supporter to use information obtained in his or her role to make an application to the court, either for personal orders or guardianship.⁷² To avoid undermining the voluntarily agreed support relationship, the circumstances in which the court's intervention may be sought could be limited to those where, objectively, the proposed decision places the individual concerned (or others) at risk of harm. This may provide a supported individual with some assurance that it is only where they are reasonably perceived to be at risk that their supporter may seek the court's involvement (and possibly a substituted decision). In this way, supported decision-making could look to uphold autonomy while also questioning capacity and the need for protection.

However, it must be recognised that supporters will have minds of their own: "[i]t seems doubtful that supported decisions can somehow be cleansed of the personality and values of the support person".⁷³ This could have a number of implications, including the possibility that the way in which options and risks around sexual relations are framed may (even unconsciously) be influenced by the supporter's views. This 'undue' influence may

⁶⁹ The Canadian model is worthy of close consideration should this option be pursued in New Zealand.

⁷⁰ See for example Decision Making, Support and Protection to Adults Act 2003 (Yukon, Canada), s 7(b) which expressly excludes a person against whom an order has been made under Family Violence Protection legislation, or who is the subject of an adult protection order under Decision Making, Support and Protection to Adults Act.

⁷¹ Above n 61, s 2(d).

⁷² See for example Decision Making, Support and Protection to Adults Act 2003 (Yukon, Canada), s 10(3)(c).

⁷³ Above n 38, at 86.

override the expressed wishes of the individual. Another issue is that those individuals who are isolated or in conflict with family may have difficulty finding an appropriate support person. Unless advocates or other volunteers are prepared to assist, the model may favour those who already have the support they need for decision-making. Nevertheless, these challenges do not necessarily undermine the support principle. With an appropriate statutory framework, education for individuals and supporters, and legal protections in place, voluntary supported decision-making might offer a person with progressively declining capacity an intermediate step before the possibility of more interventionist substituted decision-making.

B Substituted Decision-Making

Substituted decision-making refers to legally enforceable decisions that are made on behalf of an incompetent adult. Substituted decisions may be made by a welfare guardian appointed under the PPPRA (with respect to a wholly incompetent adult), an EPA appointed by a competent adult (and who has the power to act only when the donor wholly lacks capacity as to personal care and welfare) or by the court exercising powers to make personal orders under the PPPRA.⁷⁴ Substituted decisions may facilitate or override the expressed wishes of the incompetent adult. Except as limited by s 18 PPPRA, a substituted decision made by a welfare guardian or EPA has the same effect as if it was made by the incompetent adult.⁷⁵

Unlike the UK,⁷⁶ substituted decisions to consent to sexual relations are not expressly excluded by the PPPRA. While substituted decisions relating to marriage and civil unions are expressly excluded by s 18(1)(a) PPPRA, these relationships and decisions are not directly analogous with sexual relations for the reasons explained above.⁷⁷ In particular, sexual relations may occur outside of legally recognised relationships. Additionally, it is arguable that sexual relations can reasonably be regarded as a part of a person's living arrangements, about which there is the express power to make substituted decisions by way of personal order.⁷⁸ It is observed that a welfare guardian or EPA with broad or

⁷⁴ The High Court expressly retains its inherent jurisdiction, including *parens patriae*, which may permit it to make orders with respect to incompetent individuals who are unable to make decisions for themselves. See PPPRA, s 114 and Judicature Act 1908, s 17.

⁷⁵ PPPRA, s 19 and s 98(5).

⁷⁶ Mental Capacity Act 2005, s 27(1)(b).

⁷⁷ See p 6, and the comment that marriage is not solely concerned with sexual relations and, unlike most sexual relationships, it involves a potentially long-lasting legal relationship with implications for property and inheritance rights.

⁷⁸ PPPRA, s 10(1)(e).

undefined powers as to personal care and welfare could reasonably be guided as to the scope of their decision-making ability by the range of personal orders available under the PPPRA.

The High Court has held that the phrase ‘living arrangements’ encompasses “...all aspects of the subject person’s environment including where they live, with whom they have contact, and who they are cared by.”⁷⁹ Orders encompassing ‘all living arrangements’ are, therefore, potentially very wide.⁸⁰ The High Court has upheld a personal order that permitted unsupervised contact between an incompetent woman and her mother, on the basis that the order facilitated and promoted her “rights to a full family life.”⁸¹ This is judicial recognition of the right to a family life (at least in the PPPRA jurisdiction), which at international law has been interpreted as including the freedom to enter into sexual relations.⁸² If it is accepted that sexual relations form a relevant aspect of living arrangements, then it is not inconceivable that, on the right facts, substituted decisions could extend to permitting physical contact, or at least not excluding such contact, with a sexual partner in a ‘home’ environment.

Welfare guardians and EPAs considering such questions must have regard to an individual’s best interests:⁸³

The purpose of the best interests test is to consider matters from the [person’s] point of view. That is not to say his wishes must prevail...But insofar as it is possible to ascertain the [person’s] wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being.

Thus, subjective wishes must be ascertained to the extent that that is possible. Welfare guardians and EPAs, who are commonly (but not exclusively) family members, may have

⁷⁹ *T-E v B [Contact]* [2009] NZFLR 844 (HC), at [22].

⁸⁰ Above n 79, at [19].

⁸¹ Above n 79, at [26].

⁸² While this High Court decision predates Supreme Court authority rejecting the existence of a right to a private life and family life in New Zealand (above n 52), it provides some evidence of a common law right to a family life in New Zealand which may become relevant if or when a right to sex is directly examined by New Zealand courts.

⁸³ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, at [45], [2014] 1 All ER 573.

some knowledge of an individual's relationships and pre-incapacity values, behaviour or attitude to sex which can guide an understanding of expressed wishes as to sexual relations. In addition, it is likely that welfare guardians and EPAs would be provided with information from others, including resthome staff and supporters (e.g., if adopted, legally recognised supported decision-makers), as to the risks or benefits of the proposed sexual contact, the relationship with the sexual partner, and the matters discussed with the individual concerned. It is suggested that these contextual factors are not only relevant to questions of capacity, but also to determining the appropriateness of facilitating expressed wishes. It is also suggested that the consultative and encouragement requirements for welfare guardians and EPAs indicate that the law accepts that even wholly incompetent adults should retain some influence over decisions relating to their care and welfare.

There is no obligation to uphold incompetently expressed wishes. Welfare guardians and EPAs also have a responsibility to consider an incompetent person's welfare, which may require taking steps to protect individuals from decisions that place them at risk of harm. While the court's objective is to make the "least restrictive intervention possible,"⁸⁴ it too must be mindful of protecting those whose limited capacity means they are not capable of appreciating risk.⁸⁵ However, it is trite to observe that the overly protective exercise of power, without good cause, may undermine what could be said to be genuine choices in the circumstances. In the face of an expressed wish for sexual relations, which in its particular context presents no objective or reported risk to the individual, there is theoretically no reason why a substituted decision could not be accepted as valid consent.

Whether this 'third party consent' to sexual relations would satisfy the criminal law, and in particular the provisions intended to protect impaired persons from sexual activity which they are deemed incapable to consent or refuse consent to, remains to be seen.⁸⁶ However, it is relevant that a substituted decision has the same legal effect as it would have if it had been made by the person concerned,⁸⁷ and that a court order can provide legally effective 'consent' in circumstances that would otherwise be an assault (e.g. medical treatment). As such, it is arguable that a substituted decision to facilitate the desire of the subject person does not permit non-consensual sex but, instead, confirms consent on behalf of an otherwise incompetent adult.

⁸⁴ PPPRA, s 8(a).

⁸⁵ Above n 31.

⁸⁶ Crimes Act 1961, s 128A(5).

⁸⁷ PPPRA, s 19 and s 98(5).

Substituted decisions about sexual relations may, however, be problematic for other reasons. For the decision-maker, any uncertainty whatsoever as to the appropriateness of facilitating sexual relations will inevitably (and perhaps properly) err on the side of protection. The implications of a decision to refuse sexual contact could lead to practical enforcement difficulties, whether managing the expectations of the person whose wishes have been overruled or physically policing and preventing sexual contact. This could result in intrusive management strategies for resthomes rightly concerned about the risk of criminal liability.⁸⁸ For the person concerned, substituted decision-making carries the risk that they become subject to the moral judgements of others. What the decision-maker considers acceptable could be informed by unfair or incorrect perceptions that the elderly are “asexual and disinterested in sex or hypersexual to the point of perversion”.⁸⁹ This risk may be particularly stark where a person’s pre-incapacity relationships and values are unknown or not fully taken into account.

The latter emphasises the value of conversations about sexual relations taking place prior to incapacity. It is the apparent lack of focus on such conversations that is central to the argument that more can and should be done to address the question of incapacity and sexual relations in the elderly.

VI What More Can or Should be Done?

As people age they tend to make decisions that are focused on the end of their life, such as making a will or even making prospective decisions about medical treatment relevant to the end of life. However, it is much less clear whether many (if any) people consider how they might want to *live* in the event of incapacity, or the importance to them of intimate or sexual relationships in those circumstances. For some, this may be because the topic is taboo. For others, the implications of incapacity and sex are unknown or not regarded as sufficiently important to discuss or plan for. For most, it is suggested, this is a topic that is simply not raised with them, even when they enter resthome care, possibly for fear of causing offence or embarrassment.

The risks of failing to address such questions in the resthome context is illustrated by the case of a 78 year old US man charged with, and later acquitted of, sexually abusing his

⁸⁸ Crimes Act 1961, s 195A.

⁸⁹ Above n 33, at 458.

wife who suffered from alzheimers and lived in a resthome.⁹⁰ The husband’s prosecution served as a “wakeup call” for resthomes to be explicit with patients and families about sex.⁹¹ This message is equally applicable to New Zealand resthomes, and it is recommended below that industry agreed guidelines about sexual relationships should be developed. The “wakeup call” also highlights the need for older adults planning for their later years to consider ways in which others can be made aware of all aspects of their life that are important to them, including relationships with others. In this respect, an advance directive is one tool worthy of further consideration.

A Advance Directives

An advance directive is a mechanism to express competent wishes prior to incapacity. The Code of Rights affirms the ability to make an advance directive, whether in writing or orally, about possible future health care procedures.⁹² Significantly, a valid advance directive can provide lawful justification not to provide life-saving treatment where such treatment has been anticipated and expressly refused by the (now) incompetent person. This is consistent with every competent adult’s right to refuse medical treatment.⁹³ While advance directives are commonly seen and used in medical treatment, there is no logical basis why a form of advance directive could not be used to express competent wishes about any decision that may arise in the event of incapacity. In this regard, it is relevant that advance directives are considered a “natural extension” to the principles of autonomy and respect for autonomy.⁹⁴

A number of factors are applicable to the validity of an advance directive, including the circumstances in which it is made and when it is made; that is, an advance directive will become ‘stale’ with age and changing circumstances. Advance directives also have limitations. Clearly, an oral advance directive will lack force unless it is given widely and frequently. Even if the advance directive is in writing, there is no central repository for

⁹⁰ “Former Iowa legislator Henry Royhons, 78, found not guilty of sexually abusing wife with alzheimers” (23 April 2015) The Washington Post < www.washingtonpost.com/news/morning-mix/wp/2015/04/23/former-iowa-legislator-henry-rayhons-78-found-not-guilty-of-sexually-abusing-wife-with-alzheimers> accessed 24 February 2016.

⁹¹ “Rayhons: ‘truth finally came out’ with not guilty verdict” (22 April 2015) The Des Moines Register <www.desmoinesregister.com/story/news/crime-and-courts/2015/04/22/henry-rayhons-acquitted-sexual-abuse> accessed 24 February 2016.

⁹² Code of Health and Disability Services Consumers’ Rights, clause 4.

⁹³ New Zealand Bill of Rights Act 1990, s 11.

⁹⁴ Iris Reuvecamp “Advancing Individual Autonomy in Healthcare Decision Making – the Role of Advance Directives” [2015] NZLJ 79.

such directives, and therefore unless its existence (and location) is made known prior to incapacity it may never be taken into account. These are factors that require careful inquiry, particularly when someone enters resthome care.

Another key limitation is that while an advance directive purports to give legal force to anticipatory decisions, stated preferences are unlikely to override obligations to protect a vulnerable adult. In particular, if the context demonstrates vulnerability and the need for protection that will very likely take priority over a previously expressed preference for sexual contact. In light of this, it seems unlikely that an advance directive could give valid consent to sexual relations at some future point in time. That said, there is still value in a competent adult providing written guidance on future decisions affecting the way they would like to live if incapacitated. It is relevant that an EPA (and probably others) may have regard to an advance directive when making substituted decisions.⁹⁵ Importantly, it is arguable that competently expressed wishes as to sexual relations, or competent assertions relevant to sexual values and wellbeing, may be more influential than a later, incompetent, expression of wishes. For example, a (written) statement could helpfully record the existence of a longstanding, close and loving relationship, and the desire to continue with intimate contact following incapacity. It could include reference to mutually acceptable sexual contact, or requests for overnight stays and/or a double bed. Equally, it could simply record that physical relationships and/or intimacy are important to that person's wellbeing or identity. In this way, an advance directive could be a valuable source of information for others about pre-incapacity preferences.

One possible issue that might impact on the use of advance directives for the purposes described here is that the term may be associated with prospective decisions about dying. This is inconsistent with the intended focus, which is to encourage prospective consideration of decisions about living. It is suggested that older adults may be more inclined to record their wishes as "living choices" or a "values history",⁹⁶ and it is recommended that this positive language is adopted to promote the importance of documenting personal choices.

⁹⁵ PPPRA, s 99A(2).

⁹⁶ The term "values history" is taken from Inés Maria Barrio-Cantalejo, Adoración Molina-Ruiz, Pablo Simón-Lorda, Carmen Cámara-Medina, Isabel Toral López, Maria del Mar Rodríguez del Águila and Rosa Maria Bailón-Gómez "Advance Directives and Proxies' Predictions About Patients' Treatment Preferences" (2009) 16 Nursing Ethics 93.

B Guidance for Resthomes

Resthomes will undoubtedly encounter individuals with differing levels of capacity and risk factors. Some individuals entering resthome care may have a reduced physical ability to care for themselves, but are competent to make decisions about all aspects of their life. Others may have fluctuating capacity, in that they are able to make decisions about day-to-day personal choices but might not have capacity to make significant decisions, for example to sell property. Some residents will be admitted to resthome care with a welfare guardian or EPA in place to make substituted decisions on their behalf, in consultation with them, whereas others may be admitted to a resthome due to a total loss of capacity with no formal decision-making mechanism in place. Whether capacity is present, questionable, or absent, resthomes have a responsibility to manage the wellbeing of their residents.

There are currently no national or industry-wide agreed standards for managing questions about sexual relations in resthomes. In the absence of such standards, the onus rests on individual resthomes to ensure residents receive services that meet individual needs. While research suggests that sex and intimacy can remain important even for incapacitated elderly, “few care facilities have implemented policies or [staff] training” directed at sexual expression.⁹⁷ In the absence of policies, management strategies and staff training, it is arguable that resthomes might not be meeting residents’ individual needs.

The first opportunity to ensure that decisions accord with residents’ needs is on admission. It is suggested that resthomes need to be skilled and proactive to include discussion about sexual relationships as part of the admission process, perhaps as part of recording a person’s “living choices” or advance directive. This will be particularly important where the resident has capacity or partial capacity on admission, as this could represent the best chance to understand their needs before any significant incapacity occurs. The admission process might, for example, include questions about whether the resident has any close relationships, whether he or she is sexually active, and whether they wish to continue with sexual activity. The resident should have a choice about whether or not to answer, although it would be helpful to explain that their expressed wishes could become relevant in the event of incapacity.

⁹⁷ Laci Cornelison and Gayle Doll “Management of Sexual Expression in Long-Term Care” (2013) 53 Gerontologist 780.

Admission is, however, just a starting point. An ongoing process of evaluating the appropriateness of sexual relations is relevant to discharging resthomes' obligations to protect individuals from harm. Given the potential legal significance for resthomes and individuals, industry-wide agreed guidelines addressing sexual relations are recommended. Any such guidelines should be drafted in consultation with other relevant agencies, including the HDC and organisations with an interest in ageing and the rights of older people. The HDC could provide input into the applicability of the Code of Rights, and the views of the elderly could be an effective counterbalance to what might be an overly protective starting point by resthomes.

While it is accepted that resthomes need to balance individual freedom alongside their protective responsibilities, it is suggested that the guidelines should start with a presumption of competence. Staff (and family) should be reminded not to make assumptions about incapacity on the basis of the level of support that a person needs in other aspects of day-to-day life, and to take a non-judgemental approach to proposed sexual activity. Likewise, guidelines should ensure that staff are alive to the possibility that family or carers may try to influence residents not to have sexual relations, even if there is no basis for the objection. Guidelines should encourage ongoing discussion with residents about sexual relationships, including, where relevant, asking those residents who are known to be sexually active how they feel about their relationship. Similarly, guidelines should advise staff to watch for changes in behaviour after intimate contact, and to record and discuss with senior staff any incidents of concern or unusual behaviour relevant to sexual activity.

It is anticipated that guidelines would be most useful, and perhaps most instructive, where competence is questionable and the appropriate management response to the sexual contact is uncertain. In those circumstances, guidelines should require consideration of factors that could affect capacity (e.g. a diagnosis of dementia, and the stage of the disease); discussion about the resident's understanding of the functional aspects and consequences of sexual activity and their views of the relationship in question; any non-verbal cues indicating consent, and any previously expressed wishes; what, if any, support structures or persons are used by the resident, and seeking that support where appropriate; the circumstances in which any capacity assessment takes place (including any factors that could temporarily affect capacity); and any other relevant persons to consult about the genuineness of the person's choice. The guidelines could suggest specific questions to assist with determining a person's level of understanding. For example, one New York

resthome asks its staff to “pose questions like...‘what would you do if you wanted it to stop?’”.⁹⁸ Appropriately framed questions could provide practical assistance for staff.

Any guidelines should also expressly address possible signs of vulnerability, exploitation or sexual assault in recognition that incapacity may make elderly people at risk of sexual abuse. In addition to assessing any changes in mood (before or after sexual contact), guidelines might require staff to be vigilant for any signs of inappropriate pressure for sex; any indications of disinhibited sexual behaviour; and to take seriously any reports of sexually inappropriate behaviour. Staff should also be mindful that duress can vitiate consent, and guidelines could suggest circumstances in which it will be appropriate for discussions to take place without the sexual partner present. Finally, guidelines could provide direction on when intervention might be necessary and practical management tools to prevent sexual contact in the event of incapacity.

VII Conclusion

While incapacity may make an older person susceptible to sexual abuse or exploitation, diminished capacity does not always equate to vulnerability that should automatically exclude individuals from sexual relations. In some cases, older adults with impaired capacity may retain the ability to make genuine choices about sexual relations, and those relationships may be important to maintaining their overall health and wellbeing. It is argued that context, including relationships with others, can influence capacity. Therefore, to respect autonomy, those raising questions about capacity for sexual relations should be required to consider the whole context in which the (proposed) sexual relations arise, and the context in which capacity assessments take place.

Where capacity is in question, supported decision-making and substituted decision-making are advocated as effective options to support or facilitate legally valid decisions about sexual relations. Importantly, both options can allow for concerned others to question the genuineness of choice, to assess risk and vulnerability in the circumstances, and to seek protection where objectively necessary. Advance directives, or “living choices” are encouraged as a tool for individuals to ensure that their pre-incapacity values, relationships and preferences are known to others.

⁹⁸ “Sex, Dementia and a Husband on Trial at Age 78” (13 April 2015) The New York Times <www.nytimes.com/2015/04/14/health/sex-dementia-and-a-husband-henry-rayhons-on-trial-at-age-78> accessed 22 February 2016.

Finally, while resthomes seem to recognise the complexities that can arise with sexual relations in the resthome setting, there has been no industry agreed response as to how this should be managed. However, resthomes legal and professional obligations should be sufficient motivation for them to adopt a proactive approach to discussing this topic with residents (and intended residents), and for the development and implementation of guidelines on managing sexual relations. Guidelines would be a helpful, open and transparent response to the issues that can arise, and is one way to ensure that an effective balance is struck between individual autonomy and carers' responsibilities.

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