Adult Safeguarding & People with Dementia in Nursing Homes

THE Alzheimer
SOCIETY OF IRELAND

Briefing Paper December 2022

THE Alzheimer
SOCIETY OF IRELAND

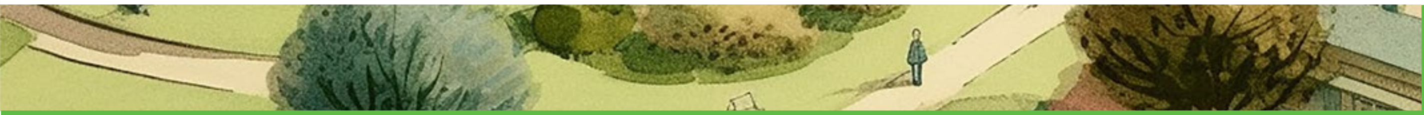
The Alzheimer Society of Ireland,
National Office,
Temple Road,
Blackrock,
Co Dublin.
A94 N8Y0

Tel: (01) 207 3800

Office opening hours – Monday to Friday, 9 am to 5 pm

Freephone Confidential National Helpline:
1800 341 341 / helpline@alzheimer.ie

General Enquiries: info@alzheimer.ie



Adult Safeguarding & People with Dementia in Nursing Homes

Briefing Paper December 2022

Dr Sarah Donnelly,
Assistant Professor of Social Work,
School of Social Policy, Social Work and Social Justice, UCD

Foreword

As Chair of the Irish Dementia Working Group (IDWG), I am very proud to write the foreword to this important publication. The last almost two years have been very challenging for us all, including those of us who are living with dementia. Against the backdrop of the pandemic, the IDWG became increasingly concerned about People Living With Dementia in nursing homes during COVID-19. We wanted to be a voice for the voiceless and advocate for those living with dementia, whose dementia has progressed to a point where they require long term care, and we believe that this policy paper helps to shine a light on their lives.

We are passionate about people living with dementia being rights holders, everyone in the world is entitled to their human rights……however many need support to exercise those rights and to ensure that their rights are protected.

Ireland’s track record regarding the protection of rights of the most vulnerable has been poor and this is also evident for people living with dementia. Policy responses have been reactive rather than proactive, usually responding to the latest scandal, and the primary adult safeguarding legislation, crucial in protecting adults at risk, hasn’t been progressed. There is a need for urgent action on this.

The deaths of so many people living in nursing homes in the early stages of this pandemic is the most unimaginable tragedy. It does appear that there was an attitude of out of sight is out of mind. The lives of those who survived the pandemic was also very seriously impacted as they were denied access to family and friends, the lifeline for us all during difficult times.

This report highlights the importance of a sense of self-worth and self-esteem, the right to agency, power and control and the need for people living with dementia to be supported to lead a more normal life. It emphasises the urgent need for a human rights-based approach to care and the need for all stakeholders to be trained and aware of rights-based approaches. It calls for a more open and transparent approach to making and addressing complaints, without fear of repercussions.

The report stresses that ‘safeguarding’ is everybody’s business, I’m proud that the IDWG made it our business.

I want to thank the members of the IDWG for all their input into this project. I want to acknowledge the excellent staff in The ASI who facilitate and support us to have our voices heard and who responded so positively to our concerns. I want to acknowledge the expertise of Professor Sarah Donnelly of UCD who worked with us in preparing this policy paper. Our work will continue to raise awareness of our paper and advocate for the implementation of the recommendations to bring about a rights-based approach to care for people living with dementia in Ireland.

Sean Mackell
Chair of the Irish Dementia Working Group

Acknowledgements

This briefing paper has embraced the ‘DEEP Guidelines’ **http://www.dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Writing-dementia-friendly-information.pdf**

Thanks to Dr Jeremy Dixon, University of Bath for permission to draw on his guidance document ‘Supporting People Living With Dementia to be involved in adult safeguarding enquiries,’ 31 Mar 2021, London: Department of Health and Social Care.

Thanks for Professor Jim Campbell, UCD, Celine O’Connor, Principal Adult Safeguarding Social Worker and Sinéad McGarry Independent Social Worker for peer reviewing the paper.

Dr Sarah Donnelly
Assistant Professor in Social Work / Director of Graduate Studies,
School of Social Policy, Social Work and Social Justice, UCD

The Alzheimer Society of Ireland is pleased to support the Irish Dementia Working Group as they advocate for the rights of people with dementia who live in Nursing Homes. This paper brings together people affected by the care currently available who have a vision for a rights-based future and academic expertise. We believe it to be a powerful collaboration with important recommendations directly from people living with dementia

We are grateful for Professor Donnelly’s time, knowledge and collaborative approach which led to a co-creation with integrity and value.

Clodagh Whelan
Advocacy Manager

Adult Safeguarding issues, human rights concerns, and the impact of COVID-19 on the lives of people living with dementia in Ireland

Introduction

While there has been an increased focus on ageing in place in the Irish context, for some people, including people living with dementia, nursing home care may be required to adequately meet their care needs as their dementia progresses and care needs increase. Nursing homes are the homes of many people living with dementia who, despite their frailty and health problems (including dementia), should be supported to enjoy a good quality of life, maintain and develop relationships, and contribute to society (ADI, 2013).

A nursing home[1] is a person's home, their permanent place of residence for an indefinite period of time (Cahill, 2018) and each residents' quality of life will be significantly impacted by the quality of care received. Nursing homes have been described as 'spaces of care' (Gelsthorpe et al., 2020) in which complex, intimate relationships unfold between the nursing home residents, care workers and people visiting the nursing home, each with their own background, identity, needs and interests (Emmer De Albuquerque Green, Tinkler and Manthorpe, 2020).

Nursing homes should provide high quality care and a homely environment however, providing 'quality care' is resource-intensive and carries significant financial costs (Wübker et al., 2014) – many front-line staff work in conditions that are far from ideal, and have exceptionally heavy and stressful workloads (Cahill, 2018). The need for staff to balance risk and safety needs against the individual's right to autonomy and independence is one key dilemma that is often encountered (Robinson et al., 2007). While nursing homes aspire to deliver the highest standards of care ensuring that residents are at the heart of everything they do (Nursing Homes Ireland, 2022), it is widely recognized that people living with dementia are frequently denied their human rights both in the community and in nursing homes (WHO, 2015).

---

[1] For the purposes of this briefing paper, the working terminology of 'nursing homes' will be used to refer to both nursing home and care home settings.

Even when there are regulations in place to protect and uphold rights, people living with dementia can be the victims of many types of harm, abuse, and neglect including physical and chemical restraint (WHO, 2015). Globally, there has been a growing awareness of a range of human rights issues affecting people living with dementia in nursing homes as well as a recognition that people living with dementia are at heightened risk of violence, abuse, and neglect. Issues identified include stigma and stereotypes, the absence of rehabilitation services, being assumed to lack agency and problems with the physical environment of some nursing homes (Devandas-Aguilar, 2019). Recent studies have identified specific human rights violations such neglect and not mobilising residents, limited, or segregated recreational activities (Walker and Paliadelis, 2016), lack of integration into local communities and restrictions on visitation of family and friends (Steele et al., 2020).

Human rights are notoriously broad and difficult to define in practice (Emmer De Albuquerque Green, 2018) and the COVID-19 pandemic has shed light on our already fragile health and social care system, exposing systems failures in its ability to protect nursing home residents (BASW, 2020). It is ironic that, whilst there is widespread recognition that older age and ill health are risk factors for COVID-19, nursing home residents were directly and indirectly discriminated against in most European countries' planning and response to the pandemic (Xiaonan and Hong, 2020; Carter Anand et al., 2021). It is therefore timely and necessary to challenge the organisational, cultural, economic, and social dynamics that influence day-to-day issues that impact people living with dementia in nursing homes in Ireland.

For a number of years, people living with dementia and their representative advocacy organisations, such as Dementia Alliance International, have been strongly advocating for equal rights for people living with dementia in nursing homes (Dementia Alliance International, 2016). This Briefing Paper has been commissioned by the Irish Dementia Working Group (IDWG) in order to support their ongoing advocacy work. The group wish to publicly support people living with dementia in nursing homes by increasing awareness of the key issues impacting on their human rights, safety, and protection, provide information on ways of seeking help and engage in discussions with service providers (public and private), policy makers, the Department of Health, the Health Information and Quality Authority and political representatives to seek meaningful change.

The Paper will first explore aspects of human rights and capacity and decision-making for people living with dementia in nursing homes in Ireland and practice considerations. It will then outline how adult safeguarding and abuse is understood and explore some of the specific issues relating to abuse of people living with dementia in nursing homes. The Paper will also examine the specific impact of COVID-19 on people living with dementia in nursing homes and current challenges to the protection of people living with dementia in Ireland who may be experiencing harm, neglect, or abuse. It concludes with concrete recommendations from IDWG for changes to current practices and policies relating to the human rights, care, wellbeing, safety, and the protection of people living with dementia in nursing homes in Ireland.

Purpose of the Briefing Paper

The Paper will:

1. Include a summary of safeguarding issues, human rights concerns, and the impact of COVID-19 on the lives of people living with dementia in Nursing Homes.
2. Provide concise policy and contexts that can help explain safeguarding in Ireland as well as for the aspects of safeguarding discussed in the paper.
3. Provide a concise summary of the numbers of people living with dementia who reside in nursing homes, and other relevant statistics.
4. Be future focussed (not simply a review of the past) and include recommendations at a time when the experience of COVID-19 has shone a light on the situation in Nursing Homes.

Methodology

A broad scoping review of the existing literature on this topic was carried out. This was supplemented by adopting a snowball strategy to identify additional relevant literature. Three co-design online sessions were convened with members of the Irish Dementia Working Group (IDWG) in order to discuss and agree on the general content and members also provided suggestions for additional research or policy papers that should be included. Co-design sessions were also used to brainstorm and reach consensus as a group on concrete recommendations for changes to practice and policy going forward. Our briefing paper provides valuable insights into the key issues relating to the human rights and safeguarding of people living with dementia in nursing homes in Ireland however *it does not provide a systemic, comprehensive overview of all issues* within the existing research and policy literature.

Numbers of People Living With Dementia in Nursing Homes

A significant number of people with dementia in Ireland are likely to live in nursing homes and other residential care settings. On any given day approximately 32,000 people reside in nursing homes. In 2020 there were 576 registered nursing homes of which 440 were private or voluntary nursing homes. Private agencies manage 80% of beds nationally (HIQA, 2020). Due to different circumstances, and at different stages of dementia, some people will need to, or will choose to move to, a nursing home care facility. Also, some people may develop dementia after moving to residential care (Diaz Ponce and Georges, 2018).

We do not know precisely what the prevalence rate of dementia is in long-stay care in Ireland (Pierce et al., 2020). It has been suggested that 37% of all long-stay beds are occupied by someone with dementia (HSE, 2015). A small-scale Irish study in 2010 showed that around one third of residents had a clinical diagnosis of dementia, and a very large number of residents had a cognitive impairment which, in around a half of the cases, was severe (Cahill et al., 2010). More recently it has been argued that we should assume a dementia prevalence rate of 72% for residents in nursing home care in Ireland (Pierce et al., 2020). People living with dementia in nursing home settings often have more complex needs, experience challenges in communicating these needs, and are less able than others to cope with inadequate care (Diaz Ponce and Georges, 2018) meaning additional considerations must be given as to how best we ensure their safety and protection.

Human Rights of People Living With Dementia in Nursing Homes

Human rights are universal, and these rights are inherent to the dignity of every person. Yet the rights of people living with dementia and their family caregivers are often overlooked or even deliberately denied (WHO, 2015). People living with dementia want rights such as a right to a private and family life, a right to intimate relationships, reablement, rehabilitation, exercise, and recreational, meaningful activities that involve contact with the local community. They also may wish to have visitors stay overnight, alongside strategies to enable independence (Swaffer and Low, 2016).

The physical environment is essential for the wellbeing of nursing home residents (Diaz Ponce and Georges, 2018). Nursing homes, however, often employ a wide range of physical and environmental barriers to movement for people living with dementia, including locked doors, lap sashes and belts, bed rails, and segregated wards (Moore and Haralambous, 2007). In addition, medication is frequently overused in nursing home settings, sometimes as a means of restraining people living with dementia without consent (Human Rights Watch, 2018).

Nursing Home residents, regardless of their disability, level of cognitive impairment or dementia have a right to good quality and safe services. They should also be supported to make complaints and speak out if their rights are impinged. The quality of the care provided is not dependent solely on the number of staff, but also on the right professional skills mix, qualifications, training, and relevant experience (Diaz Ponce and Georges, 2018).

A human rights approach means that important processes are in place, including training practitioners in human rights principles and applying these principles, for example participation, accountability, non-discrimination, empowerment, and legality, in everyday practice (WHO, 2015b). The infringement of human rights may not be intentional and can result from systemic weaknesses such as inadequacies in service delivery, failure to balance different types of risk, lack of accessible information about where to access services and supports or resource constraints such as staff shortages (SCIE, 2015).

In recent years there has been some progress in the protection of the human rights of people living with dementia living in Ireland in particular, through a number of international and national human rights treaties and other instruments. For example, The European Convention on Human Rights 2003 imposes negative, positive, and procedural obligations on States. These include stipulations about the need to safeguard adults (for example, no one shall be subjected to torture, or inhuman or degrading treatment or punishment). Empowerment means that all individuals and communities should understand their rights and be supported to participate in the development of policies and practices that affect their lives.

FRIEDA principles have been used to indicate how human rights laws should apply to people living with dementia. These principles focus on Fairness, Respect, Equality, Identity, Dignity and Autonomy (HIQA, 2019).

There are various rights that are particularly important for people living with dementia (Dixon, 2021) in nursing homes including:

- Right to life
- Freedom from torture, degrading or inhuman treatment
- Freedom of movement, including freedom from restraint
- Right to autonomy
- Freedom of expression, freedom of thought, conscience
- Right to dignity
- Right to privacy and family life
- Right to participation and social inclusion
- Right to the highest attainable standard of physical and mental health
- Right to an adequate standard of living
- Non-discrimination and equality
- Access to justice, including the right to an effective remedy.

We would like to see all nursing homes uphold and protect the human rights of people living with dementia in nursing homes including the promotion and embracing of the FREIDA principles. We would like to see explicit monitoring of this by HIQA as part of their inspection role and brief and we welcome the opportunity to work with all relevant stakeholders on these issues.

Capacity and Decision-Making

The rights of people living with dementia in nursing homes should be viewed as identical to other citizens. People living with dementia and their family caregivers also have the right to participate in all decisions which affect their lives and wellbeing (WHO, 2015) and should be able to enjoy legal capacity on an equal basis with others. Assisted decision-making is viewed as a key mechanism for delivering the rights of people living with dementia under the UNCRPD (Keeling, 2017).

The *Assisted Decision-Making (Capacity) Act (2015)* ratifies the UNCRPD has established a legal framework for assisted decision-making. It replaces the “best interest” model currently operating and applies a functional test to determine capacity which is time, issue, and context specific. It introduces a model of will and preferences, where people’s values must be central to all decision-making and “unwise” decisions are to be respected.

The Act makes it clear that all individuals have decision-making capacity and shall not be deemed to lack such capacity unless all reasonable steps have been taken, without success, to assist them in the decision-making process. It also describes the provision of appropriate assistance which maximizes the decision-making capacity of a relevant individual (Davies et al., 2019; Donnelly et al., 2021). Section 138 states that the 2015 Act does not affect the law on capacity and consent in relation to sexual relations so a decision around consent to sexual relations is not one that is capable of being supported under the new framework under Act. However, the Criminal Sexual Offences Act, 2017 recognises the right of all people to sexual expression and intimate relationships.

Promoting Autonomy and Agency

The freedom to choose the life one wishes to have, which may include using objects, is an important aspect of citizenship for people living with dementia (Pfister, 2012). It is especially relevant for people with a disability, as opportunities to live a meaningful life are often curtailed by others (Lid, 2015). Lee and Bartlett (2021) introduce the concept of ‘functional objects.’ These can be defined as ‘any inanimate item which a person can use to carry out a task, not necessarily to completion or to any perceived standard, which maintains and supports his/her identity’ (Lee and Bartlett, 2021, p.1472). Functional objects are not only an extension of the self but also making decisions about and using functional objects enable people living with dementia to take control and practice everyday citizenship, such as taking care of oneself and others. This can include encouraging the individual to bring personal belongings such as photographs or pictures that have sentimental value from their home, for example those used in the person’s day to day routine such as curling tongs, razors, make-up. Achieving a sense of home in a nursing home setting can be made easier if a person living with dementia has access to such resources and objects that help maintain and cultivate identity (Lee and Bartlett, 2021).

The autonomy of people living with dementia can also be promoted by adapting the physical environment of the nursing home to be more ‘dementia friendly’, for example through cueing, signage, assistive technology and so on and making it more accessible. It is important that those caring for people living with dementia avoid negative stereotypes and pejorative language. The person’s self-esteem and sense of worth may be enhanced when they are enabled to lead a more normal life. This model can give agency, power, and control back to the person who should be viewed as the expert by experience and whose rights should always be placed at the centre stage (Cahill, 2022 *in press*).

Strengths-based approaches are a useful way of supporting the human rights of people living with dementia. When staff use this approach, they should identify things which the person is already successful at and seek to build upon these. The approach also involves thinking about how issues of culture and diversity might have a positive or negative impact on people living with dementia (Dixon, 2021).

When an allegation of abuse or neglect is made, practitioners must consider how the person living with dementia views the alleged abuse or neglect and should ensure that they are central to decision-making. Such decisions involve thinking about risk and making proportionate judgements about it. However, research indicates that people living with dementia, carers and professionals tend to interpret risk in different ways and that people living with dementia rarely use the term ‘risk’ when talking about their situation (Dixon, 2021).

People living with dementia should be supported to share and discuss their concerns and wishes. Whilst some may wish to speak for themselves, others will feel reassured if someone close to them can help them to communicate or speak on their behalf, such as family or friends. At times they will be able to take part in decision-making fully or decisions can be made with the assistance of carers, decision-supporters, or the support of an independent advocate (Stevenson et al., 2019). Ultimately, it is important to point out that it is not simply enough to include people living with dementia in decision-making, it must also be conveyed to them that their participation matters (Bartlett & O’Connor, 2010; Donnelly, Begley, and O’Brien, 2019).

What is Adult Safeguarding?

Safeguarding means putting measures in place to reduce the risk of harm or abuse, promoting, and protecting people's human rights and their health and wellbeing, and empowering them to protect themselves (DOH, 2019, p3). Any adult may need help to protect themselves and there may be times when they are more vulnerable to abuse, neglect and exploitation. This may mean that they are unable to adequately protect themselves in these situations. Any care and support provided, however, should be balanced and proportionate to manage or mitigate risk to enable the person to live a safe and fulfilling life (HIQA and MHC, 2019, p.9). It is also critical that as a society we need to prevent abuse, exploitation, and neglect by adopting a 'zero tolerance approach' to these issues. Everyone has the right to be safe and free from fear or harm

The nursing home as an organisation is in an important 'position of trust' towards its residents and it has clear responsibility to ensure quality of care (Dixon et al., 2009:57). They have a responsibility to ensure that if abuse, harm, or neglect of a person living with dementia occurs, or is likely to occur, it is stopped and reported to the local HSE Safeguarding and Protection Team or An Garda Siochana as quickly as possible.

We would encourage all nursing home providers to have appropriate systems in place that ensure timely safeguarding referrals and investigations are carried out, that facilitates and supports residents to raise issues and seek help, ensures their immediate safety and protection, and complies with any mandated reporting requirements. For example, the mandate to report any instances of serious sexual or physical abuse under the Criminal Justice Withholding Information against Children and Vulnerable Persons Act, 2012.

What is Abuse?

Abuse, exploitation, and neglect have devastating impacts on people's lives, and it is vitally important that timely and effective measures are taken to safeguard people who are at risk of such harm (HIQA and Mental Health Commission, 2019). Abuse can be defined as 'A single or repeated act, or omission (including within a relationship where there is an expectation of trust), which violates a person's civil or human rights and/or causes harm or distress to that person' (DOH, 2019, p.3)

All people living with dementia have the right to be safe and live a life free from abuse. All persons are entitled to this right, regardless of their circumstances. It is the responsibility of all service providers, statutory and non-statutory, to ensure that service users are treated with respect and dignity, have their welfare promoted and receive support in an environment in which every effort is made to promote welfare and to prevent abuse (HSE, 2014).

Traditional terminology focused on using terms such as 'vulnerable' and 'abuse' (Mazars et al., 2021) and the current HSE safeguarding policy uses the terminology of 'vulnerable adult' (HSE, 2014). However, there is a recognition on the consequences of language in how it positions people as well as how it provides frames of reference, transforming people from objects of charity to self-determined subjects (Sherwood-Johnson, 2013). For example, there is a recent move away from using the term 'vulnerable adults' in jurisdictions such as Scotland as this has been found to have implications related to stigmatisation, discrimination, dependency, and it covertly sanctions paternalism and underpins a homogeneous view. More recent narratives have tended to focus on the less stigmatising terminology of 'adult at risk' (Donnelly et al., 2017).

Types of Abuse

People living with dementia may be subject to mistreatment and abuse in the community or in nursing homes and hospitals. This may include psychological, financial, emotional, sexual, or physical abuse, including the inappropriate prescription of anti-psychotic medication. In most cases of repeated abuse, the abuser is well-known to the older person (Alzheimer's Society, 2015). There are many different types of abuse including:

- Physical abuse
- Domestic violence or abuse
- Sexual abuse
- Psychological or emotional abuse
- Financial or material abuse
- Modern slavery/Human Trafficking
- Discriminatory abuse
- Organisational or institutional abuse
- Neglect
- Online/Digital Abuse
- Self-neglect (HSE, 2019).

Residents in nursing homes can be abused by a nursing home staff, co-residents, a family member or visitors known or unknown to the victim.

Nursing Homes and Organisational Abuse

A less well-recognised type of abuse is that caused by organisations or institutions. This is the mistreatment of people brought about by poor or inadequate care or support or systemic practices that adversely affect the whole care setting such as a nursing home, as follows:

- Organisational abuse may originate in a culture that denies, restricts, or curtails privacy, dignity, choice, and independence.
- It can be a one-off incident or repeated incidents, often the result of neglect or poor standards of professional practice,
- It can result in a failure to afford residents the opportunity to socially engage with others and be involved in hobbies/activities that are meaningful to them. This in turn can prevent psycho-social needs being met.
- It can occur when residents are treated collectively rather than as individuals. For example, when their right to privacy and choice are not respected. An example of this is when staff talk about the service user's personal or intimate details in a manner that does not respect the individual's right to privacy (Mazers et al., 2020).

Some of the issues relating to organisational/institutional abuse in care settings are highlighted in the Report of the Áras Attracta Swinford Review Group (HSE, 2016). The Report pointed to the:

- Lack of awareness training for the residents and their relatives in how to use complaints and protection policies effectively.
- Lack of staff access to and familiarity with organisational policies.
- Inadequate compliance with the national disability policy and legislation relating to people with disabilities including the Equality Act (2004), Health Act (2004), Disability Act (2005) and Citizens Information Act (right to advocacy) (2007).

The Report found that these failings tended to lead to the over-protection of some residents, and paternalistic approaches to managing risk, at the expense of approaches that can enable residents to safeguard themselves. These practices were enabled by a closed culture where the same staff worked together in same location for a long period without transparent and effective oversight allowing bad practices to become the norm and remain unchallenged by management (Donnelly and O'Brien, 2018). The report made three overarching recommendations critical to ensuring the safety and welfare of residents: (a) to move to a rights-based social model of service delivery; (b) facilitate, listen, and promote the voices of residents and to (c) strengthen and enhance leadership and management.

Our Ask:

We believe there should be a strong commitment by all nursing home providers to support and fully implement these recommendations if they have not already done so.

Moving Towards Restraint Free Environment in Nursing Homes

Nursing home staff often struggle to balance residents' rights to autonomy and liberty with the need to ensure their health and safety. While there are circumstances where the use of restrictive or restraint practices may be unavoidable and necessary to ensure a person's safety or the safety of others, restrictive practices are an infringement of a person's fundamental rights to personal liberty and bodily integrity. In recognising these ethical considerations, services such as nursing homes should explore all measures to reduce or eliminate their use (HIQA, 2019). The Department of Health's '*Towards a Restraint Free Environment in Nursing Homes'* policy document describes restraint as "the intentional restriction of a person's movement or behaviour" (DOH, 2011, p3). Such practices may involve limiting a person's choices or preferences (for example, access to cigarettes or certain foods). This can be referred to as 'rights restraints' and may be physical or environmental in nature. A nursing home resident can also experience restrictions through inaction. This means that the care and support a person requires to take part in normal daily activities are not being met within a reasonable timeframe (HIQA, 2019).

Responsive Behaviours and Chemical Restraint

Pertinent to any discussion on a restraint free environment is the issue of responsive behaviours and the chemical restraint of people living with dementia. Responsive behaviours and reactive behaviours are terms commonly used to refer to actions, words or gestures presented by a person with dementia as a way of responding to something negative, frustrating, or confusing in their social and physical environment and can include wandering, agitation, and aggression (Alzheimer Society of Canada, 2019).

Many individuals enter nursing homes because of these behaviours (ADI, 2013) or develop such behaviours following admission. There is a broad consensus that non-pharmacological interventions, including person-centred care approaches, should always be the first line of response in these situations (Cahill, 2018). Antipsychotic medication, also known as neuroleptics or drugs (tranquilizers), should only ever be prescribed when symptoms are severe, where there is immediate risk of harm, and when risks and benefits have been fully discussed and a comprehensive assessment undertaken (NICE/SCIE, 2007; Cahill, 2018).

The Department of Health has stressed it's committed to a restraint-free environment and has encouraged care providers such as nursing homes to:

- adopting a person-centred approach to care
- having staff that know residents' needs
- conducting comprehensive assessments
- monitoring, recording, and reviewing the use of restraint
- and having a policy which adheres to the principles of the national policy (DOH, 2011).

We fully endorse this commitment and welcome the opportunity to engage with nursing homes providers, the Department of Health and HQA on working together to ensure restraint free environments for people living with dementia in nursing homes.

Staff to Resident Abuse

Another type of abuse experienced by nursing home residents is that caused by staff practices, particularly in terms of neglect and psychological harm (Phelan, 2015).

An Irish study (Drennan et al., 2012) that examined staff experiences of abuse in nursing home residents found that:

- 57.6% of staff observed one or more neglectful behaviours by other members of staff in the preceding 12 months
- 26.9% of staff had observed at least one psychologically abusive act directed towards a resident in the previous twelve months by another member of staff
- Physical abuse was observed as occurring on one or more occasions by 11.7% of respondents.

Findings suggested that high levels of staff burnout, ageist attitudes, and the experience of resident-related and facility-related issues were associated with neglect of residents in this study. Other studies suggest that neglect of residents can be associated with organisational level abuse discussed earlier. Specific issues such as small, isolated nursing homes, institutional size, and for-profit status of nursing homes have been linked to higher rates of mistreatment which may be influenced by a desire to maximize profit margins may lead to adverse outcomes for residents (Phelan, 2015).

Resident to Resident Abuse

While the maltreatment of residents in nursing homes has generally focused on staff to resident abuse, resident to resident abuse is most common (Bonifas, 2015). Resident to resident abuse can be defined as '[…] negative and aggressive physical, sexual or verbal interactions between long term residents that in a community setting would likely be construed as unwelcome and have a high potential to cause physical or psychological distress in the recipient' (Pillemer et al., 2012, p2).

Types of resident-to-resident abuse includes, verbal (shouting, screaming), physical (hitting, kicking, pushing, throwing things), sexual (inappropriate touch, exposing themselves), violation of privacy and taking/damaging another's belongings and bullying. Resident characteristics that are a risk factor for resident-to-resident abuse include dementia, mental illness, behavioural symptoms that may disrupt others and a history of aggressive or negative interactions with others. It has been noted that a crowded environment, inadequate staffing levels, lack of staff training, high numbers of residents with dementia, a lack of meaningful activities, crowded common areas and excessive noise are contributory factors when abuse occurs (SCIE, 2021).

Frontline practitioners report that resident to resident abuse may also occur in situations where sex offenders may be placed in a nursing home/residential facility where the service provider and residents are not notified of previous offender behaviour so they can't put protective measures in place.

The impact and consequences of resident-to-resident abuse has been associated with:

- a reduction in life satisfaction and increased risk of depression, anxiety, and loneliness
- low self-esteem and overall negative mood
- injuries such as falls, fractures, lacerations, and cuts
- a higher likelihood of experiencing neglect by caregivers (SCIE, 2021).

What Do We Know About The Abuse of People Living With Dementia in Nursing Homes?

There is evidence to suggest however that people with dementia are over-represented amongst nursing home and care home residents (ADI, 2013). Although we still do not enough about the prevalence of abuse in nursing homes in Ireland, it has been suggested that it a common occurrence (Moore, 2017). Research studies indicate how older adults living with dementia are at greater risk of abuse and neglect than those without a diagnosis (Fang and Yan, 2018). Such abuse often goes unnoticed, because dementia may affect a person's ability to recognise abuse or to report it (Dixon, 2021).

Several studies have highlighted issues of abuse and neglect of people living with dementia in nursing homes. Self-reports by staff have identified several forms of abuse within this setting; most notably threats to residents, avoiding residents with challenging behaviours, not providing enough time when supporting residents to eat and not taking enough care when helping residents to move (Cooper et al., 2013; 2018; Dixon, 2021).

Dementia can cause difficulties with memory, thinking, language and problem-solving. As a result, people living with dementia may find it difficult to report abuse or to make choices about how they would like it to be managed. We encourage nursing home providers to give careful thought and attention to how individuals can be supported to make decisions within adult safeguarding enquiries (Dixon, 2021), in line with the underpinning principles of the Assisted Decision-Making Capacity Act, 2015.

Barriers to Reporting of Abuse

One of the major challenges in ensuring the wellbeing safety and protection of people living with dementia in nursing homes are barriers to reporting of abuse. It appears to be the case that only a fraction of the abuse that occurs is brought to the attention of safeguarding authorities such as social services departments or inspection authorities such as HIQA (Moore, 2017). Abuse in nursing homes is not always reported, and sometimes it is deliberately concealed. It has been suggested that as few as one in every four or five cases are reported (Cooper et al., 2008).

People living with dementia, staff, carers, and family may not report abuse for a number of reasons:

- fear of repercussions
- not realising that what is happening is abusive
- fear of being seen as a troublemaker (SCIE, 2021)
- Changes in behaviour being put down to dementia or mental health issues
- Instances of bruising being put down to side effects of medication
- Fear of not being believed
- Intimidation and threats from the abuser not to report/disclose.

In a recent Irish study, it was found that almost a quarter of people would not know who to report adult abuse to (Safeguarding Ireland, 2020). We also know that there is very low awareness of the existence of HSE Safeguarding and Protection Teams. It has been suggested that it is difficult to report abuse by paid carers because of fear of repercussions, being labelled difficult, and practical difficulties in identifying whom to report concerns to (Sheehan and O'Sullivan, 2021). Service users and family carers have highlighted the need for routine mechanisms such as residents' committees, service user committees and suggestion boxes to identify concerns and potential issues of harm and abuse, short of making a formal complaint (Sheehan and O'Sullivan, 2021).

The Ombudsman has also highlighted that in relation to nursing home care, it is often the case that complaints are not submitted to his Office until after a resident has left the nursing home or has passed away because of a fear of repercussions for their relative (Office of the Ombudsman, 2017).

In conclusion, these policy documents and reports highlight a number of common themes that must be dealt with in the context of safeguarding nursing homes residents in the Irish context:

1. Some institutional practices can lead to the isolation of staff, and loss of empathy towards individuals in receipt of care/services can make it more difficult to report unacceptable/abusive incidents. Institutional conditioning and control of residents can also limit opportunities for interaction with the community.
2. There is often a lack of awareness among individuals and families of their human rights, including what is legally defined as acceptable behaviour, complaints procedures and accessing advocacy.
3. Poor reporting systems and a lack of mandatory response processes can lead to inadequate systems of reporting.
4. There tends to be a lack of cooperation, consultation or information sharing within and between organisations.
5. Current organisational arrangements can obscure poor professional practices in this field.
6. Oversight by regulatory bodies has been shown as less than always fully effective.
7. There is a need for improvements in leadership, management, training and governance in order to promote positive cultural changes within organisations (Donnelly and O'Brien, 2018).

The current safeguarding regulations, including whistleblowing policies, often fail to protect nursing home residents who experience abuse. Even when reports are made, they are sometimes ignored or stifled. In this context, it is critically important that people living with dementia in nursing homes are empowered to protect themselves and that nursing homes have clear and transparent adult safeguarding reporting processes in place.

Our Ask:

We would welcome the opportunity to collaborate with nursing homes providers in helping to support people living with dementia, their family carers and nursing home staff to raise awareness of harm, abuse, and neglect and how to seek help and make a report it when it occurs.

Policy Context of Adult Safeguarding in Ireland

Ireland currently relies on a range of criminal and civil law, alongside adult protection policy and guidance to protect adults at risk of abuse. Addressing safeguarding as a public policy issue at a government level has been a relatively new development, characterised by largely reactionary responses to date. For example, the reporting of high-profile cases of the mistreatment of adults with disabilities and/or older persons, most notably with the Aras Attracta inquiry about the mistreatment of residents with severe intellectual disabilities, has led to the establishment of guidelines and policies to protect all adults at risk of abuse, harm, or neglect in all government-funded services by the Health Service Executive (HSE) in 2014.

The Safeguarding Vulnerable Persons at Risk of Abuse – National Policy and Procedures 2014 (HSE, 2014), which applies to all HSE and HSE funded services, outlines a number of principles to promote the welfare of vulnerable people, and safeguard them from abuse. These include a requirement that all services must have a ‘no tolerance’ approach to any form of abuse, and those organisations need to promote a culture that supports this ethos (HSE, 2014).

It also led to the establishment of a range of bodies including a National Safeguarding Office, a National Safeguarding Committee and nine Adult Safeguarding and Protection Teams to support the implementation of the policy. The remit of the 2014 policy included all adults aged 18 and over at risk of abuse and neglect. The policy’s operational scope, however, was limited to the HSE Social Care Division and Social Care funded services and to adults living in the community who are not linked to any formal service. It did not extend to adults using other services such as mental health, acute settings, primary care settings or private nursing homes.

The Department of Health have also been developing a national policy on adult safeguarding for the health sector since 2017 together with such legislation that may be required to underpin it however to date the policy has not yet been formally published launched of implemented.

The recent publication of the HSE National Safeguarding Office annual report for 2020, as well as publicity surrounding the deeply disturbing ‘Grace’ and ‘Brandon’ cases, involving sexual abuse of adults in foster care and residential care settings respectively, have further highlighted the significant deficiencies in Ireland’s current capability to protect adults at risk (Geiran, 2021).

Legislative Context of Adult Safeguarding in Ireland

Although Ireland has not yet implemented primary adult safeguarding legislation, a number of Acts make reference to the protection of rights and reporting of abuse:

- The Health Act 2007 (Care and Support of Residents in Designated Centres for Persons (Children and Adults with Disabilities) Regulation 2013 makes specific reference to the protection required for registered providers to notify the Health Information and Quality Authority (HIQA) of any adverse events including allegations or suspected abuse of residents.
- The Criminal Justice (Withholding of Information on Offences against Children and Vulnerable Persons) Act 2012 makes it an offence for designated professionals to withhold information on certain offences (includes rape, sexual assault, false imprisonment) against children and vulnerable persons from An Garda Síochána.
- The Domestic Violence Bill, 2018 legislated for the crime of coercive control in intimate relationships.
- In 2017, the Adult Safeguarding Bill, 2017 was introduced as a private member’s Bill in the Seanad, the upper house of the Irish parliament. The Bill aimed to put in place additional protections and supports for adults. Two key processes were proposed. Part 2 set out to establish an independent National Adult Safeguarding Authority, with the power to investigate, enter any premises, direct the Executive (the HSE), or local authority to make available health or social care, legal, accommodation or other services including emergency supports (Section 11:3). Part 3 provides for mandatory reporting by specified/named persons/professionals and others.
- The proposed Bill has not yet been signed into law and is currently being redrafted.

The Limitations of Current Policy and Practice Frameworks

It has been argued that social and health policies in Ireland have increasingly been driven by a neo-liberalist marketisation of care with the shift “towards the private”, at the expense of our most vulnerable citizens. Such policies, allied to failures to invest appropriately in supports to help people to age in place, have resulted in premature and unnecessary admission to nursing home care, particularly for people living with dementia (Donnelly, Begley, and O’Brien, 2019). Over the last twenty years, the nursing home sector has become increasingly privatised, fragmented, atomised and outside the purview of policymakers and the public sector (Dening and Milne, 2020). Currently, there are significant challenges to the protection and investigation of abuse or neglect of people living with dementia in nursing homes and concerns have been expressed about the inadequacy of legal protections (IASW, 2021; Donnelly, 2021).

The Irish State has a poor record of failing to safeguard adults who are at risk of abuse and neglect within its own institutions and in wider Irish society (IASW, 2021). At present, people are “falling through the cracks” and coming to harm because of gaps in health and social care systems. Poor standards of care, as well as neglect and abuse of residents, are not always reported, and sometimes may be deliberately concealed. The closed organisational culture in some nursing homes makes it exceptionally challenging for staff to speak up and report abuse.

Repeated concerns have also been expressed about the inadequacy of current legal protections for adults at risk in Ireland. For example, Mary Dunnion, Chief Inspector of Social Services and Director of Regulation, Health Information and Quality Authority (HIQA) in an interview with the Irish Examiner, on the 27th of November 2020 stated, ‘*People should not be subjected to significantly deteriorating care and service quality to the point their very lives are at risk because of legal limitations’.*

The HSE has highlighted the ways in which safeguarding and protection social workers are operating in a “legal lacuna” in the absence of primary adult safeguarding legislation (HSE, 2021). Simply put, safeguarding social workers do not have the legal right of entry to private nursing homes where 80 per cent of residents reside. As a result, they must seek the agreement of private care providers to do so, while HIQA cannot investigate individual cases.

HIQA can take action to cancel the registration of a failing nursing home provider. However, this is often a slow process: legislation currently permits a 28-day right to appeal and the threshold to cancel registration is high. Social workers have repeatedly asked how nursing home residents can seek help if neglect or abuse occurred during the period of the pandemic (IASW, 2021). The Oireachtas Joint Committee on Health (2017) has stated “that there is an urgent need for legislation and that this legislation is crucial in providing protection to adults at risk’ (Oireachtas, 2017: p 1).

Nursing homes should be places where residents feel safe, secure, cared for, and protected. It is evident however that deeply embedded resistance to institutional change signals an urgent need for adult safeguarding procedures to be placed on a statutory basis.

In conclusion, there are a number of common themes that must be dealt with in the context of safeguarding people living with dementia in nursing homes including:

- Some institutional practices can lead to the isolation of staff, and loss of empathy towards individuals in receipt of care/services can make it more difficult to report unacceptable/abusive incidents. Institutional conditioning and control of residents can also limit opportunities for interaction with the community.
- There is often a lack of awareness among individuals and families of their human rights, including what is legally defined as acceptable behaviour, complaints procedures and accessing advocacy.
- Poor reporting systems and a lack of mandatory response processes can lead to inadequate systems of reporting.
- There tends to be a lack of cooperation, consultation or information sharing within and between organisations.
- Current organisational arrangements can obscure poor professional practices in this field.
- Oversight by regulatory bodies has been shown as less than always fully effective.
- There is a need for improvements in leadership, management, training and governance in order to promote positive cultural changes within organisations (Donnelly and O’Brien, 2019).

Impact of COVID-19 on People Living With Dementia in Nursing Homes

The World Health Organisation (WHO) estimates that people living in nursing homes represent 50% of all COVID-19 related deaths in Europe; it describes the situation as an ‘unimaginable tragedy’ (WHO, 2020). While advanced age, and its associated health-related comorbidities, is linked to increased mortality risk from COVID-19 this, of itself, does not explain the high rate of death and serious harms experienced by nursing home residents (Carter Anand et al., 2021).

Research carried out with people living with dementia and their carers by The Alzheimer Society of Ireland (ASI) during the pandemic identified significant challenges including the cancellation or postponement of medical appointments, a marked increase in dementia symptoms coupled with an increase in responsive behaviours, the loss of routine, boredom, and anxiety. Those with dementia who took part in surveys echoed many of the concerns and challenges expressed by carers. Additional difficulties reported included loneliness, social isolation, anxiety, and worry (ASI, 2021).

In the UK, the Alzheimer Society found that nearly half of people living with dementia report that the pandemic has had a negative impact on their mental health and a third felt lonely. The most common symptoms that people living with dementia reported having increased since lockdown began were difficulty concentrating, memory loss, and agitation/restlessness (Alzheimer UK, 2020).

HIQA who has responsibility for standards and regulation of nursing homes in Ireland received a 71% increase in the number of concerns or an issue with the care provided to residents received in 2019. We also know that residents and families are often not communicated with in a timely way about concerns/risks in the nursing home environment.

A review of the existing research studies on the impact of visiting restrictions on nursing home residents found that residents experienced higher levels of depression, anxiety, isolation, and loneliness (Comas-Herrara et al., 2020; Valayudhan et al., 2020). The combined impact of self-isolation, staff shortages, curtailed visits from family and friends, the constant presence of death, and fear of becoming ill, has been seriously damaging to mental health of residents (Milne, 2020). For people living with dementia who display responsive behaviours such as wandering, agitation or aggression (usually because of an unmet need and not necessarily a symptom of the disease), – the increased use of antipsychotics and hypnotics has been reported (Howard et al., 2020), often used to ensure resident compliance with safety measures such as hand washing and social distancing (Valayudhan et al., 2020).

Many residents with dementia became withdrawn and depressed, sometimes not understanding why loved ones were no longer visiting. It has been reported that people living with dementia felt abandoned and lost cognitive and motor skills, including fundamental skills such as the ability to speak, eat or drink. Some families have described their relative with dementia as ‘disappearing’ (Alzheimer UK, 2020). Bans also increased feelings of guilt, fear, worry and isolation in residents’ families (Levere et al., 2021). For people living with dementia in nursing homes, the absence of a loved one’s regular visit to a care home or nursing home may mean a life not worth living (Cahill, 2022 *in press*). Irish practitioners have highlighted the loss of residents’ sense of ‘connection’ to their families, communities; this connectivity is an especially important dimension of Irish culture (Brennan et al., 2020).

Another disturbing example of inhuman and degrading treatment during the pandemic relates to situations of end-of-life care. Evidence from Ireland indicates that residents' wishes were either not sought or disregarded entirely (Brennan et al., 2020). As a result of relatives being excluded from visiting nursing homes, many residents died alone causing unimaginable levels of pain and distress to residents and relatives (McGarry et al., 2020).

Family members often (continue to) provide practical, physical, and psychological care to their relative in the nursing home and act as an important care partner. During the pandemic, this care was no longer available, resulting in many residents receiving lower levels of care and attention; it also disrupted the 'usual rhythm' of care (Carter Anand et al., 2021). There were many adverse consequences for family members when visiting times are limited, monitored and the residents' privacy rights may not always be strictly upheld. This suggests that such policies and practices have not complied with human rights approaches and the people living with dementia's right to a family life Questions remain about who advocates for the resident with severe dementia, who is unable to speak for herself and whose family caregiver may be silenced, frightened to complain, for fear of recrimination, (Cahill, 2022 *in press*).

Residents in nursing homes and other residential care facilities have a right to maintain meaningful relationships with people who are important to them (HPSC, 2022). We encourage all nursing homes to fully comply with the recently published Health Protection Surveillance Centre '*COVID-19: Normalising Access in Long Term Residential Care Facilities*.' Nursing home providers are responsible for ensuring people living with dementia's right to meaningful contact is respected in line with regulatory obligations and in this context restrictions on visiting should be the minimum necessary to manage the level of risk of severe disease and death from COVID-19 at the time (HPSC, 2022, p3).

Where can People Living With Dementia Seek Help If Experiencing Abuse, Harm,or Neglect

Every person living with dementia in a nursing home should be informed about and supported to understand their rights using appropriate, accessible information and forms of communication. If a safeguarding concern arises, the adult at risk should be informed about the supports available to them and facilitated to access protection and support to keep them safe. Residents should also be informed about and supported to access the justice system if there is a concern that a crime may have been committed. Examples of this may include contacting An Garda Síochána or employing legal representation (HIQA and MHC 2019).

HSE Safeguarding and Protection Teams are in place all over Ireland to investigate reports of abuse and provide help and support. Each Community Health Office has a team and the contact details for your local Safeguarding and Protection Team can be found by clicking here.

In making safeguarding ‘everybody’s business’ through awareness-raising and educating nursing home residents and the wider public about human rights will empower people living with dementia to challenge organisational norms and take action to safeguard themselves and others.

Recommendations

We believe that people living with dementia in nursing homes, regardless of their age should:

1. Be entitled to an independent clinical diagnosis of their dementia and an individualised, negotiated treatment plan.
2. Have equal and rights-based access to multidisciplinary team support and health and social care services, including access and provision of equipment and mobility aids. This includes access to primary care, frailty teams, integrated care, rehabilitation, palliative care, safeguarding and liaison social work services to ensure that the well-being of all adults is supported and safeguarded.
3. Have easy-to-access help and support from Adult Safeguarding and Protection Social Workers.
4. Have equality of access to community-based nursing home care. To have lives that are integrated into local communities including a shift towards nursing homes being an integral part of dementia-friendly communities.
5. Be cared for in a nursing home with staffing levels that align with the dependency levels of residents as outlined in each Common Summary Assessment Form (CSAR) or Care Plan. There should also be consistency in the carers who are providing day-to-day care to PLWD. This should be routinely monitored by HIQA inspections.
6. Be cared for by staff who have a minimum of a FETAC Level 5 and who have received dementia-specific training as well as training in rights-based and human rights-based approach to care. Monitoring of staff training should be carried out by HIQA.
7. Always be referred to by an individual’s preferred name or nickname, including the correct pronunciation. Be cared for by carers who have been trained on the importance of both verbal and non-verbal communication in all care interactions with PLWD and who communicate with the PLWD about the care tasks being carried out.
8. Be cared for in a dementia-specific unit/ward that adheres to dementia-friendly design principles in its environment with due regard to the specific issues that help to best support PLWD to maximise their quality of life. This should be routinely monitored during HIQA inspections.
9. Be cared for by nursing homes that uphold and protect the human rights of PLWD, the promotion and embracing of the ‘FREDA principles’, including explicit monitoring of this by HIQA as part of their inspection role and brief.

Recommendations

We believe that people living with dementia in nursing homes, regardless of their age should:

10. Be treated with the maximum dignity and respect, be fully involved in all important decision-making about support and care, including advance care planning and be able to live safely and free from harm.
11. Be presumed to have the capacity to make their own decisions and are supported to express and enact their will and preference with support from any identified care partners, Enduring Power of Attorney arrangements and/or in line with the requirements of the Assisted Decision-Making Capacity Act, 2015. This should include support and help from a decision-supporter, co-decision maker or decision-making representative if required.
12. Be consulted and involved in all healthcare decisions including changes to care plans or the decision to start or stop a prescribed medication. Care partners, those with Enduring Powers of Attorney and family members/support persons involved under the decision-making structures of the Assisted Decision-Making Capacity Act, 2015 should also be routinely involved and consulted in relation to changes to care plans or medications.
13. Receive regular and consistent GP support as and when required. Medical support should also include timely transfer to acute hospital care when deemed necessary.
14. Have any clinical multidisciplinary assessments scheduled at the time of day when the PLWD is the most lucid/optimal time of day for the PLWD.
15. Be supported to understand their human rights with support from nursing home staff to protect and promote their rights on a day-to-day basis, even if this involves some element of risk or positive risk-taking. Each person should receive information on what safeguarding is, how to prevent harm from happening and how to address harm if it does happen.
16. Be assisted by nursing home staff or an independent advocate to make a complaint or safeguarding referral, to receive support to do this and be supported to exercise choice. If necessary, they should also be provided with support to access the justice system, for example by contacting the Gardaí.
17. Have a right to a private and family life including looking after their own personal belongings and finances in a way that takes account of the will and preferences of the person. This should also include the right to regular visits from family members and friends and the right to leave the nursing home facility for day trips or overnight visits with care partners/family members/significant others.

Recommendations

We believe that people living with dementia in nursing homes, regardless of their age should:

18. Have a right to private, intimate, or romantic relationships. PLWD should be encouraged and supported to maintain personal relationships including support for intimate relationships with spouse/partner/significant others. This should be reflected in flexibility in visiting times and times for staff to meet with family members/care partners. Support should also be provided to maintain contact and relationships with pets.

19. Be supported to experience the maximum quality of life and contentment including access to stimulating activities that support the ongoing engagement of the PLWD as well as their care partner(s)/ family members so that they can better support them.

20. Have access to the outdoors and any garden areas and have a right to leave the nursing home facility.

21. Be actively supported to maintain all hobbies and past times that they enjoy and receive adequate stimulation including supporting attendance at community-based day centres if desired. Cognitive stimulation and daily activities should be readily available in all nursing homes.

22. Be supported to engage in and participate in spiritual and religious activities should they wish. Those who do not wish to engage in spiritual or religious activities should have this right respected.

23. Be empowered to have choices and not have to adhere to institutional routines. They should be accommodated and supported in a daily routine including mealtimes that best meet each individual’s needs and preferences. If the PLWD is unable/declines their food at mealtime, an alternative food/meal arrangement should be offered/provided.

24. Have a right to material citizenship and be encouraged and facilitated to bring personal possessions and functional objects of importance to the nursing home so they can live a meaningful life. Personal possessions should never be shared/worn by another resident.

25. Receive adequate support in relation to unmet needs or responsive behaviours with a focus on behavioural interventions and addressing unmet needs. Medication responses should be a last resort.

26. Receive the highest standards of care, safety, and protection, monitored by HIQA who should strongly promote and ensure dementia-specific standards of care and provide oversight and monitoring of poor standards of care, neglect, and organisational abuse.

Recommendations

We believe that people living with dementia in nursing homes, regardless of their age should:

27. Have awareness of and easy access to complaints procedures and the ability to participate in Residents' Committees alongside other residents. Care partners/family members should also have the opportunity to participate in Family Member/Relatives Committees.

28. Have access to a peer support network to seek advice and counselling if concerned about entering nursing home care..

29. Have easy access to information on all charges related to nursing home care including all additional charges, for example, activities etc.

30. Have security of tenure as enjoyed by any other citizen in rented accommodation, including not being asked to leave because of behaviours which are symptoms of dementia or because a complaint had been made by a resident.

Conclusion

This paper has explored human rights and adult safeguarding within the context of people living with dementia in nursing homes in Ireland. We know that the majority of nursing homes actively support and promote the human rights of people living with dementia and strive for the highest standards in ensuring the safety and protection of all residents when harm, abuse or neglect occurs. This paper has however identified a number of specific risk factors for people living with dementia, as well as a number of policy and legislative gaps in our current adult safeguarding framework that means it may be more difficult to adequately protect people living with dementia in nursing homes. As mentioned in the introduction, the IDWG are eager to engage in discussions and work in partnership with nursing home service providers (public and private), policy makers, the Department of Health, the Health Information and Quality Authority and political representatives to seek meaningful change going forward.

References

ADI (2013) World Alzheimer report 2013: An analysis of long-term care for dementia, London: ADI (www.alz.co.uk/research/worldreport-2013).

Alzheimer Society (2020) 'The impact of COVID-19 on People Affected by Dementia, July 2021' Available: https://www.alzheimers.org.uk/sites/default/files/2020-08/The_Impact_of_COVID-19_on_People_Affected_By_Dementia.pdf

Alzheimer's Society (2015) 'Alzheimer's Society's view on mistreatment and abuse of people with dementia' [online], Available: https://www.alzheimers.org.uk/about-us/policy-and-influencing/what-we-think/mistreatment-and-abuse-people-dementia [Accessed 13 December 2021]

Alzheimer Society of Canada (2019) 'Conversations about Dementia and Responsive Behaviours' [online]. Available: https://alzheimer.ca/sites/default/files/documents/ conversations_dementia-and-responsive-behaviours.pdf

The Alzheimer Society of Ireland (2021).'Caring and Coping with Dementia During COVID-19' Available: https://alzheimer.ie/wpcontent/uploads/2021/06/ASI_Covid_Report.pdf

Áras Attracta Swinford Review Group (2016). 'What matters most: Report of the Áras Attracta Swinford Review', Áras Attracta Swinford Review Group.

Bartlett, R., & O'Connor, D. (2010). *Broadening the dementia debate: Toward social citizenship*. Bristol: Policy Press.

British Association of Social Workers (BASW), (2020) *Statement on the latest evidence of COVID-19 in care homes* [online], Available: https://www.basw.co.uk/media/news/2020/may/basw-statement-latest-evidence-covid-19-care-homes [Accessed 14 December 2021]

Bonifas, P. (2015), Resident-to-resident aggression in nursing homes: social worker involvement and collaboration with a nursing colleague. *Health Soc Work*. 2015;40(3): e101–e109.

Brennan, J., Reilly, P., Cuskelly, K., & Donnelly, S. (2020). Social Work, Mental Health, older people and COVID-19. *International Psychogeriatrics*, 32(10), 1–11.

Cahill, S (2022) 'Dementia' in S. Torres and S. Donnelly (eds) *Critical Gerontology for Social Workers,* Policy Press, Bristol, *in press.*

Cahill, S (2018) *Dementia and Human Rights*, Policy Press, Bristol.

Cahill S, Diaz-Ponce A, Coen RF, Walsh C. (2010) The under-detection of cognitive impairment in nursing homes in the Dublin area. The need for on-going cognitive assessment. *Age and Ageing*. 2010; 39: 128–31

Carter Anand, J., Donnelly, S., Milne, A., Nelson-Becker, H., Vingare, E.L., Deusdad, B., Cellini, G., Kinni, R.L. & Cristiana Pregno (2021). The covid-19 pandemic and care homes for older people in Europe – deaths, damage and violations of human rights, *European Journal of Social Work,* Available: https://doi.org/10.1080/13691457. 2021.1954886

Comas-Herrera A, Salcher-Konrad M, Baumbusch J, Farina N, Goodman C, Lorenz-Dant K, Low L-F (2020) 'Rapid review of the evidence on impacts of visiting policies in care homes during the COVID-19 pandemic'. LTCcovid.org, International Long-Term Care Policy Network, CPEC-LSE.

Comas-Herrera, A., Zalakaín, J., Lemmon, E., Henderson, D., Litwin, C., Hsu, A. T., Schmidt, A. E., Arling, G., & Fernandez, J.-L. (2020). Mortality associated with COVID-19 in care homes: early international evidence. International Long Term Policy Network, CPEC-LSE. Available: https://ltccovid.org/wp-content/uploads/2020/05/Mortality-associated-with-COVID-3-May-final-5.pdf

Cooper C, Manela M, Katona C, Livingston G. Screening for elder abuse in dementia in the LASER-AD study: prevalence, correlates and validation of instruments. *International Journal of Geriatrics Psychiatry*. 2008;23(3):283–288.

Cooper, C., Dow, B., Hay, S., Livingston, D. and Livingston, G. (2013). Care workers' abusive behaviour to residents in care homes: a qualitative study of types of abuse, barriers, and facilitators to good care and development of an instrument for reporting of abuse anonymously. *International Psychogeriatrics*, 25(5), pp.733-741.

Cooper C, Marston L, Barber J, Livingston D, Rapaport P, Higgs P, et al. (2018) 'Do care homes deliver person-centred care? A cross-sectional survey of staff-reported abusive and positive behaviours towards residents from the MARQUE (managing agitation and raising the quality of life) English national care home survey'. PLoS One. 2018;13(3):e0193399. 10.1371/journal.pone.0193399.

Davies, C., Fattori, F., O'Donnell, D., Donnelly, S., Shé, É. N., Shea, M. O., … Kroll, T. (2019). What are the mechanisms that support healthcare professionals to adopt assisted decision-making practice? A rapid realist review. BMC Health Services Research, 19(1), 960. https://doi.org/10.1186/s12913-019-4802-x

Dementia Alliance International (2016) *The human rights of people living with dementia: From rhetoric to reality*, 2nd edition (DAI, 2016).

Dening, T., & Milne, A. (2020) Mental Health in Care Homes for Older People, in T. Dening, A. Thomas, R. Stewart., & J-P. Taylor. *Oxford Textbook of Old Age Psychiatry*, 3rd edition, OUP.

Department of Health (2019) Discussion Paper: Primary Definitions. National Policy on Adult Safeguarding for the Health Sector, Dublin: Department of Health

Department of Health (2011) Towards a Restraint Free Environment in Nursing Homes. Dublin, Department of Health.

Devandas-Aguilar, C (2019) 'Report of the Special Rapporteur on the Rights of Persons with Disabilities', UN Doc. A/74/186 (2019).

Diaz Ponce, A and Georges, J (2018). 'Residential Care for People with Dementia in Europe – Not the Same Policy Standards Everywhere', *European Neurological Review*, 13(1):14–5.

Dixon, J. (2021) *Supporting people living with dementia to be involved in adult safeguarding enquiries*, 31 Mar 2021, London: Department of Health and Social Care.

Dixon, J., Donnelly, S., Campbell, J. & Laing, J., (2021. Safeguarding People Living with Dementia: How Social Workers Can Use Supported Decision-making Strategies to Support the Human Rights of Individuals during Adult Safeguarding Enquiries, *British Journal of Social Work*, 2021; bcab119.

Dixon, J., Biggs, S.,Tinker, A., Stevens, M and Lee, L(2009) 'Abuse, Neglect And Lack Of Dignity In The Institutional Care Of Older People: Definitional Issues, Kings College/National Centre, London.

Donnelly, S (5th July 2021). Irish Time Opinion Editorial, Nursing homes must be made places of safety and protection. Available: https://www.irishtimes.com/opinion/nursing-homes- must-be-made-places-of-safety-and-protection-1.4611256

Donnelly S., Ó Coímín D., O'Donnell,D., Ní Shé, E., Christophers, L., Mc Donald, S and Kroll,T (2021). Assisted decision-making and interprofessional collaboration in the care of older people: a qualitative study exploring perceptions of barriers and facilitators in the acute hospital setting. *Journal of Interprofessional Care*, Available: https://www.tandfonline.com/doi/full/10.1080/13561820.2020.1863342

Donnelly, S., Begley, E., & O'Brien, M. (2019). How are people with dementia involved in care-planning and decision-making? An Irish social work perspective. *Dementia*, 18(7-8), 2985-3003.

Donnelly, S and O'Brien, M (2018). *Speaking Up About Adult Harm: Options for Policy and Practice in the Irish Context*. Dublin: UCD.

Donnelly, S., O'Brien, M., Walsh, J., Campbell, J., McInerney, J., & Kodate, N. (2017). Adult Safeguarding Legislation and Policy: Rapid Realist Literature Review (2017). Dublin: HSE National Safeguarding Office / Trigraph Limited.

Drennan, J., Lafferty, A., Treacy, M.P., Fealy, G., Phelan, A., Lyons, I. and Hall, P. (2012) Older people in residential care settings – result of a national survey of staff – resident interactions and conflicts. NCPOP, Dublin.

Emmer De Albuquerque Green, C., Tinker, A and Manthorpe, J. (2021) 'Human rights and care homes for older people: a typology of approaches from academic literature as a starting point for activist scholarship in human rights and institutional care', *The International Journal of Human Rights*, DOI: 10.1080/13642987.2021.1961753

Emmer De Albuquerque Green, C. (2018) Making 'Human Rights' happen in care homes for older people [online], Available from: https://www.alliance-scotland.org.uk/blog/opinion/making-human-rights-happen-in-care-homes-for-older-people/ [Accessed 14 December 2021]

Fang, B. and Yan, E., 2018. Abuse of older persons with dementia: a review of the literature. Trauma, Violence, & Abuse, 19(2), pp.127-147

Geiran, V(2021) 'No proper safeguarding for adults at risk without political will' Irish Examiner, Thursday 11th November [online], Available from: https://www.irishexaminer.com/opinion/commentanalysis/arid-40741215.html [Accessed 12 December 2021].

Gelsthorpe et al. (2020) 'Introduction: Spaces of Care: Concepts, Configurations, and Challenges', in Spaces of Care, ed. L. Gelsthorpe, P. Mody & B. Sloan (London: Hart Publishing, 2020).

Health Protection Surveillance Centre (2022) COVID-19: Normalising Access in Long Term Residential Care Facilities (LTRCFs) [online], Available: https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/guidance/infectionpreventionandcontrolguidance/residentialcarefacilities/Normalising%20visiting%20in%20LTRCF.pdf

Health Service Executive (2019). National Safeguarding Office Annual Report, 2019. Dublin: HSE

Health Information and Quality Authority (HIQA) (2019a) *Guidance on a human rights-based approach in health and social care services*. Dublin: HIQA.

Health Information and Quality Authority (2019b) *Guidance on promoting a care environment that is free from restrictive practice: Disability Services*, Dublin: Health Information and Quality Authority.

Howard, R., Burns, A., & Schneider, L. (2020). Antipsychotic prescribing to people with dementia during COVID-19. The Lancet Neurology, 19(11), 892. https://doi.org/10.1016/S1474-4422(20)30370-7

Human Rights Watch. *"They want docile": How nursing homes in the United States overmedicate people with dementia.* New York: Human Rights Watch; 2018. [Google Scholar].

Irish Association of Social Workers (IASW) (2021), *Irish Association of Social Workers Position Paper on Adult Safeguarding Legislation, Policy and Practice*.

Keeling, A. (2017). 'Organising objects': Adult safeguarding practice and article 16 of the United Nations convention on the rights of persons with disabilities. *International Journal of Law and Psychiatry*, 53, 77–87. https://doi.org/10.1016/j.ijlp.2017.05.005

Lee K, Bartlett R. (2021) Material Citizenship: An ethnographic study exploring object-person relations in the context of people with dementia in care homes. Sociol Health Illn. 2021 Jul;43(6):1471-1485. doi: 10.1111/1467-9566.13321

Levere M, Rowan P, Wysocki A. The Adverse Effects of the COVID-19 Pandemic on Nursing Home Resident Well-Being. *J Am Med Dir Assoc.* 2021 May;22(5): 948-954.e2.

Mazars, Phelan, A., O'Donnell, D. and Stokes, D. (2020) 'Evidence review to inform the development of a national policy on adult safeguarding in the health and social care sector: An evidence review', Dublin: Mazars.

McGarry, S., Cuskelly, K., Reilly, P., Coffey, A., Finucane, N., O'Loughlin, A., & Casey, L. (2020). The liaison Social work role in nursing homes and residential settings: A model for practice. Irish Association of Social Workers.

Milne, A. (2020a). Mental Health in later life: Taking a lifecourse approach. Policy Press.

Moore, K and Haralambous,B (2007)."Barriers to reducing the use of restraints in residential elder care facilities," *Journal of Advanced Nursing*, 58/6 (2007), pp. 532–540.

Moore S (2017) Reasons for staff failure to report abuse of residents in nursing homes. Nursing Times [online]; 113: 7, 53-57.

NICE (National Institute for Health and Clinical Excellence)/SCIE (Social Care Institute for Excellence) (2007) Dementia: A NICE-SCIE guideline on supporting people with dementia and their carers in health and social care, National Clinical Practice Guideline No 42, The British Psychological Society and Gaskell, London: NICE/SCIE. Nursing Homes Ireland (2022) 'Who we are' Available: https://nhi.ie/about-nhi/who-we-are/

Office of the Ombudsman (2017) 'The Ombudsman Nursing Home Casebook' NursingHome Special Edition, 2017.

Pfister, T. (2012). Citizenship and capability? Amartya Sen's capabilities approach from a citizenship perspective. *Citizenship Studies*, 16(2), 241–254.

Phelan A. (2015).'Protecting care home residents from mistreatment and abuse: on the need for policy'. *Risk Management Healthcare Policy*. 2015; 8:215–223.DOI: 10.2147/RMHP.S70191.

Pillemer K, Chen EK, Van Haitsma KS, et al. (2021) Resident-to-resident aggression in nursing homes: results from a qualitative event reconstruction study. *Gerontologist*. 2012;52(1):24–33.

Robinson, L., Gemski, A., Abley, C., Bond, J., Keady, J., Campbell, S. Samsi, K. and Manthorpe, J. (2011) 'The transition to dementia – Individual and family experiences of receiving a diagnosis: A review', International Psychogeriatrics, vol 23, no 7, pp 1026-43.

Social Care Institute for Excellence (SCIE)(2021). Resident-to-resident harm in care homes and other residential settings: a scoping review, August 2021 Available: https://www.scie.org.uk/safeguarding/evidence/ resident-to-resident-harm

Sherwood-Johnson, F. (2013) 'Constructions of 'vulnerability' In comparative perspective: Scottish protection policies and the trouble with 'adults at risk'', *Disability & Society*, 28(7), pp. 908-921

Steele, L., Carr, R., Swaffer, K., Phillipson, L., & Fleming, R. (2020). Human Rights and the Confinement of People Living with Dementia in Care Homes. *Health and human rights*, 22(1), 7–19.

Stevenson, M., Savage, B. and Taylor, B.J., 2019. Perception and communication of risk in decision making by persons with dementia. *Dementia*, 18(3), pp.1108-1127.

Swaffer K., Low L. F. (2016) "What people with dementia want from residential care homes," pp. 21–23. Diagnosed with Alzheimer's or another dementia. 2016); K. Swaffer, *Australian Journal of Dementia Care* 5/3

United Nations (2008) Convention on the Rights of Persons with Disabilities. Geneva: United Nations; http://www.ohchr.org/EN/Issues/Disability/SRDisabilities/Pages/ SRDisabilitiesIndex.aspx

Valayudhan, L., Aarsland, D., & Ballard, C. (2020). Mental health of people living with dementia in care homes during COVID-19 pandemic. *International Psychogeriatrics*, 32(10), 1253–1254. https://doi.org/10.1017/S1041610220001088

Walker H. and Paliadelis, P. (2016). "Older peoples' experiences of living in a residential aged care facility in Australia," "A qualitative study of the experiences of long-term care for residents with dementia, their relatives and staff," 2016. pp. E6–E10.pp. 119–128. *Australasian Journal on Ageing* 35/3.

World Health Organisation (2015). Ensuring A Human Rights-Based Approach For People Living With Dementia, [online], Available: https://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_human_rights.pdf

World Health Organisation. (2020). Risk Factors of Ill Health among Older People, [online] Available: https://www.euro.who.int/en/health-topics/Life-stages/healthy-ageing/data-and-statistics/risk-factors-of-ill-health-among-older-people

Wübker, A., Zwakhalen, S.M., Challis, D., Suhonen, R., Karlsson, S., Zabalegui, A. et al (2014) 'Costs of care for people with dementia just before and after nursing home placement: Primary data from eight European countries', *The European Journal of Health Economics*, pp 1-19.

The Alzheimer Society of Ireland,
National Office,
Temple Road,
Blackrock,
Co Dublin.
A94 N8Y0

Tel: (01) 207 3800

Office opening hours – Monday to Friday, 9 am to 5 pm

Freephone Confidential National Helpline:
1800 341 341 / helpline@alzheimer.ie

General Enquiries: info@alzheimer.ie

THE Alzheimer
SOCIETY OF IRELAND