Health and Social Care

# Relationships, Sexuality and Dementia

# Operational Guidance

AUGUST 2020

Final Version

## Glossary of Terms

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| BHSCT | Belfast Health and Social Care Trust |
| CQC | Care Quality Commission |
| DBS | Disclosure and Barring Service |
| DHSSPS | Department of Health, Social Services and Public Safety |
| DOH | Department of Health |
| GUM | Genito-Urinary Medicine |
| HIV | Human Immuno-Deficiency Virus |
| HSC | Health and Social Care |
| HSCB | Health and Social Care Board |
| HSCT | Health and Social Care Trust |
| LGBT+ | Lesbian, Gay, Bisexual and Transgender (and others) |
| HCPC | Health and Care Professions Council |
| NHSCT | Northern Health and Social Care Trust |
| NIASP | Northern Ireland Adult Safeguarding Partnership |
| NISCC | Northern Ireland Social Care Council |
| PHA | Public Health Agency |
| RCN | Royal College of Nursing |
| RQIA | Regulation and Quality Improvement Authority |
| SCIE | Social Care Institute for Excellence |
| SEHSCT | South Eastern Health and Social Care Trust |
| SHSCT | Southern Health and Social Care Trust |
| STI | Sexually Transmitted Infection |

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# Introduction

Caring for a person with a dementia, their partners, carers and families is becoming one of the growing challenges to our health and social care system. As the proportion of older people in the population increases, the implications for individuals, families and wider society are substantial economically, logistically, socially and emotionally.

Technological and other advances in health and social care have resulted in people being able to live longer and healthier lives and this is to be welcomed however, this has also meant an increase in the prevalence of non-communicable diseases such as dementia.

As our knowledge of dementia and our understanding of need increases, services to people with a dementia, their partners, families and carers have been progressively developed across the health and social care sector.

However, one aspect of life which has received little attention has been in relation to the sexual behaviour and needs of people with a dementia and their partners.

Research into the sexual behaviour of older people generally and people with a dementia (or other illnesses) has until relatively recently been a much neglected area. Reasons for this apparent lack of interest may be due to the discomfort felt in discussing intimate personal issues (including those with dementia, their partners and professionals) and societal bias which values youth, beauty and productiveness.

As a result, the level of knowledge that care staff have about this subject and their ability / confidence to support individuals is limited and they are increasingly finding themselves in situations where they feel ill equipped to respond.

The onset of progressive cognitive decline does not necessarily indicate an end to sexual need however, the changes brought about by dementia can lead to social, emotional and behavioural challenges including ethical, consensual and safeguarding issues. These issues need to be addressed if people with dementia and their partners are to be enabled to experience emotionally fulfilled and safe lives.

Our sexuality and the expression of that sexuality is an integral part of our daily living experience. We all need to feel loved and this is no less true for people with a dementia. The feeling of being loved and being able to express sexuality in a safe and rewarding way contributes to an individual's overall sense of self-worth and well-being.

Developing or maintaining a sexual relationship can be an enriching experience and it is important to remember that a person with a dementia has the same rights and needs as anyone else.

This Guidance starts from the premise that everyone has the right to live fulfilled and meaningful lives, free from abuse or exploitation and that this includes the right of people with a dementia to express their sexuality in a safe and non-judgemental way.

To support learning and provide practical support to staff, this Guidance includes a number of case studies (stories), all of which have been adapted from research and other literary sources (original sources are referenced in the text) or from case examples which staff themselves have been involved in.

Each story has a section entitled ‘Discussion / Learning Points’ which include statements and / or questions which should be used to facilitate reflective practice and understanding about the issues and promote learning.

**NB: The term ‘Dementia Specialist’ is used as a generic term in some of the case studies to describe the professional staff member from the Dementia Services Team (Consultant, Nurse, Social Worker, AHP, Psychologist etc) who has the appropriate level of expertise (suitably qualified and competent) and relevant authority to act in a particular capacity.**

# 1. Summary of guidance

HSC Trusts affirm the right of people living with a dementia to practise and enjoy personal and sexual relationships, if that is their choice. This Guidance has been produced to ensure that this right is upheld and to support those who work with people with a dementia, their partners, carers and families in upholding it.

This Guidance has been developed in response to a recognised need by staff working within dementia care and has been informed in its development by a similar initiative undertaken by the HSCB, PHA and HSC Trusts in relation to personal and sexual relationships of adults with a learning disability (HSCB / PHA / HSC Trusts, March 2016)

Since the prevalence of dementia is high among people with a learning disability, particularly among those with Down's Syndrome, both documents should be read in tandem.

Dealing with relationships and sexuality can be complex and challenging both professionally and emotionally as the carer seeks to balance rights, manage expectations and responsibilities and ensure that all parties are protected. There are no absolute right or wrong answers.

This Guidance cannot predict all of the issues that might arise for staff. However, it provides a framework within which staff can operate in a legal, ethical and professional manner. It provides a context for decision making that places particular focus on the human rights of individuals with a dementia, their partners, carers and families.

HSC Trusts will implement this Guidance within dementia care services in a way that enables people to have meaningful and fulfilled relationships while protecting them from exploitation or abuse.

## 1.1 Aims of this Guidance

This Guidance aims to:

- Ensure the rights of people with a dementia and their partners are upheld so that they can engage in personal and sexual relationships, if they so wish.
- Provide information about personal and sexual relationships for staff working with people with a dementia, their partners, carers and families.
- Offer practical guidelines to staff.
- Promote best practice within dementia care services.
- Support people with a dementia, their partners, carers and families to deal with and talk about sexual matters in a safe and supportive context.

- Support the maintenance of relationships or the development of new relationships as appropriate.
- Ensure that the privacy of the person with a dementia and their partner is respected.
- Provide information, education and support to people with a dementia, their carers, partners and families as appropriate.
- Promote a consistent and considered approach.
- Safeguard people with a dementia, their partners, carers, families and others from risk of harm or exploitation.

**NB: This Guidance is being developed to support staff to deliver a more person-centred service to people with a dementia, their partners, carers and families. It is important therefore that staff feel confident to address the issue of relationships and sexuality in a supportive and timely manner.**

**NB: Helping people come to terms with the changes that dementia can bring about in behaviour, understanding and sensitivity, sexual activity and moods, means that the conversation needs to begin at time of diagnosis and continue throughout the dementia journey.**

### 1.2 Strategic and Legal Context

The rationale for this Guidance includes the following:

**Improving Dementia Services in NI - A Regional Strategy (2011):** which seeks to improve the services and support arrangements currently available to people with a dementia, their carers, partners and families

**Human Rights Act 1998:** in particular Article 8 which includes the right to respect for privacy and family life, Article 10 which relates to freedom of expression and Article 12 in respect of rights to marry and have a family.

**Disability Discrimination Act (1995) (amended 2005):** which works alongside the Human Rights Act for the purpose of ensuring that persons with disabilities are valued and treated as equal citizens. The amendment of the Act in 2005, places a duty on public authorities to promote disability equality.

**Section 75 of the Northern Ireland Act 1998:** which places a duty on public bodies to promote equality of opportunity amongst nine equality categories. It is important to recognise an individual’s potential membership of any of the categories.

**UN Convention on the Rights of Persons with Disabilities:** which seeks to eliminate discrimination relating to marriage, family and personal relations.

**Mental Capacity Act 2016:** this legislation, which partially came into effect on 2nd December 2019 (in relation to Deprivation of Liberty Standards - DoLs) provides a single legislative framework to deal with all persons aged 16 and over on the basis of their capacity to make a decision in relation to their care, treatment and personal

welfare. The key principle behind the act is to support personal autonomy and self-determination, creating a legal requirement to support a person to exercise their capacity where they can. It also sets out in statute that it must be established that a person lacks capacity before a decision can be taken on their behalf, and that a lack of capacity cannot be assumed due to the person's underlying condition. If it is established that a person lacks capacity to make a specific decision at a particular time, the Act puts in place a new, alternative decision-making regime that provides important additional safeguards for the person who lacks capacity.

The Act will also require all those acting in a professional capacity, for remuneration, in relation to the care, treatment or personal welfare of a person over 16 who lacks capacity to have due regard to the associated Mental Capacity Act (NI) Codes of Practice which may be directly relevant to the issue.

**Mental Health (Northern Ireland) Order 1986:** provides a framework for the care, treatment and protection of all persons with a mental disorder and establishes systems through which the statutory rights of individuals and their relatives are protected and the duties, responsibilities and powers of professionals regulated.

**NB: All staff need to be aware of the Mental Capacity Act (NI) 2016 which partially came into effect on 2nd December 2019 in relation to Deprivation of Liberty Safeguards (DoLs). Staff need to be aware of the current Common Law position and the Mental Health (Northern Ireland) Order 1986. Staff should also be aware of any relevant Codes of Practice which accompany the Mental Capacity Act (NI) 2016**

**NB: As part of the review procedures for this Guidance, Trusts will have regard to the status of the Mental Capacity Act (NI) 2016 and amend the Guidance accordingly (see Section 1.9 below). All staff should be advised of the amendments and their duties under any change to the legal position.**

**Safeguarding Policy, Guidance and Legislation:**

**The Safeguarding Vulnerable Groups (NI) Order as amended by the Protection of Freedoms Act (2012):** outlines the safeguarding requirements when organisations are recruiting staff and volunteers to certain positions which involve contact with adults at risk. The Order makes it an offence for employers to knowingly recruit barred individuals into 'regulated activity' with adults. Organisations must also refer to the Disclosure and Barring Service (DBS) any individual who has harmed, or poses a risk of harm to adults, and who has been permanently removed (or would have been had they not left the organisation) from regulated activity.

**Adult Safeguarding: Regional and Local Partnership Arrangements (2010):** provides regional guidance on the establishment of new adult safeguarding arrangements. http://www.hscboard.hscni.net/download/PUBLICATIONS/safeguard-vulnerable-adults/niasp-publications/Adult-Safeguarding-in-Northern-Ireland-Regional-and-Local-Partnership-Arrangements-March-2010.pdf

**Adult Safeguarding in Northern Ireland: Prevention and Protection in Partnership (2015):** jointly developed by the Department of Health

and Department of Justice the regional policy sets out how the Northern Ireland Executive intends adult safeguarding to be taken forward across all Government Departments, their agencies, and in partnership with voluntary, community, independent and faith organisations.

### 1.3 Who does this Guidance apply to?

Increasingly, health and social care staff report challenges in dealing with the expression of sexuality and relationships in dementia care.

This Guidance has been developed to provide support / information for staff in all disciplines working within Health and Social Care Trusts. It is intended to improve understanding, support learning and encourage discussion and reflective practice. It also provides signposts to further reading and training opportunities which will equip staff to provide a more person-centred care and support service to people with a dementia, their partners, carers and families.

The Guidance may require some revision / adaptation if it is to be used by staff working with people with a dementia in other non-Trust settings e.g. Independent Care Homes, Domiciliary or Day Care Services, Supported Housing, Police or Prison Service.

In upholding and implementing the Guidance, all staff should give due consideration to relevant legislation and operational policies. Relevant legislation and operational policies are listed in **Appendix 1**

**NB: All staff working within HSC Trusts are expected to promote and comply with this Guidance.**

### 1.4 How will HSC Trusts support the application of this Guidance?

Trusts will:

- Support staff to implement the Guidance through induction, supervision and training.
- Ensure that the Guidance reaches all areas of the service, at all levels including those providers of service that are contracted by the Trusts.
- Provide opportunities for staff training and development (enhance knowledge and promote best practice) that enables them to fulfil their responsibilities in relation to the Guidance, monitor the effectiveness of the Guidance at regular intervals.
- Regularly review the Guidance to ensure that it remains relevant in terms of both legal requirements and best practice standards.
- Provide training to staff and undertake regular evaluations of that training to ensure that staff are competent to undertake their responsibilities in relation to the care, treatment and support of people with a dementia, their partners, carers and families.

To support people with a dementia, their partners, carers and families, Trusts will:

- Provide training programmes for people with a dementia, their partners, carers and families that includes advice on sexual health and relationships.
- Consider the development and dissemination of a shorter version of this Guidance or an Information Leaflet for persons with a dementia, their partners, carers and families.
- Consider the development of a Flow Chart to make the learning from this Guidance more accessible and enable staff to navigate complicated decision making processes.

### 1.5 Terminology used in this Guidance

In this Guidance we refer to behaviour which may be regarded as 'inappropriate' to some people however, it is important to understand that whether behaviour is inappropriate or not depends on the context, time, person and place.

We also refer to 'partnerships' but acknowledge that there are many people who are single and for whom sex is important but not with a steady partner or indeed one partner.

In this Guidance reference to 'sexuality and relationships' applies to everyone regardless of their gender or sexual orientation

### 1.6 Personal and Public Involvement / Consultation Process

This Guidance has been developed with the co-operation of staff from the five Health and Social Care Trusts (Dementia Services), staff from Trust's Learning Disability Services who developed a similar Guidance (HSCB / PHA / HSC Trusts March 2016) and Trust / PHA Sexual Health Specialists. Support and advice was also provided by DoH (Capacity Legislation and Guidance), Trust Leads for Safeguarding, Elder Abuse UK, Academics, Legal Services, RQIA, NISCC, HCPC, RCN and the voluntary sector (Dementia NI and Alzheimer's Society) whose staff consulted with people with a dementia, their partners, carers and families.

### 1.7 Equality and Human Rights

This Guidance has been drawn up and reviewed in the light of Section 75 of the Northern Ireland Act (1998) which requires the Trust to have due regard to the need to promote equality of opportunity. It has been screened to identify any adverse impact on the nine equality categories and no significant differential impacts were identified, therefore, an Equality Impact Assessment is not required.

### 1.8 Alternative Formats

This document can be made available on request on disc, larger font, Braille, audio-cassette and in other minority languages to meet the needs of those who are not fluent in English.

### 1.9 Review of this Guidance

This Guidance **will** be reviewed and updated by Trusts every three years from initial implementation **and** following commencement of the Mental Capacity Act (NI) 2016 and the publication of any associated Codes of Practice (as may be relevant to the issue).

Any review should reflect the views and opinions of people with a dementia, their partners, carers and families and have regard to:

- Emerging best practice based on research evidence
- Legislation, Policies and Procedures, Departmental Directives
- Equality and Good Relations / Disability Duties / Human Rights

The review should include the collection and analysis of data in respect of the following:

- Equality and Good Relations
- Disability Duties
- Human Rights

The Equality Screening Document in respect of the Relationships, Sexuality and Dementia Guidance has now been published on the HSC Business Services Organisation website and can be accessed via the link below:

http://www.hscbusiness.hscni.net/services/3091.htm

# 2. Principles / Values

This Guidance has been developed primarily to assist staff in undertaking their responsibilities of supporting and enabling people with a dementia, their partners, carers and families to deal with issues and concerns around sexuality and relationships.

At the core of this Guidance are the values that a person living with a dementia, their partners, carers and families have the right to be treated with dignity and respect; have their human rights upheld, their privacy respected and independence promoted. They also have a right to be involved in decision making about issues affecting their lives and to receive safe care and treatment from staff who are suitably qualified and competent to undertake their roles.

The values and principles underpinning this Guidance are:

**Equal Rights:** people with a dementia, their partners, carers and families should have the same rights and opportunities as any other citizen to live fulfilled lives, to be treated with dignity and respect and to be protected from any form of exploitation or abuse.

**Citizenship:** the right to personal relationships is enshrined in Human Rights legislation. Meaningful relationships are a fundamental component of health and social wellbeing.

**Social Inclusion:** people with a dementia will be supported to access social and leisure opportunities where friendships may be developed.

**Empowerment:** people with a dementia, their carers, partners and families will be supported to appreciate the rights, risks and responsibilities involved in personal relationships.

**Partnerships:** staff will work in partnership with people with a dementia, their partners, carers, families and others to ensure that all parties receive the best possible care, information and support in regard to sexual needs and expression, relationships and dementia care.

**Dignity and Respect:** the uniqueness and intrinsic value of individuals is acknowledged and each person is treated with respect and their dignity protected.

**Independence:** people have as much control as possible over their lives whilst being protected against unreasonable risks.

**Diversity:** people are treated equally and their backgrounds, gender identity, sexual orientation and cultures are valued. All HSC services provided, fit within a framework of equal opportunities and anti-oppressive practice.

**Choice:** people are entitled to make choices about how they live their lives and to do so in a way that is both legal and safe. Choices should be based on clear, accessible and accurate information.
**Fulfilment:** people are enabled to lead full and purposeful lives, and to realise their ability and potential.

**Safety:** people feel safe in all aspects of their care and can expect that every service will employ a zero tolerance of abuse, neglect, exploitation and harm and work to the highest standards of safeguarding practice.

**Privacy:** people have the right to be left alone, undisturbed and free from unnecessary intrusion into their affairs and there is a balance between the considerations of the individual's own and others' safety.

**Confidentiality:** people know that information about them is managed appropriately and will only be disclosed to others when this is in the interests of their welfare. Everyone involved in the service respects confidential matters.

# 3. Dementia, the brain and sexuality

### 3.1 What is Dementia?

Dementia is a common syndrome (a group of related symptoms) associated with an ongoing decline of the brain and its abilities. Dementia can affect anyone, but the risk of developing a dementia increases with age. The condition usually occurs in people over the age of 65 but is not unknown in persons much younger.

The most common causes of dementia include conditions where the brain cells degenerate and die more quickly than they would through the normal ageing process. This damage leads to a decline in a person's mental and, sometimes, physical abilities.

In dementia, the brain becomes more damaged and works less well over time and the symptoms tend to change and become more severe. The speed with which symptoms get worse and the way that symptoms develop, depends on what is causing the dementia as well as the overall health of the individual. This means that the symptoms and experience of a dementia can vary greatly from person to person.

People with a dementia can become apathetic or uninterested in their usual activities. They may have problems controlling their emotions or find social situations challenging. Their personality may change, they may lose empathy (understanding and compassion) and may see or hear things that other people do not (hallucinations).

As the dementia progresses, the individual will find planning and organising difficult. Maintaining their independence may become a problem and they will need help from friends or relatives for activities of daily living including decision making.

### 3.2 The Brain

The brain is a very complex organ and is responsible for all tasks in our daily lives, not just memory.

The brain is our body's control centre, it regulates all of our bodily functions including hunger, thirst, temperature, sex drive, movement, language, attention and social skills to name but a few.

Dementia is a condition that results from changes or damage to the brain and can affect how the brain works in many different ways.

### 3.3 Changes in Behaviour

Sometimes a person with a dementia will behave in a way that is out of character or socially inappropriate. This is because the changes in their brain make it difficult for them to make sense of a situation in the same way that other people see it. The person may get things mixed up and behave in a way that seems strange to those around them.

Sometimes the person with a dementia may behave in a way that is interpreted as sexual e.g. a person may feel too warm and may start to take off their clothes to cool down.

If dementia has impaired the individual's ability to judge what they can do in public or in private, they may undress in a communal area which appears acceptable to them but others will regard as inappropriate.

Changes to the brain can mean an increase or a decrease in the person's need for affection. The person will experience these changing needs but may lose the ability to judge / understand appropriate ways to meet this need. They might mistake somebody else for their partner or might not recognise their partner. They may also do things in public which they may have once done in private such as masturbation.

A person with dementia may get people, places and things that are happening mixed up. This can lead to confusion resulting in a response that may not be appropriate for a given situation. For example, a person may mistake receiving help with washing or dressing as a sexual advance and may respond with fear, anxiety, with a kiss, fondle or comment.

It is important to remember that all these behaviours are due to changes in the brain.

### 3.4 Finding out more about Dementia

To find out more about different types of dementia, symptoms and stages, prevalence rates, common signs and the impact of the condition on the individual, their partner, carers and families, please refer to **Appendix 2** of this document.

**Appendix 3** of this document also provides contact details for sources of information and support.

# 4. Care in communal settings including hospitals

Many people with a dementia live in care homes or supported living facilities. They may attend day care or need to spend time in hospital.

Expressing one's sexuality in communal settings can be difficult due to the lack of privacy and understanding. It can also be difficult when the person with a dementia is confused about time, place and people. This can present as a challenge to staff.

## Case Study 1

**Graham's Story (Dementia Assessment Unit)**

Graham has a diagnosis of mixed dementia. He is 89 years old and lives in a Residential Care Home. He has experienced many changes in his life over the past six months but he has good support from his daughter Sarah who visits him daily.

Due to a change in Graham's presentation which included sexualised behaviour and language towards female staff and other residents, the Care Home manager expressed concern about maintaining Graham's placement and the risk to female residents. Graham's key worker in the Dementia Specialist Team was contacted to carry out a review of his placement.

Staff reported that the behaviour occurred during personal care and in communal areas. Graham had walked out of the toilet naked, and come out of his room at night naked. These behaviours were not a daily occurrence but had become more frequent, up to five incidents in one day on one occasion. The Home Manager was concerned for other residents and some relatives had also complained.

Staff from the Dementia Specialist Team consulted with Home Manager and Sarah, who reported similar incidents in other Care Homes during periods of respite and agreed that Graham should be admitted to the Dementia Inpatient Unit for a period of assessment.

The Dementia Inpatient Unit adopted a holistic (physical, psychological and social) approach to assessing Graham's well-being and behaviour. Investigations were carried out to rule out any physical cause for his current presentation. His bloods and urine was tested to find out if any infection was present. There was evidence of a chest infection.

Graham also has a history of constipation, which has occurred more frequently since his admission to the Care Home. It was agreed to prescribe a laxative and to monitor bowel movements.

Staff used the CLEAR Dementia Care© methodology to monitor behaviour and identify frequency and possible triggers to his disinhibited sexual behaviour.  This information was monitored and all incidents of sexualised behaviours recorded.

Graham needed increased assistance with personal care and support due to the progression of his dementia therefore intervention from staff was more frequent. It was evident that this was a trigger for sexualised behaviour towards staff. Graham's insight into his behaviours was also explored. He had good verbal communication skills and he could recall some of the incidents of disinhibited behaviour with much embarrassment. He apologised to staff for his behaviours. This suggested that he was experiencing impulsivity which he struggled to control at times of infection because of his dementia. This was explained to him and he was reassured that staff were there to help and that he shouldn't feel embarrassed. The Dementia Inpatient Unit has signed up to Johns Campaign so that family members can visit at any time, especially when their loved one needs them most. Family visits and engagement are crucial to provide reassurance and support while someone is in hospital.

The outcome of the assessment was shared with Care Home staff when planning Grahams discharge from hospital.

**Physical**

It is not always obvious when Graham has an infection and it may be days before symptoms appear. Staff were advised to observe for (i) increased sleep, (ii) wheeziness and (iii) sexually disinhibited behaviours as possible signs of chest infection. Staff agreed to monitor his physical health at each stage. Early intervention and liaison with the GP to treat infection should help improve his physical well-being and reduce risk and frequency of sexually disinhibited behaviours.

As Graham's verbal skills remain intact, he is encouraged to self-report bowel movement. If he recalls some of his sexually disinhibited behaviours staff should reassure him that he is safe, they should explain how behaviours are linked to infection and possibly constipation and that he should not feel embarrassed.

**Social / Psychological**

Graham may misinterpret personal care intentions and staff should consider how their engagement (physical and verbal) with Graham at these times may be construed e.g. holding his hand while escorting him to his bedroom or bathroom or telling him that they are going to '*take off his clothes*' may give him the wrong impression.

In order to ensure that Graham and others are protected, it is important for staff to give Graham a clear explanation of what they are doing and why.

Allow family to visit to provide reassurance and support particularly at times when Graham may have an infection or is feeling unwell.

**Consistency**

It is also important that staff are consistent in their approach e.g. remain calm and remind Graham that they are members of staff and that the behaviour makes them or other people feel uncomfortable.

**Diversionary Activity**

Staff need to engage in conversation with Graham during personal care interventions to try and shift thoughts away from sexually inappropriate behaviour for e.g. '*tell me about your job, Church, hobbies*.' If they are in a communal area, staff are encouraged to try to distract Graham and then help him to move to another, more private area.

**Person-Centred Care**

To facilitate Graham's integration back into the Care Home, staff agreed to spend some time with him during the day outside of their primary caring duties to meet his need for social interaction. Family were encouraged to become involved.

**Environment**

Graham was more confused and disorientated at night time. Considering that it would not be a breach of his right to freedom of movement, it was agreed that staff would place a sensor mat on the floor at Graham's bedside which would alert staff when he gets up at night. This helped reduce the risk of him entering another resident's room. Graham and his daughter Sarah were in agreement with this.

**Collaborative Working**

It is vital that staff from both the Care Home and the Dementia Inpatient Unit work closely with Grahams daughter Sarah and that she is regarded as an essential member of that team. Together they can (i) monitor and report bowel movements (ii) look out for signs of pain associated with infections and (iii) ensure medication for both are provided.

**Staff Training Needs**

Care Home staff training needs were identified following a discharge planning meeting and included staff understanding of the impact that an infection or constipation could have on his behaviour.

**Discussion / Learning Points**

How can complying with the principles of John's Campaign enhance staff practice and provide a better experience to the person with a dementia and their family / carer?

Could the CLEAR Dementia Care© assessment have been carried out in the Care Home? What would have been the advantages or disadvantages of this?

How might the Hospital Dementia Companions service have been used in the Dementia Inpatient Unit?

***NB: This case study has been adapted from practice experience by staff working in the NHSCT, SHSCT and SEHSCT***

## Case Study 2

### June and Martin's Story (Care Home)

June was admitted to a care home and was visited frequently by her husband Martin. They were able to spend time together privately in June's room although June shared a room with another lady. On one occasion Martin was observed getting into bed with his wife.

While the fact that June shared a room was an issue, staff were also concerned about June's capacity to consent to sexual activity.

Martin accepted the inappropriateness of participating in sexual activity in a shared room but when he queried if it would be permissible in a single room, staff explained that there were issues around June's lack of capacity to consent.

Martin said that because June was his wife, there was no need for her to give consent and that she had always consented to sexual activity with him before she had dementia.

Staff spoke to June to ascertain her understanding but were unable to confirm that she had willingly consented to sexual activity with her husband in her dementia years. When staff explained this to Martin, he was unhappy but eventually agreed that he would no longer seek to have sex with his wife. Staff needed to provide Martin with support to help him understand his wife's dementia journey and how this had changed the nature of their sexual relationship.

### Discussion / Learning Points

At no point can consent be provided pre-emptively. The person (in this case June) needs to be capacitous at the time of providing consent and consent can never be given in advance. For information about the Mental Capacity Act (NI) 2016 and Codes of Practice, refer to https://www.health-ni.gov.uk/mca

It is important that staff have open and honest communication about sexual matters and capacity with partners. This may include e.g. an examination of cultural attitudes to sexuality and issues of power within relationships. What might some of the cultural attitudes be towards sexuality and power in society? How might these manifest themselves and how can they be addressed?

Staff need to be alert to the fact that couples may need support when their relationship is impacted by the onset of dementia. Staff should also consider the

need to provide access to counselling or other supports to those involved. What supports are available?

In your staff team or learning group, discuss the need for sensitivity when addressing issues such as the power balance, individual expectations or behaviour within relationships. What are the implications for you as a member of staff?

There is a need for the Dementia Specialist to discuss sexuality and relationships with the person with a dementia at an early stage and to reflect individual wishes and preferences in their Care Plan. What issues or challenges might this raise?

***NB: This case study has been adapted from practice experience by staff working in the SHSCT***

## Case Study 3

**Sam and Alice's Story (Care Home)**

Sam is a 78 year old gentleman who was described by his family as being '*a bit flirtatious and popular with women.*'

When he was admitted to a Care Home, he developed a friendship with Alice, a female resident who spent regular periods in the Home to enable her family to have a break from their caring role.

Staff noted that the friendship developed over time and when Alice returned to the Home for subsequent short-breaks, the friendship was soon rekindled. On one occasion, she was found in Sam's bedroom with the door locked and they were having intercourse. The immediate concern on the part of staff was that Sam may have instigated this activity, rather than Alice.

As a result, the Home Manager initiated a safeguarding investigation and questions and issues about capacity and consent were examined.

Sam told his GP that he and Alice were consenting adults and both wanted to have a sexual relationship. An assessment of both Alice and Sam's mental capacity and their ability to consent was completed and both were found to have capacity and therefore able to consent to a sexual relationship.

Having completed the assessment and confirmed that the relationship was consensual staff at the home made arrangements to ensure Sam and Alice could have some privacy. Additional training in sexuality and intimacy was offered to all the staff within the home to help them understand their own feelings and be supportive of Sam and Alice's relationship.

With Sam and Alice's permission, staff met with both families to ensure there was good communication and while both families were still unsure about it, they did accept Sam and Alice's close relationship.

**Discussion / Learning Points**

It should never be assumed that because a person has a dementia that they lack capacity. Assessing capacity is important to help avoid assumptions, provide protection, safeguard rights and act in an individual's best interests. Mental capacity is issue specific and time specific. Who does / should do the assessment of capacity?

Involving the person with a dementia and supporting them to express their wishes

and make decisions is central to delivering person-centred care. It should also be noted that where both persons are capacitous and consenting, any unnecessary interference in their lives by others could be illegal. How do you ensure that people are fully engaged and consulted about their wishes? How can this be improved upon?

Staff should never make judgements based on someone's lifestyle, personality or reported past behaviour (Sam was described by family as '*flirtatious*'). In your learning group, discuss how assumptions can be made incorrectly or labels attached to behaviours and individuals. Reflect on your own practice and that of your team and consider how best to promote non-judgemental practice.

Safeguarding policies should be used in an enabling way and not just for the purpose of restricting someone's liberty or freedom of expression. How do you strike a balance between promoting rights and protecting the individual?

***NB: This case study has been adapted from practice experience by staff working in the SEHSCT***

# 5. Care in the community

This section is intended to provide support to those staff working with people with a dementia, their partners, carers and families who live in their own homes (including supported housing facilities) in the community.

Although the Guidance is relevant to all staff, this section will be most relevant to community staff e.g. Nurses, Social Workers, AHPs and Domiciliary Care Staff.

Following a diagnosis of dementia in one partner, couples living at home may experience changes in their relationship and behaviours that are out of character, frightening (aggression) or emotionally upsetting (rejection). The person with a dementia, their partner, carer or family will need help to understand what is happening and support to manage particular situations / behaviours.

## Case Study 4

**Lorraine and Alan's Story (Living in the Community)**

Alan is a 64 year old gentleman and has had a diagnosis of dementia for two years. His dementia is at an advanced stage. He has only limited communication and no insight into his condition.

Alan is cared for by his wife Lorraine who is aged 62 years but whose health has recently begun to deteriorate due to the '*mental fatigue*' of the caring role.

They live in a well-established housing development near the town centre and have two grown up children whose work commitments take them away from home for long periods however, contact is maintained and relationships are supportive.
Lorraine and Alan had always enjoyed a loving and supportive relationship and were sensitive to each other's needs.

During a visit to their home, the Social Worker noticed that Lorraine had bruising to her arms and face and enquired about this.

Lorraine was upset but told the Social Worker that Alan had become very insensitive to her needs and feelings and was sexually demanding. Lorraine explained that she still loved her husband and wanted to be close to him. '*At night*' she said, '*when I feel that I want to be really close to him, and he's in a sound sleep, I would lift his arm and put it around me and hold on to it tight. Then I just drift off to sleep and feel, you know, content.'*

But Alan's behaviour was becoming more aggressive. Lorraine told the Social Worker that Alan had '*become more demanding, not asking or leading up to it and there was no follow through…and I couldn't…he was kneeling up on the bed, shouting at me and blaming me…I was scared…he grabbed me and hit me. He*

*never behaved like that ever in my life. It is frustration because his body will not react the way it is supposed to react…it must be awful for him.'*

The Social Worker was mindful of safeguarding issues. She needed to ensure that Lorraine was safe but she also wanted to ensure that Lorraine was able to continue caring for Alan, which she wanted to do. The Social Worker sought assistance from colleagues in the Specialist Dementia Team. They were able to support Lorraine by developing diversionary techniques and establishing bedtime routines which helped reduce Alan's anxiety and aggression.

Lorraine was helped to find ways that gave her some personal time for relaxation and was offered the professional services of a Counsellor and informed about dementia support groups and other activities in her area.

**Discussion / Learning Points**

Partners need help with understanding the possible impact of dementia on behaviour, cognitive functioning or ability to communicate. This information should be shared with partners in a way that does not frighten them and should include training in diversionary techniques. What diversionary techniques might you recommend to a carer?

Carers need protection too. Safeguarding procedures should be followed wherever necessary and Counselling and / or other forms of support should be available. How would the existing safeguarding procedures enable you to provide support and protection to carers?

Would it have been appropriate in this scenario to have applied the Mental Health (Northern Ireland) Order 1986?

Consider Carers Assessments - https://www.NIDirect.gov.uk/articles/assessments-carers

***NB: This case study has been adapted from the original with the kind permission of the author of McErlean, S., Younger People with Dementia and their Carers (2001)* University of East Anglia Monograph No. 188 ISBN No. 1 85784 083 6**

# 6. Lesbian, Gay, Bisexual and Transgender (LGBT+)

LGBT+ describes the lesbian, gay, bisexual and transgender community. LGB refers to sexual orientation and T refers to gender identity. The + refers to other marginalised and minority sexuality or gender identities.

It is important for staff to be aware of diversity and to understand and respect the needs of people who identify as Lesbian, Gay, Bisexual or Transgender.

The needs of people who are gay, lesbian or bisexual will be different from those of a transgender person.

This can be a complex issue for staff and it is important that training programmes help staff understand issues such as gender, sexual orientation and sexual identity.

A person's sexual orientation (sexual, romantic or emotional attraction to others) is different to their gender identity (how they see themselves i.e. male, female, both or neither). Everyone will have both a sexual orientation and a gender identity.

**Sexual orientation** is about who you are attracted to. It describes a person's physical, romantic and / or emotional attraction to another person e.g. straight, gay, lesbian or bisexual.

**Gender identity** describes a person's internal, personal sense of being a man or a woman or neither.

**Transgender** describes a person who doesn't identify with their assigned gender at birth or who see themselves as between, beyond or outside of the two standard categories of male and female.

For further guidance on these and related issues, refer to the Care Quality Commission's publication Relationships and Sexuality in Adult Social Care Services: Guidance for CQC Inspection Staff and Registered Adult Social care Providers (2019) available at https://www.cqc.org.uk/sites/default/files/20190221-Relationships-and-sexuality-in-social-care-PUBLICATION.pdf

Under the Equality Act (Sexual Orientation) Regulations 2006, it is unlawful for a public authority to discriminate against a person on the grounds of his / her sexual orientation or to subject a person to harassment in the course of carrying out any functions of the authority. Such functions include the provision of any form of health and social care.

Like all other citizens, LGBT+ people have the right to expect that when health and social care is required, it is compassionate and safe. Health and social care workers are 'public servants' and should make no distinction between those they serve. Good dementia care and the delivery of the highest standards of service is the responsibility of everyone employed within health and social care.

Staff should remain neutral and non-judgemental when working with people with a dementia who are also members of the LGBT community.

These issues need to be addressed during induction, supervision and training.

### 6.1 Gay, Lesbian and Bisexual People with a Dementia

It can be difficult for many people to talk about their sexuality and relationships. This can be even more so for people who identify as LGB particularly as they may fear the reaction of others. Research has revealed that people who are gay, lesbian or bisexual can experience homophobia when accessing health care e.g. Elliot et al (2015) found that LGB people report poorer experiences when accessing health and social care, are likely to delay access to healthcare based on previous negative experiences and fear of negative attitudes of health workers specifically in relation to their sexual orientation.

Some LGB people may be worried about meeting different care staff or going into care settings. They may worry that they will experience prejudice or discrimination. In some settings, care professionals may not have enough knowledge or awareness to support the needs of LGB people with dementia. They may not realise that LGB people access their services or understand that the person's sexual or gender identity can have a big impact on their needs e.g. reminiscence activities may focus on people's family and children, not realising that some LGBT people may not be in touch with families or have children.

People should be supported to disclose their sexual orientation and / or gender identity and they should be enabled to live in a gay-friendly and gender-affirming environment if that is their wish.

Most types of dementia cause people to experience memory problems. LGB people may be affected by these in different ways e.g. if an LGB person has told some people about their sexual orientation but not others, the person may forget who they've shared this with. They may think they have told some people when they haven't.

Some older LGB people may have gone through the process of sharing their sexual orientation, (coming out) more recently. They may forget that they have come out, which might be distressing for the person, and for those supporting them.

## Case Study 5

**Collette and Roisin's Story (Care Home)**

Roisin and Collette had lived together as a couple for several years. When Collette, received a diagnosis of Alzheimer's disease, Roisin cared for her at home for almost two years before her own health deteriorated and she found herself no longer able to cope with the physical demands of caring.

They spoke to the Social Worker and agreed that the additional care which Collette needed could best be met in a Care Home.

After Collette moved into the Home, Roisin visited frequently and Collette looked forward to these visits. She and Roisin would sit together and hold hands and were able to enjoy more intimate time together in Collette's room.

Collette's family were never happy about the relationship and felt that because Collette was more vulnerable and being cared for by staff at the Home, staff should refuse Roisin admission to the Home and certainly not allow her to be alone with Collette in her room.

The Home Manager spoke to relatives about the Home's safeguarding policy and explained that consideration had been given to Collette's past history and her relationship with Roisin. She explained too that staff would always be vigilant to signs of distress during visits and through assessments by the Dementia Specialist, it had been established that Collette had the capacity to make decisions about her continued relationship with Roisin.
Following their conversations with the Manager, and with support from the Dementia Specialist, the family decided not to visit the home at the same time as Roisin.

Some staff recognised that the relationship was a long standing and supportive one and were concerned about the attitude of the family.

However, some staff continued to find this relationship between two females difficult to accept or comprehend.

Additional training on sexuality and intimacy was offered to all the staff in the Home. This helped the staff who had reservations about the relationship to understand their own feelings and enable them to be supportive of the relationship.

**Discussion / Learning Points**

People with a dementia and who live in a Care Home, have the same psycho-social and emotional needs as anyone else in the community. What challenges might there be for staff in seeking to have these needs met?

Staff need to acknowledge and be sensitive to the views of relatives but must also promote and safeguard the rights of the individual with a dementia. Discuss the challenges of conflicting rights and opinions.

Staff training and supervision needs to tackle issues of stigma and where necessary staff's own personal beliefs and prejudices.

Training and awareness programmes need to address issues around same sex relationships, rights, equality and identity.

Care staff and providers have a duty to promote equality, diversity and human rights in their service, including for their staff. How is this achieved within your organisation and what could be done to improve practice.

Care staff and providers need to promote inclusive practices. LGB people need to be proactively supported by staff who understand the need to adequately balance risk and responsibility toward the individual concerned. This will help LGB people to form and maintain personal, loving, intimate and sexual relationships. How is this achieved within your organisation and what could be done to improve practice.

Care Plans must include reference to sexual orientation.

Do families have a right to decide who should visit a resident in a Care Home? How can you ensure that the rights of all those involved are respected and upheld?

***NB: This case study has been adapted from the original with the kind permission of the authors of The Last Taboo ILC-UK (2011)***

### 6.2 Issues for Transgender People with a Dementia

Although transgender issues are frequently considered with lesbian, gay and bisexual issues, people who present as transgender have different needs from individuals who are gay, lesbian or bisexual.

It is important to remember that some people who identify as transgender may or may not have completed the physical transition process but express their identity through their style of dress. If an individual has not had gender reassignment surgery, and is receiving personal care, HSC staff may become aware of the person's gender identity even if they haven't chosen to disclose it. This can make the individual uncomfortable if they feel intimate care or physical examination "outs" their biological sex

Another issue faced by people with dementia who have changed gender (or are in the process of doing so) may be that they do not remember that they have been through this process. A transgender person might forget that they have, or have not, started the process of changing gender (gender reassignment). This can be distressing and confusing

A transgender person may also be taking hormones or undergoing long-term hormone therapy. If the person forgets to take the hormones or suddenly stops, they may develop health problems (for example, an increase in their risk of developing osteoporosis). It is important for those supporting the person to be aware of the treatment the person is having and to support them to take the right medications.

It is also important that the individual feels respected and this can be done by building relationships early with that person, so that they feel safe and comfortable with staff.

If someone chooses to tell a care worker about their previous gender, or the worker was to find out, it can be reassuring to know that this information cannot be disclosed to others, without the person's consent. This means that the care worker must treat this information as confidential and not tell others unless the person wants them to.

## Case Study 6

### Pat’s Story (Day Care)

Pat is a 73 year old transgender male who has had a diagnosis of dementia for 5 years. He lives with his partner of 35 years who is finding it difficult to care for him and feels that a few days day care would benefit them both.

Pat and his partner came to view the Day Centre and were both impressed with the surroundings, meals and daily activities on offer. However, Pat’s partner was nervous about how Pat would be received by staff. Pat’s partner was reassured by the manager and it was agreed that Pat would come for day care two days a week.

On day one, other members at the centre commented on Pat’s appearance / looks and behaviours and some staff ‘giggled’ at these without showing concern for Pat and his feelings.

After the third week Pat's partner spoke to the manager and stated that Pat was getting upset on the days he was due to attend day care. Pat came home from day care upset and agitated. He felt that he was being ignored, laughed at and excluded from activities.

The Manager agreed to observe the situation when Pat was next in the centre. He observed that Pat seemed to sit at a table on his own for meals and he wondered why Pat was not always invited to participate in games and activities when he could participate.

The Manager spoke to staff regarding Pat's time in the centre and explained that Pat's partner had identified some issues of concern.

The Manager organised to speak with staff and planned a training and development programme for them, focusing on sexual identity and orientations, human rights, diversity and respect for personhood.

### Discussion / Learning Points

In your learning group, discuss the following:

People living with a dementia have the same psycho-social and emotional needs as anyone else in the community.

Staff should not make assumptions about sexual orientation or gender identity and these issues need to be addressed in training and supervision.

Care Plans should adopt a rights based approach and must include reference to sexual orientation or identity.

Staff should respect all service users and never make judgements about that individual's sexual orientation or identity.

Staff should work in a proactive and sensitive way to promote tolerance and understanding among work colleagues and, where appropriate, members of the public

Staff training and supervision should address issues such as stigma, diversity, rights and respect. Where necessary and appropriate, training and supervision should provide a supportive environment for staff to reflect on their personal beliefs, practice and prejudices.

Staff should remember that it is their duty to protect and safeguard the rights of all persons in their care and balance this against the views and concerns of partners, families and carers.

The person with a dementia should never be left to feel that they are alone and should be offered support to deal with painful feelings of rejection and prejudice.

Care staff and providers have a duty to promote equality, diversity and human rights in their service, including for their staff.

Care staff and providers need to promote inclusive practices. Transgender people need to be proactively supported by staff who understand the need to adequately balance risk and responsibility toward the individual concerned. This will help all people to form and maintain personal, loving, intimate and sexual relationships.

***NB: This case study has been adapted from practice experience by staff working in the SEHSCT in collaboration with staff from the University of Ulster***

## 7. Information / Support to a person with Dementia, their partners, carers and families

Talking about sexuality and relationships can be difficult or embarrassing. People may be reluctant to discuss intimate details of their personal lives or their feelings with others even when those relationships are the source of physical pain and emotional distress. There may be cultural reasons also why someone would not want to discuss these issues with others.

Staff need to be mindful that the onset of dementia can cause changes to an individual's understanding of the world around them and that their behaviour can change too. This can have an impact on others around that individual.

Staff need to sensitively raise these issues in their meetings with the person with dementia, their partner, carers and family. It can be helpful to address the issue of relationships and sexuality at an early stage in the dementia journey so that people are prepared for situations that may occur and be better prepared to deal with them.

Discussions about the impact of dementia on relationships, including sexual relationships, should take place at the time of diagnosis or throughout the dementia journey when the need arises.

The most important message to give to anyone is to let them know that support and information are available and that they should feel free to ask for help.

## Case Study 7

### Frank and Helen's Story (Day Care)

Frank has a diagnosis of vascular dementia. His daughter Louise has supported him in the community for the past 15 years, since his wife died. Frank became depressed and both he and Louise thought that attendance at a Day Centre would provide him with opportunities to socialise and engage in activities of interest to him.
Frank easily made the transition into Day Care and within a month he had struck up a close but non-sexual relationship with Helen, who had also been diagnosed with dementia. They clearly enjoyed each other's company and sat together at mealtimes and in the lounge. Sometimes they held hands. Frank's depression lifted, his outlook brightened and his behaviour changed.

At first, Frank and Helen's friendship was difficult for Louise to accept. She told a member of staff that it seemed to her that her father had cast the memory of her mother aside. Initially she felt confused and betrayed but she talked with staff who had attended an advanced dementia training course. They encouraged her to see that both Frank and Helen had the capacity to choose to have a close relationship and that this was making them happy.

By talking to staff, Louise was able to accept the friendship between Frank and Helen and accept that he was happier in himself. Louise learned to enjoy the free time which she now had from caring and do things with friends which had previously been severely limited due to her caring role.

In addition to socialising with friends, Louise also attends a carer's support programme that includes awareness raising and education around dementia.

### Discussion / Learning Points

It is important that family carers are given time, support and information to help raise their awareness and deal with their emotions / feelings. How can this be best achieved?

Staff need to be aware of the social and emotional needs of family members including their feelings of loss and betrayal. What feelings and emotions might family members have and how can these be addressed sensitively?

***NB: This case study has been adapted from the original with the kind permission of the authors of The Last Taboo ILC-UK (2011)***

## Case Study 8

### David and Susan's Story (Care Home)

David was diagnosed with a dementia but his wife Susan found it difficult to continue to care for him at home. David was admitted to a local Care Home and settled reasonably quickly. Staff were understanding and supportive of his needs. Susan visited every day but found it increasingly difficult as David's relationship with another resident, Karen developed. Karen also had a diagnosis of dementia and she and David would walk around the Home and the garden holding hands. Susan felt hurt and rejected when she found her husband hugging Karen in Karen's bed room.

Susan could not understand how her husband could not love her anymore and she reduced her visits to the Home. Emily, the Manager of the Home, noticed that Susan's visits were less frequent and was concerned about this. She rang Susan at home and it became obvious that Susan was very upset about her husband's relationship with Karen. Susan was reluctant to visit the Home so Emily arranged to meet her at a local café to discuss her feelings.

Emily listened carefully as Susan talked of her distress at the growing affection that her husband appeared to have for Karen and how he no longer seemed to be interested in her or have any regard for her feelings or the fact that they had been married for many years and raised their family.

Emily tried to reassure Susan that her husband still loved her but that his dementia was impacting on his cognitive abilities and behaviour. She suggested that Susan speak to the Dementia Specialist and actually arranged an appointment for her.

Susan found the support from Emily reassuring and felt that the information and support that she received from the Dementia Specialist was extremely helpful. Susan was keen to learn more about David's condition and was invited to attend the carers support programme.

Emily kept in touch by phone and eventually, Susan started to feel more relaxed about David's friendship with Karen and has since increased the frequency of her visits to the Care Home.

### Discussion / Learning Points

Individuals need to feel that they are not alone and should be offered support to deal with painful feelings of rejection and loss.

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### 7.1 Sources of Help may include:

- **GP** - The GP is not only involved in the diagnosis of dementia, but s/he can also play an important role in the on-going support to the person with a dementia, their partners, carers and family. The GP knows the person's medical history and can help manage conditions that can occur alongside certain forms of dementia e.g. high blood pressure, high cholesterol, and depression. The GP can also refer into more specialist dementia services and give advice on how to lead a healthy lifestyle.

- **Consultant** - Consultants may be involved in diagnosing dementia but also in the on-going assessment and support for those affected. The Consultant can be a Psychiatrist, Geriatrician or Neurologist.

- **Local Memory Service Team** - This is a team that specialises in providing a range of support services to people with a dementia and those who support them. These include assessment, diagnosis and treatment as well as information, education and support. The members of a Memory Service Team are multidisciplinary and can include a Specialist Memory Nurse, Social Workers, Occupational Therapists and an Independent Nurse Prescriber.

- **Other Healthcare Professionals** - Speech and Language Therapists, Clinical Psychologists, Dieticians and Physiotherapists can provide vital support for the person with a dementia in helping them communicate and lead a full and independent life for as long as possible. They also provide help and support as the condition progresses to the later stages.

- **Dementia Navigators** - These are professionals within each Health and Social Care Trust whose role it is to provide information and support to those affected by a dementia. They will be with the person from the beginning of their journey and provide support throughout the whole experience. They will provide support either in a face to face capacity or over the telephone and will be a vital link person for all those affected by a dementia.

- **Community and Voluntary Organisations** - These organisations can provide great support to all those affected by a dementia. They can provide information in various ways and also run information sessions. They provide some excellent peer support services for people with a dementia and their carers, and can be a strong voice for all those affected by a dementia in the region.

If you want to find out more about the different Community and Voluntary Organisations that can help, contact details are available in **Appendix 3** of this Guidance.

- **Wider Healthcare** - It is important that when someone gets a diagnosis of a dementia, they do not neglect other aspects of their health as this can lead to the symptoms of dementia becoming more pronounced. For this reason, it is important to look not only at the individual's physical needs (eye care, hearing, oral hygiene etc) but also their sexual health.

  For more information about physical and sexual health, please refer to Section 10 of this Guidance.

### 7.2 Awareness Raising and Training

As far as possible, people with a dementia, their partners, carers and families should be encouraged to take part in awareness raising and training programmes which ensure that they are better informed and therefore less vulnerable to abuse from other people or less likely to become the perpetrators of abuse.

In addition, they may feel more empowered and better able to give or withhold consent to sexual relationships.

## 8. Legislation, capacity, consent and safeguarding

### 8.1 Legislation

It is important that staff are aware of relevant legislation which applies to Northern Ireland as it cannot be safely assumed that what is lawful or unlawful in England and Wales is necessarily so in Northern Ireland.

The Sexual Offences (Northern Ireland) Order 2008 lists sexual offences against a person with a mental disorder (includes dementia). These include:

- Sexual activity with a person with a mental disorder impeding choice.
- Causing or inciting a person, with a mental disorder impeding choice, to engage in sexual activity.
- Engaging in sexual activity in the presence of a person with a mental disorder impeding choice.
- Causing a person with a mental disorder impeding choice, to watch a sexual act.
- Inducement, threat or deception to procure sexual activity with a person with a mental disorder.
- Causing a person with a mental disorder to engage in or agree to engage in sexual activity by inducement, threat or deception.
- Engaging in sexual activity in the presence, procured by inducement, threat or deception of a person with a mental disorder.

- Causing a person with a mental disorder to watch a sexual act by inducement, threat or deception.

A person guilty of an offence could be liable to a term of life imprisonment.

Whilst the Mental Capacity Act 2005 (England) is not applicable in Northern Ireland, it is good practice to refer to that legislation and its code of practice to assist decision making in relation to capacity. The relevant legislation in Northern Ireland is the Mental Capacity Act (2016) which was partially implemented on 2nd December 2019 in respect of Deprivation of Liberty Safeguards (DoLs)

**NB: Taking legal advice on all of these complex issues is strongly advised.**

### 8.2 Capacity and Consent

Capacity should be judged in relation to a specific decision at a particular time i.e. some decisions are easier to make than others.

Principles of assessing mental capacity are that:

- No assumptions should be made in relation to a person's capacity
- A person is not to be treated as unable to make a decision unless all practical steps to help him or her to do so have been taken without success
- A person is not to be treated as unable to make a decision merely because he or she makes a decision that others believe to be unwise
- An act carried out, or decision made for or on behalf of a person who lacks capacity must be done, or made, in his or her 'best interests'
- Any decision or action taken on behalf of a person lacking capacity should aim to be the least restrictive option available

In accordance with the Mental Capacity Act (2016) the person should be able to demonstrate decision making capacity by:

- Understanding the information relevant to the decision, including the benefits, risks and alternatives, and the consequences of refusing to follow the proposed course of action
- Retaining this information for long enough to make a decision
- Using or weighing this information as part of the process of making the decision.
- Communicating his or her decision

When completing a Capacity Assessment the key principles to consider are:

- What previous knowledge of the issue does the individual have?
- Does the person comprehend the information relevant to the decision?
- Can the person retain the information relevant to the decision?
- Can the person use and weigh this information in the decision making process?

- Does the person have the ability to communicate the decision (by any means)?

**NB: These principles are decision and time-specific, and apply equally to each decision that a person makes with regard to their sexuality, as with other decisions about their life. Practitioners must be able to evidence their compliance with these principles when applying this guidance to their practice.**

Staff should refer to the DHSSPS (2003) Good Practice in Consent Guidance

Anyone wishing to engage in a sexual relationship with another person can only do so with the consent of that other individual. The principle of consent applies regardless of whether or not one or both persons have a dementia.
It is important to note that the notion of 'best interests' i.e. if a person lacks capacity, cannot be used in relation to sexual activity. If a person lacks capacity, sexual activity cannot happen.

Consent means that both people are happy and agreeable to the act of intimacy and can understand what is happening. If for whatever reason one person does not wish to participate in a sexual encounter, then their wishes must be respected and safeguarded.

Simply having a diagnosis of dementia does not mean that someone lacks the capacity to make their own decisions and to understand the implications of those decisions. Furthermore, capacity is always specific to a particular decision at a particular time. The ability of a person to understand the implications of a decision may also vary on different occasions.

It is important to consider whether the person with a dementia has the ability to recognise who the other person is, and most importantly, whether they have the ability to say no or express their wishes in other ways.

## Case Study 9

### Joe and Carol's Story (Care Home)

Joe and Carol live in a Care Home and both have a diagnosis of dementia. Over time, they began to spend more time together in the lounge, at the dining table and in their rooms. It soon became clear to staff and their families that their relationship had become more intense and more sexual in nature.

Both families objected to this relationship. Joe and Carol were widowed and their families felt that the relationship was inappropriate.

In response to requests and concerns of family members, the Dementia Specialist undertook assessments of Joe and Carol's capacity to make decisions for themselves and concluded that they were both capable and that the relationship was a positive one.

Both families are still unsure about it, but they did accept Joe and Carol's close relationship.

Shortly afterwards, Carol's health began to decline. She had a serious fall and numerous other health problems. Joe's dementia had also become more severe and he lacked the capacity to understand just how ill Carol was and wanted to continue the relationship as before. Carol could not continue the relationship and was spending a lot of time in bed in her room, which unfortunately confused Joe further, as he kept trying to get into bed with her.

Professionals continued to monitor Carol and Joe's mental capacity and when this deteriorated, it was felt that the sexual relationship should end. It was not in the best interests of Carol for the relationship to continue and it was becoming clear that Joe was not sufficiently able to relate to Carol's feelings or needs. To help him adjust to the changing circumstances Joe could still be able to see Carol when accompanied by a female member of staff.

Some months later, Carol died and Joe would continue to visit her room despite her not being there. It was decided that Joe should attend the funeral and he was also given extra support by the care staff to help him overcome this loss.

**Discussion / Learning Points**

If a person no longer has capacity to consent to sexual activity, there is a duty on staff to protect both the person with the dementia and the other party. For more information about the Mental Capacity Act (NI) 2016 and Codes of Practice, refer to https://www.health-ni.gov.uk/mca

Need for touch / closeness can be met in other non-sexual ways such as hand massage, holding hands, hugs (refer to Case Study 13).

Because capacity can change over time, it is important that assessment is continuous both to safeguard the individual and to act in their best interests.

Supporting the person who is '*left behind*' when capacity or circumstances change needs to address issues of loss and grief.

It is important that when assessing capacity, the process includes and is supportive to the person with a dementia, their partners, carers and family.

In your learning group, discuss the issues of touch, loss and grief that are raised in this scenario.

***NB: This case study has been adapted from the original with the kind permission of the authors of The Last Taboo ILC-UK (2011)***

## Case Study 10

### Simon and Hilary’s Story (Care Home)

Simon is a 75 year old man with vascular dementia who has lived in a Care Home for three years. He developed a friendship with Hilary, another resident in the Home. Hilary has advanced Alzheimer’s.

Simon told staff and Hilary that he increasingly felt attracted to Hilary although he referred to her as Sarah, the name of his late wife.

He would be attentive to Hilary and would hold her hand. As the relationship progressed, Simon was seen trying to give Hilary a kiss and on another occasion he was found with Hilary in his bedroom in a state of arousal with his trousers undone.

Some staff were shocked that both people had sexual urges as they were ‘*old and both had dementia.*’ Staff were unsure if this was what Hilary wanted, if she understood what was happening or if she had the capacity to consent. They did note that she did not appear to be distressed.

A multi-disciplinary team meeting was convened that included the Psycho-geriatrician. Both families were separately, given the opportunity to participate and discuss the issues fully.

As a result of the meeting, it was agreed that a capacity assessment of both Simon and Hilary should be undertaken. It was concluded from these assessments that neither resident was found to have sufficient capacity to consent to sexual activity.

A Protection Plan was developed which facilitated some supervised contact between the two residents without depriving them of their liberty. There was an opportunity for diversionary activities when both residents were located in the same area of the home which the staff monitored.

### Discussion / Learning Points

Should the capacity assessment have happened before the meeting with families? If both people have capacity, then the family has no right to be included in discussions without the consent of the persons with dementia. Discuss the legal issues of this scenario and consider some of the challenges that might arise for the persons with dementia, their families and staff.

Awareness raising and training programmes need to tackle attitudes to age, dementia and sexuality.

Staff need to respect the right and the need of the person with a dementia for physical intimacy and reassurance.

Good assessments of mental capacity and consent are central to the delivery of person-centred care.

Staff should be mindful of issues around the deprivation of liberty of the individual and be careful not to overly restrict the individual's interaction / engagement with others. However, should there be a need to monitor contact or behaviour, this should be done in a way that is discrete, non-intrusive and does not offend or embarrass the individual's involved.

- A restriction of an individual's interaction with others is not a restriction of liberty. Staff should be mindful of the requirements of the Mental Capacity Act (2016) in relation to the Deprivation of Liberty and should seek professional and / or legal advice if necessary
- A deprivation of liberty is where a person who lacks capacity is in a place of continuous control and supervision and not free to leave
- Others not being allowed to enter is not a deprivation of liberty
- Prevention from entering a particular room / building / house is not a deprivation of liberty

What are the challenges for staff in balancing the rights of the individual and their need for protection?
Staff should discuss what is meant by 'Deprivation of Liberty' and their duties in relation to this.

Where complex issues relating to the law are concerned, staff should always seek legal advice.

***NB: this case study has been adapted from a number of sources, the origins of which are uncertain***

### 8.3 Mental Capacity Act (NI) 2016

The new Mental Capacity Act (Northern Ireland) 2016 was partially implemented on 2$^{nd}$ December 2019. Other relevant legislation remains the Mental Health (Northern Ireland) Order 1986 and the Sexual Offences (Northern Ireland) Order 2008 which must be followed to inform decision making in cases where a person's ability to consent is in question.

Staff may also wish to refer to the Mental Capacity Act 2005 (England). See advice above in Section 8.1 regarding the Mental Capacity Act 2005

### 8.4 Safeguarding

All care services should have safeguarding arrangements that are compliant with regional policy and operational guidance. Staff should be aware of these policies / procedures and be trained in their use and application (see Section 1.2 above).

## Case Study 11

**Robert, Jack and Joy's Story (Care Home)**

When Jack's mother died unexpectedly, he and his family returned from abroad, to attend the funeral and to spend some time with his father Robert. Jack, an only child, hadn't seen his father for nearly two years although he had communicated with his parents very regularly by phone and Skype. Jack's father had been an engineer and was quite confident in the use of technology.

Over the period of the funeral, Robert appeared a bit confused and forgetful but Jack thought that this was just the result of his shock at the loss of his wife of nearly 47 years. When, a few days later, Robert failed to return from a trip to a nearby shop and was found by police three hours later wandering around a disused factory site, Jack sought medical assistance and agreed with the GP that his father should be admitted to hospital for observation.

Although his wife and family went back home, Jack with the approval of his employers, had remained with his father until his care and accommodation needs could be satisfactorily addressed. It also became obvious, from conversations with neighbours and other relatives, that Robert had been having difficulties for some time but that his wife had managed to keep these facts hidden from Jack.

With help from the GP and Memory Services Team, Robert received a diagnosis of dementia and in the absence of any alternative, was admitted to a Care Home. Jack felt reassured that this was in his father's best interests and returned to work. He maintained regular contact with his father and the Home

Within weeks of arriving at the Home, Robert had struck up a relationship with a female resident called Joy. They would spend a lot of time together and enjoyed each other's company. In time, the relationship became more intimate and sexual and this was discussed by staff and other professionals. However, after an assessment of their capacity to consent, it was felt that neither resident was being exploited; they were both more relaxed and were a good support to each other. As a result, there was no need to stop the relationship.

Six months later, Jack returned to visit his father at the home and although he had been informed by staff that his father '*had made friends*,' and was '*very friendly with Joy*' he was annoyed and angry that this '*friendship*' was more intimate than he had been led to believe.

Jack had found his father and Joy in an affectionate embrace in his father's room. He felt that his father was being taken advantage off and since his parents had been devoted to each other for such a long time, this relationship was an '*insult to his mother's memory.*' Jack demanded that the relationship be stopped and that his father be moved to another Home

Staff felt that to separate Robert and Joy would have been detrimental to them both and they were aware of their duty to safeguard the rights of their residents while acknowledging and respecting the views and opinions of family. This was a professional and ethical dilemma that many care workers face in carrying out their duties but they had discussed these issues in staff meetings and had received training and regular supervision which addressed these dilemmas.

The Home Manager spoke to Jack initially and explained that Robert and Joy '*enjoyed each other's company,'* they '*looked out for each other*' and that their friendship had '*boosted their confidence and sense of self-worth*.'

The Manager arranged for a further meeting with Jack and the Social Worker to discuss in more detail, Robert's physical and mental health and the all-round benefits for Robert of remaining at the Home. He had friends there and sense of purpose. A move to another home might cause confusion, distress and isolation.

The Manager and Social Worker acknowledged the importance of the long term relationship that Robert had with Jack's mother and they acknowledged the sense of betrayal that Jack would feel on behalf of his mother but, they explained, Robert needed to have support to live his life now and that staff would be working to ensure that he was not being exploited.

The Manager took time to explain the Home's safeguarding policy and how it was applied to ensure that no-one was abused or exploited. She explained to Jack that his father and Joy had been closely observed and assessed as being able to give their consent to the relationship and that this monitoring / assessment was an on-going process.

Although the situation was difficult for Jack to accept, staff were very supportive and helped him to understand (i) the need for intimacy, (ii) the sense of personal well-being that can come from a relationship and caring for another person, (iii) the duty of staff to protect residents from any form of exploitation or abuse and (iv) even though his father had a diagnosis of dementia, it did not mean that he was without capacity to make decisions.

**Discussion / Learning Points**

Did Jack have the right to '*demand*' that the relationship between his father and Joy be stopped and that his father be moved to another Home?

If Robert has capacity, is it right that Jack was informed when he visited the home six months later? Does Robert have to give his consent for Jack to be informed?

Should Robert and Jack each been offered the services of an Independent Advocate?

If both people have capacity, a sexual relationship can continue, if not, it cannot.

Staff have a duty to safeguard those in their care but the rights of the individual to sexual expression, privacy and intimacy have to be balanced with the duty to protect.

Staff should consider how much information they share or need to share with families. In this case Jack, because of what he was told in telephone conversations with staff believed that this father's '*friendship*' with Joy was no more than that.

Staff should consider their duty to protect and safeguard the rights of persons in their care and balance this against the views and concerns of relatives.

It is important that the person with a dementia, family members and partners have support and that their voices / wishes are heard. Staff may need to consider referral to Independent Advocacy services.

***NB: this case study has been adapted from a number of sources, the origins of which are uncertain***

# 9. Staff support and training

It is possible to hold different values and beliefs about sex and sexuality and implementing this Guidance does not mean that an individual will necessarily agree with every aspect of it. It should be accepted however, that the Guidance will assist practice and decision making and have benefits for anyone living with a dementia i.e. the person with dementia themselves, their partners, carers and families.

Staff whose personal views conflict with this Guidance should discuss these issues with their Manager and solutions should be sought, including staff development and training in these areas of their work.

Issues around sexuality and relationships can be difficult to address. By their very nature, they are intimate and personal and people may be reluctant to discuss their own lifestyles and experiences. Equally, some staff may be uncomfortable about raising such issues.

Staff will require training and support in order to respond appropriately to the needs of people with a dementia, their partners, carers and families. Staff need to be given time and space in supervision and within staff groups to discuss sexuality, relationships and dementia. They need support to examine their own feelings and to deal with the challenges that this issue will present.

Training programmes can benefit from input by experienced dementia care professionals and from people with a dementia themselves, their partners, carers and families however, this will have to be handled in a sensitive and supportive way.

Staff need to be aware of the personal and sexual relationship needs of people with dementia and ensure that these individuals and their partners are helped to understand their circumstances and express their sexuality in a way that is safe and legal for them to do so. Carers and families will also need a lot of support from informed and competent staff.

People with a dementia, their partners, carers and families need to feel supported and respected and have opportunities to live the fulfilled and meaningful lives that they are entitled to.
All staff will be offered appropriate training on sexuality and relationships:

- As an integral part of their induction into the work.
- To ensure that they have consistent and up to date information.
- That reflects their different roles and levels of engagement with people with a dementia, their partners, carers and families.

Staff should also receive training on Discovering Diversity. An on-line learning programme is available at www.diversity.hscni.net or http://diversity.hscni.net

Staff have a key role to play if people with dementia, their partners, carers and families are to benefit from a positive approach to sexuality and self-image. This means that particular attention should be paid to the responses that are made to people with a dementia, their partners, carers and families about sex and sexuality, by everyone who supports them.

This will allow for good practice, ensuring that an opportunity is provided for all staff to discuss the messages they give to people with dementia, their partners, carers and families both explicitly and implicitly; and that all staff work to dispel some of the attitudes commonly held regarding sexuality and people with a dementia.

Staff have a right to expect from management:

- A consistent approach to issues on sexuality and relationships from all levels of staff and management.
- Clarity about lines of responsibility and accountability.
- Guidance, support, training and supervision.
- Specialist Training for specific staff as deemed appropriate.

To equip and support staff to undertake their roles, the Trust will provide access for staff to a Rights based awareness / training programme on Sexuality, Relationships and Dementia Care appropriate to their professional requirements that may include any or all of the topics listed in **Appendix 4**

Support, including supervision, should be available for all staff.

Staff teams should develop reflective practice sessions.

Managers (service providers) should use the Northern Ireland Adult Safeguarding Partnership (NIASP) Framework (HSC 2016) to identify and set out training and development pathways for their staff and volunteers, to ensure they have the appropriate skills and knowledge to engage in preventative activity and respond to safeguarding concerns commensurate with their role.

Training programmes should be in line with the thematic and tiered approach set out within the Regional Dementia Learning and Development Framework which is available at: www.hscboard.hscni.net/our-work/social-care-and-children/dementia/learning-development-framework/

Senior Managers within the Trust will identify the appropriate levels of training for staff within Dementia Care Services. The training will be planned and co-ordinated by the Dementia Care Team in conjunction with Social Services Training, Health Improvement Service and specialist training organisations. This training should be designed and delivered in such a way that it meets the training and development needs of both individual staff and teams.

Trusts should collaborate on the design and delivery of these programmes to ensure a consistent and informed approach and staff need to be aware of what is being covered in the programme.

Trusts should also ensure that Providers with whom the Trust has a contract should provide appropriate training programmes to staff.

## Case Study 12

**Sean's Story (Domiciliary Care)**

Sean has a dementia but with support from his two married daughters and the Domiciliary Care Service he has been able to continue to live in his own home.

He needs support with personal care such as washing and dressing and the preparation of simple meals but in recent months his behaviour and his language towards staff has become overtly sexual and explicit.

Sean would grab staff inappropriately and they found this uncomfortable and at times physically hurtful.

The Domiciliary Care Manager was concerned when staff reported an incident and became reluctant to undertake visits to Sean's home. One member of staff even said that she was '*afraid'* to go into his house particularly when her duties included intimate personal care, which they frequently did.

The Manager did not always have a male member of staff available to support Sean and asked the Dementia Specialist for help. The Manager did not want to withdraw

the service but she was keen to understand the reasons for Sean's changed behaviour and ensure that she could still offer this much needed support to Sean and his daughters.

By talking to Sean's daughters, the Dementia Specialist was able to understand more about his background and explain to them also how dementia can change a person's perspective and behaviour.
By gaining a better understanding of Sean, the Dementia Specialist was able to talk to staff and help them develop strategies that would allow them to continue to support Sean and diverting his attention (e.g. talking about the weather, his hobbies or football) without offending his feelings.

The Dementia Specialist also facilitated access to other social outlets for Sean and staff continue to provide a Domiciliary Care service. There is on-going support for staff from Managers and the Dementia Care Team. As a result, Domiciliary Care staff are feeling more confident and better able to support Sean.

**Discussion / Learning Points**

Staff induction and training needs to include the use of diversionary techniques which re-directs the individual's attention or behaviour and does so in a way that does not offend or embarrass the person with a dementia.

Any response / intervention by staff designed to divert the attention of the person with dementia should be person-centred. What diversionary techniques might be used by staff or family members?

Building up Life Story knowledge is a more person-centred way of engaging with and supporting a person living with a dementia.

Staff require on-going support through training and supervision.

Managers must ensure that staff are supported through 'Lone Worker' procedures.

***NB: This case study has been adapted from the original with the kind permission of the authors of The Last Taboo ILC-UK (2011)***

# 10. Care practice

At the core of this Guidance are the principles of person centred care, treatment and planning as well as support for partners, families and carers. At all times the aim will be to put the person with dementia at the centre of the care they receive and, so far as their understanding and capacity allow, in control of their lives and decisions.

### 10.1 Personal, Social and Emotional Care

A person living with a dementia may require support with their personal care. This can be a difficult or embarrassing experience for that individual, particularly if they are anxious or confused about who is delivering their care. Their anxiety can be more pronounced when care giving includes activities such as washing, dressing and eating. These activities can involve care interventions that are considered to be intimate and requiring great sensitivity.

People with dementia should always be encouraged and given the opportunity to carry out those aspects of personal care that they can do for themselves so as to maintain their independence and dignity.
Wherever possible, the person with a dementia should always be consulted as to their preference regarding the gender of the member of staff providing intimate personal care to them and these preferences should be respected as far as resources allow. Their care plan should reflect their choices and state clearly how care is to be delivered.

Everyone, including those with a dementia, will have different ways of expressing their sexuality and this is part of their personality.

With the onset of dementia, sexual feelings can become stronger or lesser and sexual behaviour may be exhibited in different ways.

Services should reflect and respect the wide variation in personal, social and emotional experience of persons with a dementia, their partners and carers.

In addition to the activities that are essential for daily life and comfort, the expression of sexuality and sexual needs should be a routine aspect of the assessment, care planning, intervention and evaluation process. The issue should be raised sensitively and as appropriate and not just when a problem arises

The individual's sexual orientation should also be respected, although their wishes may not necessarily be for a carer of the same or the opposite gender. There may be reasons why a person with a dementia would prefer one person rather than another that have nothing to do with their sexual orientation.

Support to meet the needs of people with a dementia, their partners, carers and families includes:

- Information
- Access to counselling
- Space and time to talk
- Respect for intimacy
- Privacy and sensitivity (for new or existing relationships)
- Help in maintaining the personal and social skills that support a relationship to continue or progress
- Help in modifying behaviour (including a holistic assessment to help understand the behaviour, particularly where those behaviours are challenging

- Protection from exploitation or abuse
- Recognition and response to capacity issues

Situations of intimate personal care may be regarded as erotic by the person in receipt of the care. Staff should be aware of this possibility, and seek support from management if it occurs.

Management support should include:

- Induction
- Supervision
- Training
- Additional staff or change of staff (if appropriate)

Staff who provide intimate personal care to people with a dementia will need training and support to understand and respond to situations:

- Understanding how interventions may be misconstrued
- Knowledge of diversionary activity
- Sexual arousal and harassment

Where a member of staff engages in any activity that may be construed as inappropriate or unprofessional, they may be committing an offence and, if proven, be liable to dismissal and criminal prosecution.

The Sexual Offences (Northern Ireland) Order 2008, Part 4, Sections 43 - 57 describes those activities which if engaged in would constitute an offence and render the offender liable, on conviction, to a period of imprisonment.

Sexual offences may include the following:

- Inappropriate touch - for example of breasts, genitals, anus, mouth
- Masturbation of either or both persons
- Penetration or attempted penetration of anus, mouth, vagina with or by penis, fingers or other objects.
- Involvement in pornography
- Indecent exposure
- Sexual harassment

## Case Study 13

### Aayushi and Peter's Story (Day Care)

Aayushi and Peter had been looking forward to enjoying their retirement together. Then Aayushi was diagnosed with Alzheimer's disease. As her dementia progressed, she was offered two days per week in a Day Centre in order to help maintain her social interaction and provide a short break for Peter. At first Peter

insisted on accompanying her to the Day Centre and staying with her for part of the day. It was clear that he found the changes in his wife difficult to cope with, despite support from staff. He said he had lost the woman he fell in love with. Aayushi found verbal communication very difficult and would approach all men in a sexual manner.

Aayushi would smile, hold hands, kiss and rub herself against any man who was near or approached her. Staff had attended dementia training and, in line with best practice, maintained records of their observations of Aayushi's behaviour. They also sought further advice from the Dementia Specialist. Following a Multi-Disciplinary Team meeting and in line with guidance from the Dementia Specialist, the staff were encouraged to promote appropriate physical contact for Aayushi.

An Aromatherapist came to the Centre to give Aayushi regular gentle hand and foot massages every week. Aayushi was also supported to become involved in a full programme of activity that was meaningful and pleasurable for her.

During work to develop her life story, staff found that Aayushi had been interested in clay modelling and pottery. She was also keen on fashion and make-up and always took great pride in her appearance. Aayushi also enjoyed going out for long walks. All of these activities were incorporated into her care plan and as a result, Aayushi appeared much happier and no longer seemed to need explicitly sexual contact when she was meaningfully occupied and receiving the regular massage. The massage provided an alternative, appropriate, and pleasurable means of touch. But for Peter the situation remained difficult as he no longer found his wife desirable. He found it helpful to have the support of staff on his visits, and with support from the Centre he asked his GP to be referred for bereavement counselling to help him come to terms with the personal loss he felt.

**Discussion / Learning Points**

Working on Life Stories is important and must include details of the individual's previous interests and hobbies.

Meaningful activity can provide the person with a dementia with a sense of fulfilment and self-worth. Diversionary activity can also help to reduce inappropriate or compromising behaviour. What types of diversionary activity might be appropriate for a person with a dementia?

How might staff try to establish effective communication with a person with a dementia whose verbal communication is limited?

Staff should be aware of the impact of a changing relationship on partners including feelings of grief and loss and should refer individuals for appropriate counselling and support.

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### 10.2 Relationships and Friendships

People with a dementia should be enabled to engage in a wide variety of relationships as they wish as long as these are within the law, mutual and consenting.

Relationships of all sorts are important to our sense of well-being. It is important for people with a dementia to have the opportunity to maintain existing relationships or develop new relationships.

People with a dementia may not have speech and it is important to recognise that they may be trying to communicate in other ways. To help with understanding how and what a person with a dementia may be communicating, a guide to effective communication in dementia care is available at: www.publichealth.hscni.net/publications/communicating-effectively-person-living-dementia

Having difficulty with communication should not mean that the persons need for relationships and sexual expression is underestimated or overlooked. Living with people for long periods of time, in a family, care home or other care facility, is likely to create familiarity and security between some individuals which could be very important to their lives. People vary in their attitudes and expectations of relationships and staff will be expected to deal with all situations with sensitivity.

Staff should take positive steps to enable people with a dementia to maintain relationships or develop new ones which include providing support to:

- Maintain and extend their network of friendships
- Find new relationships and renew old ones
- Use methods like “life story” books to acknowledge old friendships
- Develop links within the local community, for example through clubs, sporting activities and adult education classes

Staff should also ensure that:

- Individual friendships are supported where there is no exploitative behaviour
- The relationships formed by people with a dementia who do not use speech to communicate are not underestimated
- There is no pressure exerted on those who do not wish to have links or sexual relationships with others; service users are free, if they so wish, not to engage in sexual relationships
- Partners, carers and families feel supported

### 10.3 Sexual Orientation and Sexual Behaviour (refer to Section 6)

Within the limits of the law, sexual diversity and expression should be respected and supported.

In society today there is a diversity of sexual needs and expression. This is no different for people with a dementia. People with a dementia may form sexual relationships with either sex, as other people do.

A sexual relationship can offer mutual support and pleasure to the partners involved and it is important that staff do not make assumptions about anyone's sexual orientation / gender, identity or the status of a relationship.

In practice, staff should respect any mutual relationships that are formed and should not discourage consensual sexual activity. Consent and capacity are important elements to be considered in any sexual relationship.

If a person with a dementia tells a member of staff about any sexual relationship, or their desire for such a relationship, this should be treated positively and with sensitivity:

- By keeping information confidential unless otherwise indicated (e.g. issues of vulnerability).
- By offering support if needed, in the form of information and relevant resources.
- By contacting outside agencies for further support and advice if required with the individual's consent.
- By advising on safer sex practices.
- By giving support if the individual wishes to tell others e.g. partners, carers and / or family.

The needs and sexual expression of people with a dementia are no different than is to be found in the population at large. The person with a dementia may just have more difficulty expressing that need and those around him or her i.e. partners, carers and families will have their own views and / or concerns about any particular situation.

Any behaviour that seems to be giving rise to concern should be discussed with a Line Manager, named worker or designated officer for vulnerable adults. Clarity on whether this issue is of a value-base or a legal issue will need to be established. For example, even if your own value base or attitude to sexual relationships or practices is different from that of the person with a dementia with whom you are working, it is not proper for you to pass judgement or discriminate against the individual in any way. Concerns that you may have which may be based on your personal values should be discussed immediately with your Line Manager or supervisor

All the above applies equally to heterosexual and LGB relationships. If there are issues around the vulnerability of the individual(s), staff must ensure full compliance with relevant safeguarding policies and procedures.

### 10.4 Planning for the Future

Dementia is a progressive condition. This means that the symptoms will gradually get worse over time and planning ahead for future care and treatment is important.

Staff should be aware of the following:

**Advance Directives** are limited to the issue of 'refusing treatment.' These are governed by common law instead of any statutory act. This means that they should be followed by the health and social care team as long as they know about it.

**Power of Attorney** enables an individual to identify someone (called an Attorney) to deal with their 'property and affairs.' Whereas a Power of Attorney ceases when the individual no longer has capacity to manage their affairs, an **Enduring Power of Attorney** will continue.

For more information about Enduring Power of Attorney, refer to The Office of Care and Protection at: https://www.nidirect.gov.uk/contacts/contacts-az/office-care-and-protection

**NB: Neither the Advance Directive nor the Power of Attorney cover relationships**

Some further guidance for planning ahead with dementia is available at: https://www.publichealth.hscni.net/publications/planning-ahead-dementia

### 10.5 Confidentiality

Unless otherwise agreed with the person with a dementia, confidentiality about their sexuality and practice must be maintained.

In those situations where maintaining confidentiality may not be possible (legal or health reasons, safety issues or disclosure of abuse) and other parties need to be informed, staff should follow agreed procedures and always try to get the consent / agreement of the person with dementia (or person acting in their best interests). If confidentiality is to be breached, the person with dementia (or person acting in their best interests) should be informed.

HSC Trusts must use existing procedures and legislation to protect the rights of a person with a dementia to privacy and respect for the processing of their personal data.

Confidentiality will need to be breached when a disclosure of abuse, sexual or otherwise, has been made. Staff members have the responsibility under their duty of care to protect the service user from further abuse and to report it as per safeguarding requirements.

The person with dementia (or person acting in their best interests) must be informed of these responsibilities and the consequences of breaching confidentiality.

In situations which are not clear, staff should seek support and advice immediately from their Manager or in supervision.

Relevant legislation includes:

**The Data Protection Act (2018)** which became effective from May 2018, controls how personal information is used by organisations, businesses or the government.

**The General Data Protection Regulation (GDPR) 2018** which was agreed by the European Parliament and Council in 2016 and became effective from May 2018, is the primary law regulating how organisations, businesses and governments protect the personal information of individuals.

### 10.6 Privacy

People with a dementia, their partners, carers and families have the right to privacy and this right should be acknowledged and respected at all times by staff and others.

Relationships need privacy in places where the person with dementia can relax and entertain. It should be remembered that communal areas in care homes and day care centres are public spaces and are therefore not appropriate places for sexual activity.

Certain behaviours, like masturbation, nudity and sexually intimate contact are acceptable only in private however, a person with a dementia may, because of the changes to their brain, feel less inhibited and behave in ways that are considered inappropriate and / or distressing for others. Staff must encourage the person with a dementia to move to somewhere more private (bedroom or bathroom). This is as much about protecting the individual's rights, privacy and dignity as it is about avoiding public embarrassment or negative reaction.

As part of the individual care planning process staff should discuss with the person with a dementia, their partners, carers and families, expectations around privacy, relaxation and space to entertain and as far as possible, facilitate the wishes of everyone involved.

To offer dignity and increase the safety of people with a dementia who live in a communal setting and who are sexually active, staff should ensure that private space is available for that individual to engage in sexual relationships, ideally in their bedrooms where appropriate.

## Case Study 14

### Citlali and Aleksy's Story (Care Home)

Citlali had been married to Aleksy for 38 years when she received her diagnosis of dementia. Aleksy cared for her until he was no longer physically able to do so and Citlali moved to live in a Care Home. Aleksy visits every day and he and Citlali spend much of their time together in Citlali's room.

Unfortunately, they were often disturbed by staff, particularly staff doing cleaning and laundry tasks. On one occasion Aleksy and Citlali were in bed together when they were disturbed by staff. Although staff apologised immediately, Aleksy and Citlali were embarrassed and upset.
An assessment by staff from the Dementia Care Team concluded that Citlali did have capacity to consent to a sexual relationship with her husband however, this had not been communicated to all staff.

The Manager apologised to Aleksy and Citlali and reassured them that she would take steps to address the issue with staff.

All staff including ancillary staff were reminded of the rights of residents and their families to privacy.

Laundry, cleaning and other household tasks were rescheduled so as not to coincide with Aleksy's visits and the Manager gave Citlali a '*Do Not Disturb*' sign which she or Aleksy could place on the door for others to see and respect.

**Discussion / Learning Points**

All staff need to respect resident's privacy at all times including the right to be intimate. How can this need for privacy be supported in a Care Home, family home or other group care setting?

Information about the needs and rights of people with a dementia should be shared with all staff on a need to know basis, including those who are not providing direct personal care e.g. ancillary / catering staff.

Awareness raising and training programmes must include non-care staff.

Care Plans and staff practice should support the rights of individuals to intimacy and privacy.

Because a person's capacity to give consent may change over time, staff should continue to monitor this aspect of the individual's care.

Who does / should do the assessment of capacity?

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### 10.7 Masturbation / Self-pleasuring

It is normal behaviour for both men and women to masturbate. It is a safe way to reduce stress and explore one's own sexuality.

Staff should not prevent people with a dementia from masturbating but the individual should be helped to understand that masturbation / self-pleasuring should take place in private (bedroom or bathroom with door closed) and that it is inappropriate to engage in such activities in a public / communal space.

Staff need to inform the individual of what is acceptable in a sensitive and non-judgemental way. Reprimanding someone for masturbating is not appropriate and may leave them feeling frustrated and humiliated.
For some people, masturbation can give physical pleasure, release tension and relieve boredom. Others may become very frustrated by being unable to masturbate. It is rare but, constant masturbation may bring about minor physical harm.

If there is a concern about masturbation this should be discussed with the Line Manager. If it is felt necessary, the Line Manager should set up a meeting of relevant professionals, (and the person with a dementia, their partner, carer and family if appropriate) to discuss the issues and develop an appropriate plan. The meeting should consider the needs of the individual and how these may be best addressed. Specialist advice may be necessary.

### 10.8 Pornography

Pornography is a controversial subject however, its use may sometimes help people with dementia to achieve sexual satisfaction which they might otherwise be unable to attain.

People with a dementia have the same right as others to obtain and enjoy material that is publically available e.g. ‘top-shelf’ magazines. However, there is a need to draw a distinction between different ‘types’ of pornography.
Although some pornographic material is publicly available, it can be regarded as offensive and degrading. A person with a dementia cannot readily be denied something that is available to others; it is their choice if they wish to use it.

People with a dementia who use pornographic materials must be helped to understand that:

- Certain pornography is illegal
- Most people do not behave as the people in the magazines / videos do.
- People can be offended by pornography
- It must be kept and used in private and not brought into any public part of the establishment. A bedroom is usually considered the most appropriate place for such material

Case Study 15 below, highlights some of the challenges / conflicts that staff may face in relation to this issue. All staff should be aware of their employer’s policy in relation to assisting persons with a dementia to access or purchase pornographic material.

It would also be important that staff assure themselves that the person with a dementia has capacity to make choices in respect of this issue and its use should be kept under review.

Staff need to strike a balance between protecting the rights of the individual with the requirements of the law and any potential damage to the person with a dementia and others. When issues arise, staff must inform their Line Manager.

## Case Study 15

**Steve, Mike and Ethan (Care Home)**

Steve is 68 years old and has a diagnosis of dementia. He lived alone and had managed to care for himself reasonably well until one evening three months ago, he was found wandering a good distance from his home dressed only in trousers, shirt and bedroom slippers. It was a cold and wet evening.

Steve has no known relatives living nearby; an elderly neighbour had kept an eye on him. Because he was deemed to be vulnerable, the Social Worker arranged for his admission to a Care Home. Steve was happy to move to the home and knew that he would be properly cared for.

When he lived at home, Steve went to the local shops and would occasionally purchase a pornographic magazine.

One evening, he gave some money to Mike, a member of staff, and asked if he would purchase a magazine for him on his way to work the following day. Mike refused and said that he wouldn't buy such material as he felt it was inappropriate and immoral.

Steve was upset but a few days later, he made the same request of Ethan, another member of staff. Ethan made the purchase and gave the magazine, receipt and change to Steve in a plastic carrier bag. Ethan advised Steve to keep the magazine in his bedroom.

**Discussion / Learning Points**

What is your employer's policy regarding the purchase / use of pornographic material including use of internet sites?

Can a distinction be made between 'top-shelf' magazines and internet material?

Was Mike right to refuse to make the purchase because he believed that the material was inappropriate and immoral?

Was Ethan right to purchase the material and bring it on to the premises?

Should either member of staff have discussed the request from Steve with their Line Manager first.

Staff need to respect the right of the person with a dementia to engage in activity that does not harm themselves or others.

All staff need to respect the right of the person with a dementia to privacy and choice. How do you protect the individual's rights to privacy, choice, independence and fulfilment?

Staff need to be given time and space in team meetings and supervision to discuss the issues raised in this Operational Guide and feel supported to deal with the moral, practical and legal challenges that may present themselves in the course of their work.

***NB: This case study has been adapted from discussions with staff from across a number of HSC Trusts***

### 10.9 Prostitution

Under the Human Trafficking and Exploitation (Criminal Justice and Support for Victims) Act (Northern Ireland) 2015 it is a crime to pay for sex.
https://www.nidirect.gov.uk/articles/paying-sexual-services

### 10.10 Internet / Social Media / Chat-lines

The internet can be a positive and enjoyable way to learn, keep in touch with friends, watch movies or play games. However, at times it can be abused and can make its users vulnerable. It is important that staff support people with dementia to stay safe on-line and inform them about safety.

This may be difficult for someone whose memory is failing due to their dementia and staff should offer advice and practical guidance about:

- Privacy on-line
- Passwords
- Sharing personal details

Chat-lines, dating-lines or sex-lines also pose an opportunity for exploitation. These tend to use premium rate numbers and a person with a dementia may believe that they are forming a meaningful relationship with a person on the telephone but be unaware of the impact upon them emotionally and financially.

People with a dementia may be able to access pornography online via the internet or Smart phones. This can be a growing problem for some services. In law, any on-line extreme pornography is considered illegal. It is possible to restrict access to the internet so that illegal pornographic sites cannot be visited.

Dealing with this requires the Trust to agree clear guidelines about what is / is not acceptable, a clear protocol on what must be reported to police and who is responsible for this.

The guidelines will need to balance the rights of the individual, the requirements of the law, and any potential damage to the person with dementia, their partners, carers, families or others. When these issues arise, staff must inform their Line Manager.

### 10.11 Exploitation and Abuse

All staff have a duty of care to protect the people to whom they provide treatment, care and support from any form of harm, abuse or exploitation. In the case of harm, a member of staff could be found negligent if it were assessed that harm could reasonably have been foreseen.

Everyone with a dementia, their partners, carers and families have the right to be protected from abuse and exploitation from whatever source.

All staff must be trained in the Trust's Safeguarding Procedures and apply these to their work with people with a dementia, partners, carers and families

Abuse can never be condoned, irrespective of who is alleged to have caused the harm.

Members of staff must have no sexual contact or intimate relationship with a person with a dementia, their partners, carers or family.

In cases where staff are concerned that an individual is being or is suspected of being exploited or sexually abused, then it is their statutory and professional duty to respond and report their concerns in line with Safeguarding Vulnerable Adults Policy and Procedures

There are always potential and actual risks of abuse (i) service user towards another service user(s), (ii) staff towards service users and (iii) service users towards staff.

Provider organisations need to ensure that their procedures cover all of these scenarios. In the case of someone using health and social care services, most abuse is perpetrated by someone known to them.

### 10.12 Disclosure and Barring Arrangements

The Safeguarding Vulnerable Groups (Northern Ireland) Order (2007), as amended by the Protection of Freedoms Act (2012), provides the legislative framework to ensure unsuitable people cannot undertake specific types of work. These are known as 'Disclosure and Barring Arrangements.'

The Disclosure and Barring Services (DBS) is responsible for maintaining the lists of individuals barred from engaging in 'regulated activity' with children and adults across England, Wales and Northern Ireland. Regulated activity is work which a

barred individual must not undertake. It is a criminal offence for a barred person to seek or undertake work from which they are barred, and it is an offence for organisations to 'knowingly employ' a staff member or involve a volunteer in regulated activity if they are barred. In order to determine this, organisations must request an Enhanced Disclosure with Barred List check through Access NI.

Employers, Trusts, professional regulators and other bodies also have a responsibility to refer to the DBS anyone who has harmed or poses a risk of harm to a child or adult and who has been removed from working (paid or unpaid) in regulated activity, or would have been removed had they not left. The DBS will consider whether the person is unsuitable to work in regulated activity and make a decision as to whether the person should be barred.

### 10.13 Involvement of Partners, Carers and Family

It is important for the overall well-being of everyone, particularly the person with dementia, that staff work in partnership with partners, carers and families. The relationship should be a supportive one and take into account, human rights and the principles of consent and best interests.

It is considered good practice to keep partners, carers and families informed about the personal and sexual needs of the individual with a dementia however, under the Data Protection Act 2018, partners, carers and families are not entitled to have access to the individual's personal information without the consent of that individual.

Furthermore, partners, carers and families cannot substitute their consent for the person who is incapacitous.

Some people with dementia may prefer that their partner, carer or family would not be involved in discussions and may wish to have an advocate (named worker, social worker or independent agency) involved for support.

If there is disagreement with partners, carers or families about any aspect of sexuality, the matter should be discussed with a Line Manager.

Sometimes the wishes of the partner, carer or family regarding sexual behaviour may conflict with the wishes of the person with dementia.

Such situations are usually resolved after discussion but if no agreement can be reached, the wishes of the person with dementia should be supported as long as those wishes are not illegal or abusive.

It is important that the principles of person-centred planning are upheld.

### 10.14 Partnership, Marriage and Divorce

People with a dementia have the same right as others to form relationships and partnerships. A wish to live together or to marry should be respected and supported.

People with a dementia may have existing or form a variety of new relationships. It should not be assumed that these will always be with other people with a dementia.

The legal, emotional and psychological aspects of living together should be discussed with both partners. No greater expectations should be held about the viability of the partnership than would be held about any other partnerships in the community. An experienced counsellor may help to ensure that the couple are aware of the commitment they are entering into.

Same sex couples who wish to co-habit will be offered the same support as heterosexual couples.

There is no restriction in law on the right of a person with a dementia to marry. If they are over 18 they may marry as long as the Registrar of Marriages is satisfied that both parties understand the commitment they are making.

With regard to divorce, there is no difference in law between people with a dementia and others who wish to divorce. The Matrimonial Causes Act (1973) states that marriage can be made void if either party was suffering from a mental disorder (this definition would include people with a dementia). In practice, it is unlikely that this would be used as grounds for annulment.

Under Part 4 of the Civil Partnerships Act (2004) partners of the same sex may enter into civil unions.

Forced marriage is regarded as an abuse of human rights and a form of domestic abuse. It can happen to both men and women. Article 12 of European Convention on Human Rights upholds the right to marry and to have a family. The courts now have the powers to prevent forced marriage from occurring or offer protection to those who have been forced to take part in a marriage. For further information, see The Right to Choose: Statutory Guidance for Dealing with Forced Marriage (2014) https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/70194/forced_marriage-right-to-choose.pdf

With regard to any of the issues above the client's capacity to consent should be fully considered.

**10.15 Sexual Health: Awareness, Screening and Testing**

Good sexual health is as important for people with a dementia and their partners as for anyone else and everyone has the right to access timely and appropriate sexual health screening and testing services.

All staff have a duty to promote good sexual health awareness and care for people with a dementia and their partners and should provide appropriate information and support.

Information and advice should be given in a way that will support good interpersonal and sexual relationships and encourage positive self-image and good self-esteem.

Information should include advice about safe sex, personal health care and preventing STIs including HIV and should be provided in a way that maintains confidentiality.

All staff should comply with any procedures / guidance that are in place including policies on sexual health and safeguarding standards.

People with dementia who are sexually active should be given information about safe sex and use of condoms / femidoms.

Training in Sexual Health and HIV Awareness, including infection control, is necessary for all staff and should be available to people with dementia, their partners, carers and families also.

Staff should be aware of and be able to facilitate access to services relating to sexual and health e.g. GUM / Sexual Health Clinics. Details of GUM / Sexual Health Clinics within NI are available at: [www.sexualhealthni.info/gum-clinics-northern-ireland](www.sexualhealthni.info/gum-clinics-northern-ireland)

Not all services will have experience of working with people with dementia and therefore staff should ensure that appropriate support is given to individuals who wish to access these services. People with a dementia may need help with understanding the process / interventions and their consent will be required if they are to have a third party act on their behalf in any consultations.

### 10.16 General Healthcare

In addition to sexual health screening and testing, staff should be aware of and facilitate access for people with dementia to allied screening programmes such as those for Cervical and Breast cancer for women and testicular cancer for men.

People with a dementia, their partners, carers and families should be given information about best practice in relation to methods of testicular self-examination for men and breast self-examination for women.

People with dementia should have information about and access to the full range of health care services including, dental care, hearing, foot care, eye sight and skincare.

# 11. Guidance sign-off (Typed Name / Scanned Signature Sufficient)

__________________________________
Lead Guidance Author

__________
Date

__________________________________________________________
*Director / Assistant Director / Clinical Director / Associate Medical Director

__________
Date

(*Delete those not applicable)

**Appendix 1**

# Legislation, protocols and guidance

**NB: The Legislation, Protocols and Guidance listed below was examined during the development of this Guide and not all of it may be equally pertinent to Northern Ireland. It is strongly advised that staff take legal advice on all of these complex issues.**

Carers Assessments https://www.NIDirect.gov.uk/articles/assessments-carers

Civil Partnerships Act (2004)

Criminal Justice and Immigration Act 2008

Criminal Justice and Public Order Act (1994)

Criminal Law Act (NI) (1967)

Data Protection Act (2018)

DHSSPS (2003) Good Practice in Consent Guidance

DHSSPS (2007) The Safeguarding Vulnerable Groups (NI) Order as amended by the Protection of Freedoms Act (2012)

DHSSPS (2010) Adult Safeguarding: Regional and Local Partnership Arrangements (2010)

DHSSPS (2011) Improving Dementia Services in NI - A Regional Strategy

DHSSPS (2015) Adult Safeguarding in Northern Ireland: Prevention and Protection in Partnership

Disability Discrimination Act (1995) (amended 2005)

DoH (2017) Keeping Adults Safe: A Shared Responsibility - Standards and Guidance for Adult Safeguarding
https://www.volunteernow.co.uk/app/uploads/2019/04/Keeping-Adults-Safe-A-Shared-Responsibility.pdf

Equality Act (Sexual Orientation) Regulations 2006

European Convention on Human Rights

Freedom of Information Act (2000)

General Data Protection Regulation (GDPR) (2018)

Human Rights Act (1998)
Human Trafficking and Exploitation (Criminal Justice and Support for Victims) Act (Northern Ireland) 2015 https://www.nidirect.gov.uk/articles/paying-sexual-services

Marriage Equality Act
Matrimonial Causes Act (1973)

Mental Capacity Act (England and Wales) (2005)

Mental Capacity Act (England and Wales) Code of Practice (2005)

Mental Capacity Act (NI) 2016 https://www.health-ni.gov.uk/mca

Mental Capacity Act (NI) Code of Practice (2016) https://www.health-ni.gov.uk/mca

- Deprivation of Liberty (DoLs)
- Research Money and Valuables

Mental Health (Northern Ireland) Order (1986)

Offences Against the Person Act (1861)

Safeguarding Vulnerable Groups (NI) Order as amended by the Protection of Freedoms Act (2012):

Section 75 of the Northern Ireland Act 1998

Sexual Offences (Northern Ireland) Order 2008

The Right to Choose: Statutory Guidance for Dealing with Forced Marriage (2014) https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/70194/forced_marriage-right-to-choose.pdf

UN Convention on Human Rights

UN Convention on the Rights of Persons with Disabilities

Appendix 2

# Bibliography and recommended reading

Age UK (2017) Safe To Be Me: Meeting the Needs of Older Lesbian, Gay, Bisexual and Transgender People using Health and Social Care Services - A Resource Pack for Professionals www.ageuk.org.uk/globalassets/age-uk/documents/.../safe_to_be_me

Alzheimer's Australia (2014) Dementia, Transgender and Intersex People: Do Service Providers Really Know What Their Needs Are? https://www.dementia.org.au/sites/default/files/130739_LGBTI%20Discussion%.2_21.pdf

Alzheimer's Society (February 2015) Factsheet 482: Moving into a Care Home: Advice for Lesbian, Gay and Bisexual People with Dementia

Alzheimer's Society (April 2015) Factsheet 458: The Progression of Alzheimer's Disease and Other Dementias www.alzheimers.org.uk/factsheet/458

Alzheimer's Society (July 2015) Factsheet 514LP: Sex and Intimate Relationships www.alzheimers.org.uk/factsheet/514LP

Alzheimer's Society Scotland (October 2003) Information Sheet 28: Sexuality and Dementia www.alzscot.org/assets/0000/0163/sexuality-and-dementia.pdf

Alzheimer's Society (February 2017) Factsheet 480LP: Supporting a Lesbian, Gay, Bi-sexual or Trans-person with Dementia https://www.alzheimers.org.uk/sites/default/files/pdf/supporting_a_lesbian_gay_bisexual_or_trans_person_with_dementia.pdf

Archibald, C., (March 1994) Sexuality and Dementia: A Guide. University of Stirling

Bartlett, P. (2010) Sex, Dementia, Capacity and Care Homes. Liverpool Law Review. Vol 31:137-154 www.springerlink.com/article/10.1007/s10991-010-9077-6

Bauer, M., Fetherstonhaugh, D., Nay, R., Tarzia, L., and Beattie, E. (2013) Sexuality Assessment Tool (SexAT) for Residential Aged Care Facilities. Australian Centre for Evidence Based Care. La Trobe University

BHSCT (June 2015) Dementia and Behaviour: Affection, Intimacy and Sex - Information for Relatives - http://www.belfasttrust.hscni.net/services/3149.htm

BHSCT (January 2016) Procedure on Expressing Sexuality and Intimacy for People with a Dementia and Related Illnesses in Elderly Residential Homes

Cadwaladr, B (2018) Supporting Me To Be The Person I Want To Be: Understanding, Reflecting and Responding to Transgender Issues in Dementia

Care, University Health Board, Wales
http://www.wales.nhs.uk/sitesplus/documents/861/Supporting%20Me%20Transgender%20%20Dementia%20-%20final.pdf

CQC (2019) Relationships and Sexuality in Adult Social Care Services: Guidance for CQC Inspection Staff and Registered Adult Social Care Providers - available at: https://www.cqc.org.uk/sites/default/files/20190221-Relationships-and-sexuality-in-social-care-PUBLICATION.pdf

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Dourado M., Finamore C., Barroso M F and Laks J (2010) Sexual Satisfaction in Dementia: Perspectives of Patients and Spouses in Sexuality and Disability Vol 28 (3) pages 195-203

Duffy, F., and Richardson, J. (2018) CLEAR Dementia Care: Handbook on Implementation with Case Presentations

Duffy, F (2019) CLEAR Dementia Care: A Model to Access and Address Unmet Need. Jessica Kingsley. ISBN: 9781785922763

Elliot, M et al (2015) Sexual Minorities in England Have Poorer Health and Worse Health Care Experiences: A National Survey, Journal of General Internal Medicine, Vol 30 (1) pages 9-16

Family Planning Association (2017) Disability and Sexuality Policy
http://www.fpa.org.uk/sites/default/files/disability-and-sexuality-policy-statement.pdf

HSC (2016) Communicating Effectively with a Person Living with a Dementia
www.publichealth.hscni.net/publications/communicating-effectively-person-living-dementia

HSC (2016) Regional Dementia Learning and Development Framework
http://www.hscboard.hscni.net/dementia/learning-development-framework

HSC (2016) The Early Stages of Dementia
www.publichealth.hscni.net/publications/early-stages-dementia

HSC (2016) Northern Ireland Adult Safeguarding Partnership (NIASP) Framework Training Strategy
http://www.hscboard.hscni.net/download/PUBLICATIONS/safeguard-vulnerable-adults/niasp-publications/NIASP-Training-Framework-revised-7-June-2016.pdf

HSC (2016) Northern Ireland Adult Safeguarding Partnership (NIASP) Framework

HSC (2017) Are You Worried about Dementia?

www.publichealth.hscni.net/publications/are-you-worried-about-dementia
HSC (2017) Sexuality, Relationships and Dementia
www.publichealth.hscni.net/publications

HSCB / PHA / HSC Trusts (March 2016) Adults with Learning Disabilities: Personal and Sexual relationships - Operational Protocol

ILC-UK (2011) The Last taboo: A Guide to Dementia, Sexuality, Intimacy and Sexual Behaviour in Care Homes. International Longevity Centre - UK, London

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Lichtenberg, PA and Strzepek, DM. (1990) Assessments of Institutionalised Dementia Patients' Competencies to Participate in Intimate Relationships. Gerontologist. Vol 30 No 1 pages 117-120

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Lipinska, D., (2017) Dementia, Sex and Well-Being: A Guide for People with Dementia, their Partners, Caregivers and Professionals. Kingsley. London

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www.scie.org.uk/dementia/living-with-dementia/difficult-situations/sexual-expression.asp

Steele, D., (May 2012) Intimacy and Sexuality Practice Guidelines for Long Term Care Homes in Lanark, Leeds and Grenville Draft #21

White, M. (2010-11) The Eternal Flame: Capacity to Consent to Sexual Behaviour Among Nursing Home Residents with Dementia. Elder Law Journal. Vol 18 pages 133-158

World Health Organisation (2015) First Ministerial Conference Report on Global Action Against Dementia. WHO Geneva. Switzerland (ISBN 978-92-4-150911-4)

World Health Organisation (2018) Towards a Dementia Plan: A World Health Organisation Guide. WHO Geneva. Switzerland (ISBN 978-92-4-151413-2)

**Publications**

PHA Dementia Publications are available on the following links:

www.publichealth.hscni.net/publications/dementia

www.publichealth.hscni.net/publications/delirium

**Appendix 3**

# Sources of information and support

**Age NI**
3 Lower Crescent
Belfast BT7 1NR
Tel: 08088 087 575
www.ageuk.org.uk/northern-ireland

**Alzheimer's Society**
30 Skegoneill Street
Belfast BT15 3JP
Tel: 028 9066 4100
Helpline: 0300 222 1122
Email: nir@alzheimers.org.uk
www.alzheimers.org.uk

**British Deaf Association**
Weaver's Court, Unit 5c
Linfield Rod
Belfast BT12 5G
Tel: 028 9043 7480
https://bda.org.uk/belfast-office

**Carers Northern Ireland**
58 Howard Street
Belfast BT1 6PJ
Tel: 028 9043 9843
www.carersuk.org/northernireland

**CAUSE**
Building 2
Lesley Office Park
393 Holywood Road
Belfast BT4 2LS
Helpline: 08456 030 291
www.cause.org.uk

**Dementia NI**
North City Business Centre
2 Duncairn Gardens
Belfast BT15 2GG
Tel: 028 9693 1555
Email: info@dementiani.org
www.dementiani.org

**GenderJamNI**
Tel: 028 9099 6819
www.genderjam.lgbt

**HSC Trusts**

Belfast Health and Social Care Trust
info@belfasttrust.hscni.net
www.belfasttrust.hscni.net

Northern Health and Social Care Trust
www.northerntrust.hscni.net

Southern Health and Social Care Trust
www.southerntrust.hscni.net

South Eastern Health and Social Care Trust
http://www.setrust.hscni.net

Western Health and Social Care Trust
http://www.westerntrust.hscni.net

**Informing Choices NI**
24-31 Shaftesbury Square,
Belfast BT2 7DB
0345 122 8687
www.informingchoicesni.org

**Institute of Psychosexual Medicine**
www.ipm.org.uk

**Interpreting Service NI HSC**
Tel: 028 9536377 (Mon to Fri 9.00am-5.00pm)
Tel: 028 9056 5565 (Out of Hours)
Email: interpreting@hscni.net

**John's Campaign** (for the right of people with a dementia to have a friend, carer or family member remain with them during their stay in hospital or care home)
www.johnscampaign.org.uk

**Mencap NI**
5 School Road
Castlereagh
Belfast BT8 7US
Tel: 028 9069 1351
www.northernireland.mencap.org.uk

**National Health Service (UK)**

www.nhs.uk/conditions/dementia-guide/Pages/about-dementia.aspx

**NI Direct**
www.nidirect.gov.uk/dementia

**Northern Ireland Health and Social Care Interpreting Service**
Business Services Organisation
Franklin Street
Belfast BT2 8DQ
Tel: 028 9536 3777
www.hscbusiness.hscni.net

**Office of Care and Protection**
Room 1.24, First Floor
Royal Courts of Justice
Chichester Street
Belfast BT1 3JF
Tel: 028 9072 4732

**Patient and Client Council**
Ormeau Baths
18 Ormeau Ave
Belfast BT2 8HS
Tel: 0800 917 0222
www.patientclientcouncil.hscni.net

**Rainbow**
LGBT Centre
23-31 Waring St
Belfast BT1 2DX
Tel: 028 9031 9030
www.rainbow-project.org

**Relate**
3rd & 4th Floors
3 Glengall Street
Belfast BT12 5AB
Tel:  028 9032 3454
Email: office@relateni.org
www.relateni.org/contact

**SAIL NI**
Tel: 028 9532 0023
www.sailni.com

**Sexual Health NI**
www.sexualhealthni.info

**Together in Dementia Everyday (Tide)**
3 Lower Crescent
Belfast BT7 1NR
Tel: 07841 457596
Fiona@lifestorynetwork.org.uk
http://www.tide.uk.net/

**TransgenderNI**
www.transgenderni.com/community

**Appendix 4**

# Suggested topics for inclusion in a staff training programme

Training programmes should be developed in line with the thematic and tiered approach set out within the Regional Dementia Learning and Development Framework which is available at www.hscboard.hscni.net/our-work/social-care-and-children/dementia/learning-development-framework/

**NB: The list below is not exhaustive and should be adapted or amended to meet the requirements of staff and the service**

Understanding Dementia: The Ageing Process and Types of Dementia

Communicating with a Person with a Dementia

Person-Centred and Relationship-Centred Dementia Care

Understanding and Managing Dis-inhibited Behaviours

Values, Rights and Principles in Care

Promoting Physical, Psychological and Social Well-Being in Dementia Care

Sexual Health and HIV Awareness, including infection control

Legal and Ethical Considerations in Dementia Care

Consent and Capacity including Legislation and Codes of Practice

Equality, Cultural Diversity and Inclusion in Dementia care

Working in Partnership with Families and Carers

Protection of Adults at Risk of Harm or in Need of Protection

Involvement in Decision Making

Learning Disability and Dementia

Trust Procedures and Protocols

Confidentiality

Involving Partners, Carers and Families

Medication and the Use of Non-Pharmacological Interventions

Gender, Sexual Identity and Orientation

**Apps4Dementia**

https://apps4dementia.orcha.co.uk

**CLEAR Dementia Care ©**

The CLEAR© Assessment Handbook is available to staff who have completed Level 2/3 CLEAR © training. For further details of available training, please contact the Dementia Lead or Dementia Service Improvement Lead for your Trust.

Duffy, F., and Richardson, J. (2018) CLEAR Dementia Care: Handbook on Implementation with Case Presentations

Duffy, F (2019) CLEAR Dementia Care: A Model to Assess and Address Unmet Need. Jessica Kingsley. ISBN: 9781785922763

**Delirium (training video)**

https://youtu.be/_c9M4FnDwOc

**Dementia Care Pathway**

https://vimeo.com/266497861/7c3be1ab9b

https://vimeo.com/266497861/7c3be1ab9b

**Dementia Learning and Development Framework**

The Dementia Learning and Development Framework and a promotional video are available at:
http://www.hscboard.hscni.net/our-work/social-care-and-children/dementia/learning-development-framework/

**Diversity**

Staff should also receive training on Discovering Diversity. An on-line learning programme is available at www.diversity.hscni.net or http://diversity.hscni.net

## Learning Packs

The Dementia Together NI project has purchased training packs for HSC staff. ‘Supporting Derek’ is a training pack on Learning Disability and Dementia while ‘Barbara’s Story’ is a more general programme on dementia. Details of these can be found at:

https://www.youtube.com/watch?v=O3ekO4QdKXU - Supporting Derek

Supporting Derek - circulated to all Trust - main contact LD&D Leads

https://www.youtube.com/watch?v=DtA2sMAjU_Y - Barbara’s Story

Barbara’s Story - circulated to all Trusts - main contact HSC Trust Dementia Leads

**Mental Capacity (Legislation and Codes of Practice)**

https://www.health-ni.gov.uk/mca

## NISCC Apps

https://learningzone.niscc.info

## Publications

PHA Dementia Publications are available on the following links:

www.publichealth.hscni.net/publications/dementia

www.publichealth.hscni.net/publications/delirium

## Safeguarding

Managers should also use the Northern Ireland Adult Safeguarding Partnership (NIASP) Framework (HSC 2016) to identify and set out training and development pathways for their staff and volunteers, to ensure they have the appropriate skills and knowledge to engage in preventative activity and respond to safeguarding concerns commensurate with their role - available at: http://www.hscboard.hscni.net/download/PUBLICATIONS/safeguard-vulnerable-adults/niasp-publications/NIASP-Training-Framework-revised-7-June-2016.pdf