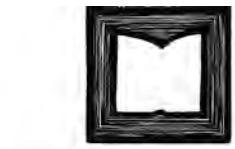
NORTHERN IRELAND HUMAN RIGHTS COMMISSION

In Defence of Dignity

The Human Rights of Older People in Nursing Homes



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Temple Court, 39 North Street, Belfast BT1 1NA
Tel: (028) 9024 3987 ■ Fax: (028) 9024 7844
Textphone: (028) 9024 9066 ■ SMS Text: 07786 202075
Email: information@nihrc.org ■ Online: www.nihrc.org ■ twitter.com/nihrc
facebook.com/nihrc ■ youtube.com/nihrc

Foreword

Moving into a nursing home can be a distressing experience. Notwithstanding the tremendous efforts and dedication of many of the nursing homes and their staff, a new resident in a nursing home will experience a radical change in his or her physical and emotional environment. Nursing home residents often require help with their everyday needs from the dispensing of medication to the provision of food and clean clothing. Many are also dependent on nursing home staff for socialising, mental stimulation and physical activities. There is a risk of multiple forms of human rights abuse. It is for these reasons that the Commission has found it necessary to conduct a strategic investigation into the rights of older people in nursing homes.

The investigation fieldwork was conducted in carefully selected homes in Northern Ireland to allow for an in-depth analysis of key themes that are identified in the substantive chapters. In addition, the Commission invited members of the public to come forward with their experiences of nursing home care through a dedicated phone line or an on-line questionnaire.

Human rights standards are relevant to the way in which older people are encouraged and enabled to spend their day, how personal care is offered, as well as how and when medication and medical treatment is provided. This investigation report outlines the human rights legal framework that applies to older people in nursing homes. Each chapter compares the human rights standards to the domestic law and policy. It then discusses the findings of primary fieldwork which examines the practice in nursing homes. It concludes that for older people to be afforded the dignity and human rights protections to which they are entitled, changes are required in the law and regulation. It calls on human rights principles to be made the foundation of the relevant laws, regulation and training.

Our recommendations are mainly directed to the Northern Ireland Executive which is the primary duty-bearer under human rights law. It is hoped the NI Executive will implement the necessary changes to meet its human rights obligations as a matter of urgency. The Commission stands ready to provide further advice and assistance to the NI Executive and the range of bodies involved in delivering and overseeing care to older people in nursing homes.

The Commission offers its sincere gratitude to all those who participated in the investigation, including those who took part in the call for evidence as well as the management and staff of those nursing homes that agreed to be investigated. Many of the residents of the homes visited and their relatives contributed directly to this investigation and to them we are extremely grateful. The Commission would also like to thank Dr Ian MacKenzie and the late Ms Pauline Neill for the medical analysis which contributed to Chapters 6 and 7 of this report.

It was under the previous Commissioners led by Professor Monica McWilliams that this investigation began. The present Commission offers its gratitude to them.

Professor Michael O'Flaherty
Chief Commissioner

Contents

Terminology

Care home: In this report, the term 'care home' is used to encompass both residential and nursing homes.

EMI home: An 'EMI' or Elderly Mentally Infirm home is one that is registered to provide specialist 24-hour nursing care for older people with mental disability including cognitive impairments such as dementia and Alzheimer's disease.

Nursing home: A nursing home refers to a home in which older people live where there are nursing and care staff available 24 hours each day. As well as assistance with personal care, nursing homes provide 24-hour nursing care.

PRN: 'PRN' is an abbreviation of the Latin term, 'Pro Re Nata' ('as the circumstances arise'). In this report, the term is used to describe the prescription of medical drugs by a qualified medical practitioner: a PRN prescription means that nursing staff can administer the named drug "as and when needed".

Resident: While generally accepted, the term 'resident' in a care home context, (as with the term 'patient' in a medical context), carries with it socially constructed notions that engender a view of an individual as primarily vulnerable and in need and, as a consequence, risks undermining the importance of their human rights, particularly their right to personal autonomy. For practical reasons, it has not been possible in this report to refer continually to 'older people who live in nursing homes' and, therefore, the term 'resident' or 'residents' is often used; it is intended to describe the situation in which a person lives and in no way reflects or sums up who they are as a person.

Residential home: In the context of this report, a residential care home refers to a home in which older people live and in which care staff are available 24 hours each day to provide personal care. Residential care homes do not provide 24-hour nursing care.

Executive summary

The key chapters in this report demonstrate how, in practice, failure to place international human rights standards at the core of the legal and regulatory framework applicable to nursing homes can undermine residents' human rights. Chapter 2 outlines the international, regional and domestic human rights standards applicable to older people in nursing homes. The main findings from this investigation are then presented as follows:

- **Chapter 3: Quality of life –** the evidence shows that availability of activity is crucial to residents' quality of life. Chapter 3 identifies the importance of organised activity and meaningful social interaction. It demonstrates how the provision of devoted activities staff and ensuring time for staff and residents to 'chat' and interact can significantly improve protection of residents' human rights.
- **Chapter 4: Personal care –** this chapter reveals how the provision of appropriate and timely help with continence needs is vital to respecting residents' human rights. Among the other key findings in Chapter 4 is the importance of respecting residents' choice, independence and personal identity in relation to their personal care needs.
- **Chapter 5: Eating and drinking –** the evidence in Chapter 5 shows how appropriate assistance with eating and drinking can enhance residents' human rights. However, it also reveals instances where the manner in which help is provided undermines residents' dignity. The findings therefore highlight the importance of enabling residents to enjoy a dignified dining experience. It also sets out residents' access to adequate food and water as a fundamental human right.
- **Chapter 6: Medication and health care –** medication and health care are important for residents' right to life and also for enhancing the quality of life. An examination of a sample of nursing home and GP records of 25 residents, revealed a lack of uniform approach by GPs to the review of residents' medication and a lack of evidence to show that residents' mental health needs are regularly reassessed. In addition, there are concerns about access to health care professionals other than GPs, such as physiotherapists and dentists.
- **Chapter 7: Restraint –** residents' freedom of movement may at times be restricted in nursing homes due to physical measures of restraint, such as bedrails, or the use of medication with sedating effects. The findings show how existing concerns about the use of restraint in nursing homes in Northern Ireland are compounded by the lack of a statutory definition of restraint and the absence of formal guidance that draws on international human rights standards.
- **Chapter 8: Conclusions and recommendations –** the Northern Ireland Human Rights Commission's recommendations are directed mainly to the Northern Ireland Executive, which bears primary responsibility for implementing international human rights obligations applicable to older people in nursing homes. The Commission calls for a range of legislative and policy measures that explicitly link human rights standards with nursing home care. To ensure that care delivery improves the lives of residents the report concludes with practical recommendations to nursing homes. This includes ensuring that residents are enabled to access the outdoor environment of the home, that they receive appropriate and timely assistance with continence needs, and have adequate food and water accessible at all times of the day and night.

Setting the scene

"[…] the ageing world's most important challenge is to ensure the enjoyment of the human rights of older persons." (Anand Grover, UN Special Rapporteur on the Right to Health)[1]

Investigation powers of the Northern Ireland Human Rights Commission

The Northern Ireland Human Rights Commission (the Commission) was established under the *Northern Ireland Act 1998* (the 1998 Act). Section 69(8) of the 1998 Act provides the Commission with powers to conduct investigations. Since the introduction of the *Justice and Security (Northern Ireland) Act 2007*, the Commission has powers to compel evidence and to access places of detention. During this investigation, the Commission did not have to use its investigatory powers due to the high levels of co-operation from the nursing homes selected for examination. This investigation is therefore not a formal 'powers' investigation. Nonetheless, the findings and recommendations in this report are presented in discharge of the Commission's statutory functions, including the duty to review the adequacy and effectiveness of law and practice relating to the protection of human rights in Northern Ireland.[2]

The need for an investigation

Human rights principles call for full recognition of the human rights of older people to enjoy a healthy and fulfilling life, while acknowledging the experience and wisdom of older people to control their own lives and, more generally, to participate actively in society.[3] Significantly, human rights discourse also acknowledges that societal concepts and stereotyped perceptions about ageing render older people particularly vulnerable to abuse.[4] At the core of relevant domestic laws and policies, therefore, there should be appropriate mechanisms to promote and protect older people's fundamental human rights.

It is reported widely that the global population is ageing rapidly: already there are almost 700 million people worldwide over the age of 60 and, by 2050, over 20 per cent of the global population will be 60 or over, representing almost 2 billion people.[5] Although this increase will be greatest in the developing world, the challenge to ensure the enjoyment of the human rights of older people applies worldwide. Reporting specifically on the human rights of older people, the UN Special Rapporteur on the right to health notes that, in developing countries, mechanisms to protect the rights of those in institutional care are lacking; however, "Developed countries […] feature only relatively better in developing such mechanisms".[6]

In Northern Ireland, where it is projected that by 2047 there will be twice as many people aged 65 and over than there are today,[7] an increasing number of older people are cared for in residential and nursing homes.[8] This increase has been greatest in relation to nursing homes, with the number of nursing home care packages for people aged 65 and over showing just over a 51 per cent increase in the ten-year period from March 1999 to March 2009.[9] Unlike residential homes, nursing homes provide 24-hour nursing care and the increase in available nursing care packages is indicative, perhaps, of the growing health needs of older people receiving long-term care. As well as physical health needs, older people in nursing homes have significant mental health requirements

1 UN Human Rights Council (2011) *Thematic Study on the Realisation of the Right to Health of Older Persons by the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health,* 4 July 2011, A/HRC/18/37, para 9.

2 Section 69(1) *Northern Ireland Act 1998*.

3 UN Second World Assembly on Ageing (2002) *Political Declaration*, 8-12 April 2002, Articles 5 and 10.

4 Above, UN Human Rights Council (2011) para 70.

5 UN General Assembly (2011) *Follow-up to the Second World Assembly on Ageing: Report of the Secretary-General*, 22 July 2011, A/66/173, paras 3 and 4.

6 Above, UN Human Rights Council (2011) para 48.

7 Northern Ireland Statistics and Research Agency (2011) *Statistical Report: 2010-Based Population Projections*, 26 October 2011, p3.

8 The DHSSPS Adult Community Statistics show an increase in the number of care packages in residential and nursing homes for those aged 65 and over (see: DHSSPS *Adult Community Statistics 1998/99 to 2008/09* (available: http://www.dhsspsni.gov.uk/index/stats_research/stats-cib/statistics_and_research-cib-pub/adult_statistics/statistics_and_research-cib-community_statistics.htm); see also: Northern Ireland Audit Office (2010) *Arrangements for Ensuring the Quality of Care in Homes for Older People*, 8 December 2010, para 1.2.

9 In March 1999, 4,345 nursing home care packages were in place for those aged 65 and over compared to 6,579 in March 2009 (See: DHSSPS *Adult Community Statistics, 1998/99* at Table 3.2 and DHSSPS *Adult Community Statistics, 2008/09* at Table 2.2).

due to the prevalence of cognitive impairments in older age such as dementia and Alzheimer's disease. Indeed, research estimates that almost half (47 per cent) of those with late-onset dementia in Northern Ireland live in residential care or nursing homes (compared to just over one third (36.5 per cent) in the rest of the UK).[10]

In August 2007, the Parliamentary Joint Committee on Human Rights published the report of its inquiry into the human rights of older people in health care.[11] Focusing on those in hospital and care homes, the Committee reported serious concerns relating to, among other matters, abuse, malnutrition and dehydration, inappropriate use of sedating medication, and a lack of privacy, dignity and confidentiality.[12]

Residents in nursing homes often have complex medical needs but most are not there to receive a specific course of medical treatment. A nursing home is the resident's home, their permanent place of residence for an indefinite period. The Commission wished to investigate how nursing homes ensure the highest possible standard of health care for residents while not compromising residents' rights in all other areas of life. National, regional and international human rights standards along with their developing jurisprudence recognise that a uniform approach between someone living in their own home and someone living in a nursing home is not always possible or, in some cases, desirable. However, it is clear that the same human rights apply to all regardless, even if the application of those standards requires different actions from the duty bearers.

In Northern Ireland, the Regulation and Quality Improvement Authority (RQIA) has a statutory duty to inspect all residential and nursing homes in Northern Ireland at least twice in every 12-month period.[13] However, other than the RQIA reports of its inspections, which are set against the DHSSPS *Nursing Homes Minimum Standards (2008),* there has been no systematic analysis of the extent to which the State discharges its human rights obligations toward older people in nursing homes in Northern Ireland. This absence coupled with a recent legislative amendment,[14] which means that in certain circumstances the *Human Rights Act 1998* now applies to private care homes, prompted the Northern Ireland Human Rights Commission to conduct an investigation into the human rights of older people in nursing homes.

The investigation

Human rights instruments relating to older people address the importance of the right to health but also other factors that are related to health, including the availability of supportive environments that enhance older people's capabilities and promote their quality of life.[15] The methodology for this investigation is therefore designed to examine how nursing homes address the complex health needs of residents while also advancing their quality of life.[16] With this in mind, following an extensive scoping exercise informed by its meetings with academic experts as well as representatives from the voluntary and community sector in Northern Ireland, the Commission devised terms of reference that ensured an appropriate balance between an examination of the medical and non-medical aspects of residents' care.[17] The terms of reference for the investigation identified areas on which the Commission's investigation focused, including sedation, review of medication, nutrition, dignity and non-discrimination. The terms of reference for the investigation were

10 Dementia UK (2007) *A Report into the Prevalence and Cost of Dementia: Northern Ireland Supplement*, Alzheimer's Society, London, p6; Dementia UK (2007) *A Report into the Prevalence and Cost of Dementia: Summary of Key Findings*, Alzheimer's Society, London, pp5-6 (See also: DHSSPS (2011) *Improving Dementia Services in Northern Ireland: A Regional Strategy*, November 2011, para 10.1).

11 House of Lords, House of Commons Joint Committee on Human Rights (2007) *The Human Rights of Older People in Healthcare: Eighteenth Report of Session 2006-2007*, Vol I, TSO Ltd, London.

12 Above.

13 *Regulation and Quality Improvement Authority (Fees and Frequency of Inspections) Regulations (NI) 2005*, Regulation 6.

14 *Health and Social Care Act 2008*, Section 145.

15 See, for example: Priority Direction II and III of the United Nations (2002) *Report of the Second World Assembly on Ageing (Madrid International Plan of Action on Ageing).*

16 For a detailed methodology, see Appendix 2.

17 See Appendix 1 for the terms of reference.

launched in November 2009; the main fieldwork began in December 2009 and extended to September 2010.

When deciding the scope of this investigation, the issue of funding care in a nursing home was raised by a number of individuals and organisations. The cost of nursing care in Northern Ireland is funded by the Health and Social Care (HSC) Trusts and is currently set at a rate of £100 per week, per resident. HSC Trusts also pay an element of the cost of personal care for the majority of residents in nursing homes and this is means tested. Those residents deemed to have greater economic assets are expected to make a financial contribution to their own personal care. Many individuals and organisations questioned the formula for calculating nursing home fees and stressed the financial burden on older people and their families. The Commission had to consider whether or not to include this within the ambit of its investigation. While not underestimating the significance of decisions regarding funding, the issues raised by the financing of nursing care are quite different from those pertaining to the treatment of older people once in nursing care. The Commission concluded that the investigation should concentrate on the latter, assessing the everyday realities for older people in nursing homes and the extent to which their human rights are promoted and protected.

Selected nursing homes

At the time of the fieldwork there were 252 nursing homes registered in Northern Ireland, offering approximately 10,500 registered places.[18] From the outset, it was clear to the Commission that in order to conduct a systematic analysis of the implementation of human rights standards in nursing homes, it would not be possible to examine all nursing homes in Northern Ireland; however, focusing on a small number of homes would allow a level of in-depth analysis. An initial landscape and demographic analysis resulted in the decision to conduct primary research in four nursing homes.[19] The combined sample represented a mix of small/medium/large, rural/urban and corporate/single ownership homes. Given the prevalence of dementia among older people in nursing homes, two of the homes were also selected because they provide care for older people with mental disability, known as 'Elderly Mentally Infirm' or 'EMI' homes. The primary fieldwork relied on extensive interviews with staff, residents and family members or friends visiting the home. A close examination of the written policies and procedures of each home and an analysis of a sample of nursing home and General Practitioner (GP) records of 25 residents was also completed.

Call for evidence

To add to the information gathered from its primary fieldwork in the four nursing homes, the Commission held a public call for evidence. Members of the public, who had experience of nursing home care, were invited to call the Commission using a phone line established for this purpose. The Chief Commissioner (then, Professor Monica McWilliams) participated in a number of media interviews and posters were sent to every nursing home in Northern Ireland inviting calls from the public. As a result, the Commission recorded 163 calls for the investigation and 25 written submissions. In all instances, the Commission was struck by how much of their own time callers gave to help with the investigation and by the level of detail provided in their evidence, which often involved the disclosure of extremely painful personal accounts. The information received during the call for evidence served a particularly valuable role both as a source of evidence and as a mechanism to confirm or add to the findings from the Commission's primary fieldwork. In many instances, members of the public in the call for evidence reported concerns that were also

18 Regulation and Quality Improvement Authority (2010) *A Quarterly Report, October to December 2009*, RQIA, Belfast, pp3-4 (available: http://www.rqia.org.uk/publications/quarterly_reports.cfm). At the time of writing, this figure had risen to 264 registered homes (available: http://www.rqia.org.uk/cms_resources /NurshingHomese_Dec11.update.xls).

19 See the methodology at Appendix 2.

identified by the Commission during its fieldwork, often casting further light on problem areas. At other times, as might have been expected, callers reported concerns that had not been discovered during the primary fieldwork.

Analysis of medical and nursing home records

The Commission received consent to access the GP and nursing home records for 25 residents in the four selected homes in order to examine the appropriateness of residents' medication and the extent to which medication is reviewed. It was important that the analysis of this material was completed on a peer-to-peer basis. This required an appropriately qualified nurse to review the records which had been compiled and updated by nursing staff in the home, and a GP to review the records which had been compiled and updated by the resident's GP. Two qualified clinicians from outside of Northern Ireland were commissioned to undertake this analysis and their findings are included in Chapters 6 and 7 of this report.[20] The clinicians evaluated the content of the records against a number of professional standards.[21] The human rights evaluation for their review is the Commission's own.

The investigation report

The aim of this report is to improve human rights protection for older people across all nursing homes in Northern Ireland and for that reason it does not identify any individual home. Neither the four nursing homes in which primary fieldwork was conducted or the homes identified in the call for evidence are named in this report.

To allow the reader to assess how conclusions have been reached, the report indicates where a finding relates primarily to information received as part of the call for evidence or to evidence gathered first hand during the primary fieldwork.

The chapters and main findings contained in this report are derived from, and grounded in, the data received by the Commission during the primary fieldwork in the four selected nursing homes, the public call for evidence and the review of a sample of nursing home and GP records concerning 25 residents. The findings from the primary fieldwork and the public call for evidence reveal patterns of practice that led the Commission to structure the report around key themes, as identified in the chapter titles:

- Chapter 3: Quality of life
- Chapter 4: Personal care
- Chapter 5: Eating and drinking
- Chapter 6: Medication and health care
- Chapter 7: Restraint

Throughout, the Commission uses international and domestic human rights standards to frame its findings and it is upon these standards that its recommendations are based.

The Commission's overarching recommendations are presented in Chapter 8. They call for a legal and regulatory framework that is expressly linked to all the relevant human rights standards. If followed, this would be of benefit to residents in all nursing homes. A failure to take account of the recommendations would leave in place the current human rights regulatory and practice gap, thus leaving nursing homes residents exposed to the risk of human rights abuse.

Chapter 3 to 7 begin by outlining the human rights standards that should inform the legislation, policy and practice of nursing homes. Each chapter then discusses the legislation and policies under which the nursing homes currently operate. The discrepancy between the human rights standards and the domestic measures is then discussed

20 For further information, see: Appendix 3.

21 These standards are: General Medical Council (2006) *Good Medical Practice;* General Medical Council (2008) Consent: Patients and Doctors making Decisions Together; National Institute for Health and Clinical Excellence (2011) *NICE Technology Appraisal Guidance 217: Donepezil, Galantamine, Rivastigmine, and Memantine for the treatment of Alzheimer's disease*, NICE, London, March 2011; Nursing and Midwifery Council (2008) *Standards for Medicines Management*; and Nursing and Midwifery Council (2009) *Record Keeping: Guidance for Nurses and Midwives*.

before presenting the primary evidence from the investigation, which illuminates why this discrepancy can lead to problematic practices on the ground.

To whom is this report addressed?

The obligation to comply with, and implement, international human rights standards rests firmly with States Parties and, in Northern Ireland, at least in relation to devolved matters, this duty belongs to the Northern Ireland Executive and its relevant Departments. The Department of Health, Social Services and Public Safety (DHSSPS) has primary responsibility to ensure implementation of human rights standards for older people in nursing homes. Many if not all of the concerns identified in this report relate to the lack of an overarching framework to ensure the systematic application of human rights standards to all aspects of care provided to older people in nursing homes. To remedy this, action and leadership is required from the NI Executive and the DHSSPS and, consequently, it is to each that many of the recommendations in this report are addressed.

The entry into force of the *Health and Social Care Act 2008* means that obligations under the *European Convention on Human Rights and Fundamental Freedoms* (the ECHR), under Section 6(1) of the *Human Rights Act 1998,* now extend to all nursing homes insofar as they provide care to people who are partly or wholly funded by a HSC Trust. Certain of the recommendations in this report are, therefore, aimed directly at the "legally responsible person", that is, the individual in each nursing home who is legally accountable for its everyday care.

2 Human rights law and standards

Older persons should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility …]. (UN Principles for Older Persons)

Introduction

Human rights standards have, from their inception, paid attention to the distinct needs of various groups considered to be particularly vulnerable. Specific treaties exist, for example, in respect of women, children, racial and ethnic groups, and people with disabilities. In November 2010, the United Nations (UN) established a working group to consider the possibility of an international treaty to strengthen the protection of the human rights of older people.[1] To date, no treaty has been designed but this does not mean that human rights law is irrelevant when it comes to older people. On the contrary, international treaties and 'soft law' standards, as well as regional and domestic law, contain guarantees and guidance that is particularly relevant to the human rights of older people.

This report does not provide an exhaustive account of the human rights standards that are applicable to older people; rather, the general application of the main international human rights treaties, relevant regional and domestic law, and soft law standards applicable to older people is detailed below. In the chapters that follow, the provision of activity, personal care, food, medication and health care and the use of restraint in nursing homes are examined against a more detailed analysis of the relevant human rights law and guidance.

The legal status of international human rights instruments in Northern Ireland

Before discussing the various human rights standards, it is useful to explain briefly their legal status and application in Northern Ireland. The European Convention on Human Rights (ECHR) is the only human rights instrument that is incorporated directly into UK law (via the *Human Rights Act 1998*) and is therefore the only one that is directly enforceable in domestic courts. In addition, the obligations placed upon the State by the ECHR extend beyond the Northern Ireland Assembly and Executive to include public authorities.[2] This means that, unless a measure of primary legislation prevents it from acting otherwise, it is unlawful for a public authority, such as a local Health and Social Care (HSC) Trust, to act in any way which is incompatible with a person's Convention rights. As explained further below, these obligations under the *Human Rights Act 1998* now extend to all nursing homes insofar as they provide care to people who are partly or wholly funded by a HSC Trust.

International human rights treaties are not directly enforceable in domestic courts; however, they do impose legal obligations upon States Parties. Consequently, international treaties ratified by the UK contain obligations that are binding on government as a matter of international law.[3] Given that, in Northern Ireland, health and social care is a devolved matter, responsibility for implementing international human rights obligations applicable to older people in nursing homes rests directly with the Northern Ireland Executive and its relevant Departments for privately owned nursing homes as well as those owned and run by the State. In the context of nursing homes, the relevant Department is the Department of Health, Social Services and Public Safety (DHSSPS).

International human rights law

Civil and political rights

The *International Covenant on Civil and Political Rights* (ICCPR) contains the civil and political rights guarantees applicable to all people within the jurisdiction of a State Party. Potentially all of the human rights contained in the ICCPR are relevant

1 UN General Assembly Resolution 65/182 on the *Follow-up to the Second World Assembly on Ageing*, 16 November 2010, A/C 3/65/L.8/Rev 1 (available: http://www.ohchr.org/Documents/Issues/OlderPersons/A_C_3_65_L_8_rev1.pdf para 28.

2 *Human Rights Act 1998*, Section 6.

3 *Vienna Convention on the Law of Treaties* 23 May 1969, Article 26.

to older people. For those in nursing homes, however, a number of the provisions are particularly significant, for example, the right to life (Article 6), the right not to be subjected to cruel, inhuman or degrading treatment (Article 7) and the right to private and family life (Article 17). Therefore, for instance, the UN Human Rights Committee responsible for monitoring States Parties' obligations under the ICCPR has considered the use of restraint in social care and other settings under Article 7 and, at times, Article 6 of the ICCPR. [4]

In addition, the Committee, under Article 7 of the ICCPR, has examined the more general conditions in nursing homes. Assessing the situation of older people in nursing homes in Germany, the Committee noted:

> […] the vulnerable situation of elderly persons placed in long-term care homes, which in some instances has resulted in degrading treatment and violated their right to human dignity.[5]

The Committee was responding to inspection outcomes that had revealed various concerns in nursing homes, including insufficient documentation, disempowering care that was not co-ordinated with resources or residents' potential, a lack of care in relation to continence needs and a lack of knowledge about the provision of food and liquids.[6] It is clear therefore that deficiencies in the living conditions and levels of care provided in nursing homes can amount to inhuman and degrading treatment within the meaning of the ICCPR.

Economic, social and cultural rights

Given the particular circumstances of older people in nursing homes, the protections afforded by economic, social and cultural rights are particularly important. Older people living in nursing homes may, for example, have physical or mental ill health and may be reliant on others for their food, health care and, more generally, their quality of life. These matters are all crucial to the human rights of older people in nursing homes and are dealt with primarily in the *International Covenant on Economic, Social and Cultural Rights* (ICESCR). Article 12 of the ICESCR, for example, guarantees the "highest attainable standard of physical and mental health", while Article 11 guarantees "the right of everyone to an adequate standard of living for himself and his family, including adequate food, clothing and housing".

Many of the human rights guaranteed by the ICESCR contain obligations that State Parties are required to realise progressively over time. However, there is an obligation placed upon government to move immediately towards this goal.[7] In addition, the UN Committee on Economic, Social and Cultural Rights, the supervisory body charged with overseeing the implementation of the ICESCR, is clear that each right contains minimum core obligations which States Parties should aim to meet immediately:

> […] a minimum core obligation to ensure the satisfaction of, at the very least, minimum essential levels of each of the rights is incumbent upon every State party. Thus, for example, a State party in which any significant number of individuals is deprived of essential foodstuffs, of essential primary health care, of basic shelter and housing, or of the most basic forms of education is, prima facie, failing to discharge its obligations under the Covenant.[8]

Therefore, government is likely to fall foul of its obligations under the ICESCR if a significant number of older people in nursing homes are deprived of the basic essential levels of care, such as the provision of adequate food and water or medical assistance.

4 For example: UN Human Rights Committee (2001) *Concluding Observations: Switzerland*, 12 November 2001, CCPR/CO/73/CH, para 13; UN Human Rights Committee (2003) *Concluding Observations: Slovakia*, 22 August 2003, CCPR/CO/78/SVK, para 13.

5 UN Human Rights Committee (2004) *Concluding Observations: Germany*, 4 May 2004, CCPR/CO/80/DEU, para 17.

6 UN Human Rights Committee (2002) Germany: Fifth Periodic Report, 13 November 2002, CCPR/C/CEU/2002/5, para 113.

7 UN Committee on Economic, Social and Cultural Rights (1990) General Comment No 3: *The Nature of States Parties Obligations*, 14 December 1990, para 9.

8 Above, para 10.

The Committee has considered in detail the significance of the rights set out in the ICESCR for older people. Therefore, in its *General Comment No 6* the Committee focuses specifically on the human rights of older people,[9] observing that although older people are not specifically referred to in the ICESCR:

> […] it is clear that older persons are entitled to enjoy the full range of rights recognized in the Covenant. […] Moreover, in so far as respect for the rights of older persons requires special measures to be taken, States parties are required by the Covenant to do so to the maximum of their available resources.[10]

The Committee notes further that, during times of economic recession, States Parties have a duty to protect vulnerable people, including older people, who are particularly at risk.[11] Therefore, in spite of the current economic difficulties facing Northern Ireland, the minimum obligations contained in the ICESCR should continue to be respected.

In its examination of States Parties, the Committee has paid particular attention to the human rights of older people. Therefore, the availability of pensions, welfare programmes and social assistance for older people have been considered under the right to social security (Article 9) and the right to family protection (Article 10).[12] As part of the right to health in Article 12, the Committee has examined the availability of integrated health and social care services for older people[13] and has recommended that priority is given to home care rather than to the institutionalisation of older people in need of assistance.[14] In relation to the UK and Northern Ireland, the Committee has noted a lack of training and public awareness about dementia and Alzheimer's disease. As a result, training is recommended for doctors and health care professionals about government's obligations under the ICESCR generally, as well as the implications for the prevention and treatment of dementia and Alzheimer's disease.[15]

More recently, in its 2010 examination of the Kingdom of the Netherlands, the Committee paid particular attention to the human rights of older people in nursing homes. Examining the realisation of the right to health for older people, the Committee notes concerns about the denial of appropriate care due to insufficient numbers of staff, lack of training in nursing homes and the absence of a comprehensive system for geriatric health care. In response, the Committee recommends, among other matters, the development of effective inspection mechanisms to monitor the quality of services provided to older people.[16]

The rights of people with disabilities

Not all older people and, indeed, not all older people in nursing homes are people with disabilities. However, the human rights contained in the *UN Convention on the Rights of Persons with Disabilities* (CRPD) are particularly relevant in the context of nursing homes because many older people are there for nursing care related to long-term physical and, or, mental impairment. Moreover, the circumstances of older people are recognised explicitly in the text of the CRPD – in Article 25 on the right to health and in Article 28 on the right to an adequate standard of living.

9 UN Committee on Economic, Social and Cultural Rights (1995) *General Comment No 6: The Economic, Social and Cultural Rights of Older Persons*, 8 December 1995.

10 Above, para 10.

11 Above, para 17.

12 For example: UN Committee on Economic, Social and Cultural Rights (2008) *Concluding Observations: Nicaragua*, 28 November 2008, E/C 12/NIC/CO/4, para 22; UN Committee on Economic, Social and Cultural Rights (2009) *Concluding Observations: Republic of Korea,* 17 December 2009, E/C 12/KOR/CO/3, para 23.

13 UN Committee on Economic, Social and Cultural Rights (2006) *Concluding Observations: Slovenia*, 25 January 2006, E/C 12/SVN/CO/1, para 35; UN Committee on Economic, Social and Cultural Rights (2004) *Concluding Observations: Italy*, 14 December 2004, E/C 12/1/Add 103, para 51.

14 UN Committee on Economic, Social and Cultural Rights (2005) *Concluding Observations: Serbia and Montenegro*, 23 June 2005, para 55.

15 UN Committee on Economic, Social and Cultural Rights (2009) *Concluding Observations: United Kingdom of Great Britain and Northern Ireland*, 12 June 2009, para 34.

16 UN Committee on Economic, Social and Cultural Rights (2010) *Concluding Observations: The Kingdom of the Netherlands*, 9 December 2010, E/C 12/NDL/CO/4-5, para 29.

The CRPD is the most recently established international human rights treaty and was ratified by the UK on 8 June 2009. Article 1 sets out the treaty's purpose:

> […] to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

People with disabilities are defined as including:

> […] those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Although the CRPD does not explicitly define "long-term physical, mental, intellectual or sensory impairments", existing standards establish that dementia is a form of mental disability within the meaning of human rights law.[17] As explained in Chapter 1 of this report, cognitive impairments such as dementia affect an increasing proportion of older people in nursing homes.

Of particular relevance is the obligation on States Parties to ensure access to the physical environment (Article 9) and to take effective measures to ensure personal mobility with the greatest possible independence (Article 20). Also of relevance to all aspects of care provided in nursing homes, including the availability of activities and social stimulation, is Article 26 which requires States to:

> […] take effective and appropriate measures to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.

States are also required to take all appropriate measures to protect people with disabilities from exploitation, violence and abuse (Article 16). As part of this, independent authorities are required to monitor facilities designed to provide services for people with disabilities, which would include nursing homes.

Other provisions of the CRPD that are discussed in more detail in the relevant chapters of this report include the right to the highest attainable standard of health without discrimination on the basis of disability (Article 25) and the right to respect for physical and mental integrity on an equal basis with others (Article 17). Importantly, the CRPD is the first international human rights treaty to contain a separate and distinct right to physical and mental integrity (which has traditionally been considered an aspect of the right to be free from inhuman and degrading treatment, and the right to private life). The development of the Committee's jurisprudence in relation to Article 17 of the CRPD may provide further detail on, for instance, the acceptability of types and use of restraint in social care settings, including nursing homes.

Finally, in the context of the situation of people with disabilities, the right to effective participation in cultural life is also reaffirmed in Article 30 of the CRPD:

> States Parties recognize the right of persons with disabilities to take part on an equal basis with others in cultural life.

This, in accordance with Article 30(5) includes an obligation to enable "persons with disabilities to participate on an equal basis with others in recreational [and] leisure activities". In the context of nursing care, this would require homes to provide or facilitate access to recreational activities and events for older people.

The rights of older women

Women experience various forms of discrimination throughout their life course meaning that, as women age, there are cumulative negative effects. This is recognised by the UN Committee on the

17 Council of Europe Recommendation (2004)10 *Concerning the Protection of the Human Rights and Dignity of Persons with Mental Disorder, Explanatory Memorandum*, para 20.

Elimination of Discrimination against Women in its General Recommendation on older women and the protection of their human rights, which states:[18]

> While both men and women experience discrimination as they become older, older women experience ageing differently. The impact of gender inequality throughout their lifespan is exacerbated in old age and is often based on deep-rooted cultural and social norms.

States Parties to the *UN Convention on the Elimination of All Forms of Discrimination against Women* (CEDAW) are required to recognise the gendered nature of ageing in domestic law and policies impacting on older people. Therefore, for example, the Committee recommends the development of comprehensive health policies that ensure, among other matters, training of health workers in geriatric illnesses, the provision of medicine to treat age-related diseases, and long-term health and social care, including care that enables independent living and palliative care.[19] States Parties should also:[20]

> […] take necessary measures to ensure older women have access to adequate housing that meet their specific needs, and all barriers, architectural and other, that hinder the mobility of older persons and lead to forced confinement should be removed.

The reference to adequate housing includes housing in the community but can also include other places where older women may live, such as residential care and nursing homes. In the particular context of nursing homes, the provision of activity and recreation for older people is important. Noting the obligation on States to eliminate discrimination in economic and social life, the Committee recommends that particular attention is paid to the development of recreational facilities for older women and the provision of accessible and affordable transport to enable participation in social and cultural life, including community activities.[21]

Regional instruments

Council of Europe instruments

The Convention on the Prevention of Torture and Inhuman or Degrading Treatment or Punishment

Building on Article 3 of the ECHR, the Committee on the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (the CPT) was created under the Council of Europe's *European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment* to prevent ill treatment of people deprived of their liberty. The CPT carries out a programme of visits to the Member States that have ratified the Convention to assess the treatment of people deprived of their liberty. The guidance of the CPT can be found in its reports of visits to Member States, in its annual general reports and in the 'CPT Standards' revised in 2010.[22] From the CPT's standards and developing jurisprudence, it is clear that inhuman and degrading treatment can relate to everyday living conditions, the availability of therapeutic activity, eating arrangements, staffing levels, training and the use of restraint.[23]

The CPT's standards are often developed in the specific context of psychiatric units and social care homes where people are involuntarily detained. While the CPT has not been explicit on how it would assess the conditions in a home in which residents are not, and are not likely to be, detained under the provisions of domestic law, the standards serve as useful guidance on an institution's treatment of any person with cognitive impairments or fluctuating capacity. Residents in nursing homes with dementia would come under this category.

18 UN Committee on the Elimination of Discrimination against Women (2010) *General Comment No 10 on Older Women and the Protection of their Human Rights*, 16 December 2010, para 11.

19 Above, para 45.

20 Above, para 48.

21 Above, para 47.

22 European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (2002) *CPT Standards*, CPT, Council of Europe, Strasbourg [Revised 2010], para 35 (available: http://www.cpt.coe.int/en/documents/eng-standards.pdf).

23 Above, pp39-44.

Therefore, the jurisprudence and guidance of the CPT is potentially relevant to the situation of older people living in nursing homes. Indeed, although the Committee's visits have traditionally focused on criminal justice establishments and psychiatric facilities, they have included residential and nursing homes for older people since 2000. [24]

European Social Charter

The *European Social Charter* sets out the social human rights that Member States of the Council of Europe should secure for everyone in their respective jurisdictions. The human rights particularly important for older people include the right to benefit from measures for enjoyment of the highest possible standard of health (Article 11), the right to social and medical assistance for those without adequate resources (Article 13) and the right to benefit from social and welfare services (Article 14). It its examination of the UK, the European Committee of Social Rights, the body responsible for monitoring implementation of the Charter, has been interested in measures to assist specific groups in Northern Ireland, including older people who may be especially disadvantaged in their access to health care.[25]

Rights additional to those contained in the original Charter of 1961 are contained in the *Revised European Social Charter* of 1996. While the UK has not yet ratified this and is therefore not legally bound by its provisions, it is an instrument that government should ratify without delay. Importantly, it contains human rights that are particularly relevant to older people. Indeed, it is the only legally binding human rights instrument that refers explicitly to the rights of older people in institutions within the main text of its articles. Therefore, Article 23 relating to the right of "elderly persons to social protection" requires States to guarantee:

> […] elderly persons living in institutions appropriate support, while respecting their privacy, and participation in decisions concerning living conditions in the institution.

Charter of Fundamental Rights of the European Union

The *Charter of Fundamental Rights of the European Union*, which gained legal effect on 1 December 2009, recognises "the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life" (Article 25).[26] The Charter is not intended to create new rights but rather to reaffirm and consolidate the human rights that are traditional to the domestic and international obligations of Member States, including those contained in the (ECHR) and the European Social Charters.[27] Although at the time of writing there appears to be some uncertainty about whether there are circumstances in which the rights in the Charter of Fundamental Rights can be enforced directly in domestic courts,[28] at the very least, domestic courts are required to consider the provisions of the Charter when interpreting national measures that are implementing EU law.

Importantly, although human dignity is a principle inherent in many if not all other human rights and freedoms, the EU Charter ensures that it has now received a legal recognition of its own. As well as devoting a chapter to the human rights associated with dignity, Article 1 of the EU Charter states that "human dignity is inviolable. It must be respected and protected". Where care is provided in an environment such as a nursing home, which may have many residents and limited resources, it is all the more important that each individual's right to dignity is respected. For instance, where an older person requires help with eating, it is

24 European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) *Report to the German Government*, CPT/Inf (2003) 20.

25 European Committee of Social Rights (2009) *Conclusions XIX-2: United Kingdom: Article 3, 11, 12, and 14 of the Charter*, January 2010, p11.

26 *Charter of Fundamental Rights of the European Union*, 14 December 2007 (given legal effect by the Lisbon Treaty, 1 December 2009).

27 *Charter of Fundamental Rights of the European Union*, Preamble.

28 At the time of writing, the status of the Charter in the UK is the subject of a referral to the European Court of Justice (see *R (Saeedi) v Secretary of State for the Home Department* [2010] EWHC 705).

important that support is provided in a manner that respects their dignity. Similarly, although there may be circumstances where an older person's safety requires the use of measures of restraint, inappropriate use of physical control or sedatives may violate the right to dignity even where such treatment does not amount to degrading treatment within the meaning of Article 3 of the ECHR or Article 7 of the ICCPR.

Domestic law

ECHR and the Human Rights Act (HRA) 1998

As explained at the outset of this chapter, the ECHR is the only human rights instrument that is incorporated directly into the domestic law. It protects a range of civil and political rights, for example, the right to life (Article 2), the right to freedom from torture, inhuman or degrading treatment (Article 3), the right to liberty (Article 5) and the right to private and family life (Article 8). The HRA has given domestic legal effect to many of the rights contained in the ECHR. In interpreting the scope and application of these rights UK Courts must, by virtue of Section 1(a) of the HRA, take into account judgments and decisions of the European Court of Human Rights.

Until recently, the HRA was regarded as applying only to a limited category of people in residential homes, including nursing homes, namely those whose care was financed wholly out of public funds. This was a significant limitation since, although nursing care in Northern Ireland may be provided in homes run by HSC Trusts, many individuals reside in privately run, for-profit establishments where their care is only partly funded by the Trust. Indeed, in some cases it is possible that care may not be publicly funded at all.

In the case of *YL v Birmingham City Council and Others*,[29] the House of Lords considered this matter and concluded that a privately owned, for-profit care home providing care and accommodation for a publicly funded resident was not exercising functions of a public nature within Section 6(3)(b) of the HRA. This position has, however, been changed by Section 145 of the *Health and Social Care Act 2008*, which states:

> A person ("P") who provides accommodation, together with nursing or personal care, in a care home for an individual under arrangements made with P under the relevant statutory provisions is to be taken for the purposes of […] the Human Rights Act 1998 […] to be exercising a function of a public nature in doing so.

The effect is that nursing homes that provide care to individuals wholly or partly funded by one of the Trusts are performing a public function and obliged to uphold the rights and freedoms contained in the ECHR. On the other hand, the provision of care by nursing homes to individuals who are wholly self-funded is not subject to the provisions of the HRA. This means that it is still possible, albeit in limited circumstances, for there to be nursing homes in which the human rights obligations set out in the HRA are binding in respect of the nursing care provided to some individuals but not to other individuals.[30] It is, however, hoped that the applicability of the HRA to publicly funded residents (which in practice is most residents) will lead to human rights compliant policies and practices that are of benefit to all. Nevertheless, all residents are entitled to protection of their human rights and this leaves an unacceptable gap whereby some are able to enforce the human rights guaranteed by the ECHR directly against the nursing home and others are not.

The right to life

The right to life is set out in Article 2 of the ECHR. This right not only places an obligation on public authorities to refrain from the intentional and unlawful taking of life but also places a positive

29 *YL v Birmingham City Council and Others [2007]* UKHL 27.

30 This would be a rare circumstance and most likely relate to a case where the individual chooses not to involve the Health and Social Care Trust or where they do not have an assessed nursing need but wish to live in a particular nursing home.

obligation on the state and its public authorities "to take appropriate steps to safeguard the lives of those within its jurisdiction".[31] This has implications with regard to health care, including nursing care. Where a person's life is at risk without access to treatment, which the state has undertaken to make available, failure by the relevant public authorities to provide this treatment may violate the right to life.[32] In the context of nursing homes, failure to provide life-saving medication to an older person which is readily available, whether intentionally, through negligence or for some other reason, may amount to a violation of the right to life should death occur as a result. Moreover, a failure to protect a nursing home resident from risks to his, or her, health by a lack of monitoring or medical assistance may also breach the right to life.[33]

The duty to protect the right to life also has implications for the handling by nursing homes (and, of course, by other public authorities, including the police and social services) of suspected cases of abuse or ill treatment. Where a person's life is at risk and the State knows, or ought to have known, there is a positive obligation on the authorities of the State to take measures to protect the person.[34] Although this obligation is particularly relevant for the police and other law enforcement agencies, it is also relevant for nursing homes which should have in place procedures to identify and address suspected instances of abuse or ill treatment. Moreover, this obligation relates not only to suspected abuse by staff but also by other residents of the nursing home, the families of residents, visitors, those contracted by the home to provide services and anyone else who may have physical access to the home.[35] Further, the duty extends to nursing homes ensuring the safety of residents through its physical layout and security arrangements, including having adequate safeguards against someone who may attempt to enter the home forcibly.

The prohibition on torture and inhuman or degrading treatment

Article 3 of the ECHR states that, "no one shall be subjected to torture or to inhuman or degrading treatment or punishment". It is an absolute right from which there can be no derogation. Despite a degree of overlap, "torture", "inhuman treatment" and "degrading treatment" are all conceptually distinct, with a cumulatively higher threshold between degrading treatments at one end of the spectrum to torture at the other. The threshold for each is therefore different and, in the case of torture, it must be inflicted intentionally. Neglect on its own will not therefore amount to torture, which has been defined as the deliberate infliction "of inhuman treatment causing very serious and cruel suffering".[36]

Treatment is degrading if it:

> […] is such as to arouse in the victims feelings of fear, anguish or inferiority capable of humiliating and debasing [an individual].[37]

There is no requirement that humiliation or debasement is intended, thus neglect which results in humiliation can equally violate the right not to be subjected to degrading treatment.[38] Inhuman treatment is of a different character, with the emphasis being on the physical or mental consequences of the acts. To amount to inhuman treatment, conduct must "cause either actual bodily harm or intense physical or mental suffering."[39] However, in deciding if treatment reaches the entry level 'threshold' of being inhuman or degrading, the court can take note of the sex, age and state of health of the victim. This means

31 *LCB v UK* (9 June 1998) 27 EHRR 212, para 36.
32 *Cyprus v Turkey* (10 May 2001) 35 EHRR 731, para 219.
33 *Anguelova v Bulgaria* (13 September 2002) 38 EHRR 659.
34 *Osman v UK* (28 October 1998) 29 EHRR 245, para 116.
35 *Paul and Audrey Edwards v UK* (14 March 2002) 35 EHRR 487.
36 *Ireland v UK* (18 January 1978) 2 EHRR 25.
37 *Kudla v Poland* (26 October 2000) 35 EHRR 198.
38 *Price v UK* (10 July 2001) 34 EHRR 1285.
39 *Kudla v Poland* (26 October 2000) 35 EHRR 198, para 92.

that the threshold for inhuman treatment is not objective or absolute. It is dependent on the impact of the treatment on the individual concerned and not just the nature of the treatment itself. Indeed, in the context of degrading treatment the Court has held that it may well suffice that the victim is humiliated in his or her own eyes, even if not in the eyes of others.[40]

Much of the European Court's case law with respect to living conditions and Article 3 of the ECHR has related to the treatment of people deprived of their liberty, often in criminal justice establishments, and does not focus specifically on the treatment of older people in nursing homes. Nevertheless, much of the courts jurisprudence is relevant to the provision of care in nursing homes. Therefore, for example, failure to provide adequate nutrition or fluids for hydration, particularly if combined with other failings, such as lack of provision for exercise, may amount to inhuman and degrading treatment or, in particularly severe cases, even torture.[41] The improper use of restraints has also been found to fall within the ambit of Article 3. The European Court has, on occasion, found that different measures of restraint violate the prohibition on torture or inhuman and degrading treatment.[42]

The prohibition on torture or inhuman and degrading treatment does not merely impose an obligation on public authorities to refrain from subjecting an individual to ill treatment. It also has implications for the measures which public authorities, including those institutions involved in the provision of nursing care, are required to take to prevent and, where necessary, investigate suspected abuse or ill treatment. As is the case in respect of the right to life, where an individual is at risk of torture or inhuman and degrading treatment and the State knows, or ought to know, the relevant authorities must take reasonable measures to protect them.[43] As before, this positive obligation does not only require measures to address suspected abuse by, for example, the staff of a nursing home but also applies to abuse by others, including residents, family members, visitors or those contracted to provide services.[44]

The right to private and family life

The right to private and family life is particularly important for the residents of nursing homes. Article 8 of the ECHR provides that "everyone has the right to respect for his private and family life, his home and his correspondence". Often older people are reliant on a nursing home to facilitate contact with other family members. Equally, in an institutional environment where many residents, some of whose physical needs are considerable, live in relatively close proximity to one another, it is important that an older person's individual identity and private space are respected.

Although the right to a private life includes a right to privacy, it is much broader than this. It also addresses the infringement of the individual's moral and physical integrity;[45] the circumstances in which it is permissible to provide personal care or medical treatment without an individual's consent;[46] the power of an individual to make decisions as to personal risk[47] and protections to safeguard respect for aspects of an individual's personal identity, including matters such as personal choice as to one's mode of dress.[48] In addition, the right to a private life also

40 *Costello-Roberts v UK* (25 March 1993) Application No 13134/87.

41 *Starokadomskiy v Russia* (31 July 2008) Unreported, Application No 42239/02, para 58; *Moiseyev v Russia* (9 October 2008) Unreported, Application No 62936/00, para 142; *Moisejevs v Latvia* (15 June 2006) Unreported, Application No 64846/01, paras 79-80.

42 For example: *Henaf v France* (27 November 2003) 40 EHRR 990 (shackling to a bed amounted to degrading treatment) or *Mouisel v France* (14 November 2002) 38 EHRR 735 (handcuffing of ill prisoner in hospital amounting to degrading treatment).

43 *Z v UK* (10 May 2001) 34 EHRR 97, para 74. See also: *Watts v UK* (4 May 2010) Unreported, Application No 53586/09 (dealing with the potential harm caused to an older person through the closure of her care home).

44 Above.

45 *X and Y v Netherlands* (26 March 1985) 8 EHRR 235, para 22.

46 *Storck v Germany* (16 June 2005) 43 EHRR 96.

47 *X v Belgium* (6 February 1968) 18 DR 225.

48 *McFeeley v UK* (15 May 1980) 20 DR 44.

encompasses an individual's relationship with others.

The European Court has affirmed on a number of occasions that one's private life includes "a zone of interaction […] with others, even in a public context".[49] In *McFeeley v UK*, the European Commission for Human Rights underlined the importance of relationships with others, finding that private life required the State to ensure a degree of association for those in its care.[50] All of these elements of the right to private life may be engaged in different ways in nursing homes, including through the provision of activity and social stimulation and help with personal care. As regards the right to family life, this encompasses *inter alia* a right to "enjoy each other's company", an obligation that a state must respect and act to facilitate.[51] The public authorities of a state, including nursing homes, are required therefore to take reasonable steps to help those in their care maintain contact with family members[52] and accommodate spouses or same sex couples who wish to live together and continue their relationship in the home.

Freedom from discrimination

Article 14 of the ECHR provides for the enjoyment of Convention rights:

> […] without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.

This does not provide a freestanding right to protection from discrimination but rather requires the complaint to fall within the ambit of another Convention right. Importantly, the grounds of discrimination listed in Article 14 are not exhaustive, leaving open the possibility of additional grounds within the meaning of "other status". For instance, domestic courts have considered personal characteristics such as marital status[53] and, in principle, homelessness[54] to fall within the meaning of "other status" in Article 14. While, to date, neither the European Court nor domestic courts have stated that age is a ground within the meaning of "other status" in Article 14, jurisprudence does not preclude this.[55] Indeed, it is likely that other personal characteristics relevant to many older people in nursing homes may be considered under Article 14, such as health status or disability.[56]

'Soft law' standards

A number of 'soft law' standards exist to help inform the meaning of international human rights applicable to older people in the context of nursing homes. They are not legally binding; however, they generally provide clarity on, or extrapolate, legally binding standards and therefore should be considered by States Parties in the development of domestic law, policies and practice.

UN Principles for Older Persons[57]

Alongside the legal protections contained in the international human rights treaties, the *UN Principles for Older Persons* provide guidance to States on how the rights of older people can best be protected. Governments are encouraged to incorporate the principles into national programmes for older people. The principles are centred on five core areas: independence, participation, care, self-fulfilment and dignity. While each of the principles are potentially relevant to older people in nursing homes, Principles 13 and 14 are designed specifically for those in social care environments, including nursing homes:

49 *Peck v UK* (28 April 2003) 36 EHRR 719, para 57.
50 *McFeeley v UK* (15 May 1980) 20 DR 44, para 91.
51 *Olsson v Sweden* (30 October 1992) 11 EHRR 259, para 59.
52 See: *McCotter v UK* (9 December 1992) 15 EHRR 98 and *X v UK* (8 November 1982) 30 DR 113.
53 *Re P [2008]* UKHL 38.
54 *R (RJM) v Secretary of State for Work and Pensions* [2008] UKHL 63.
55 *Bouamar v Belgium* (1989) 11 EHRR 1.
56 For further analysis in relation to Article 14 ECHR and mental disability, see: Bartlett P, Lewis O, and Thorold O (2007) *Mental Disability and the European Convention on Human Rights*, Martinus Hijhoff: Leiden / Boston. In relation to Article 14 more generally, see: O'Connell R (2009) 'Cinderella comes to the ball: Article 14 and the right to non-discrimination in the ECHR', in 29(2) *Legal Studies* 211-229.
57 Adopted by General Assembly Resolution 46/91, 16 December 1991.

Principle 13: Older persons should be able to utilize appropriate levels of institutional care providing protection, rehabilitation and social and mental stimulation in a humane and secure environment.

Principle 14: Older persons should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives.

UN Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care[58]

Many older people in nursing homes experience long-term cognitive impairments such as Alzheimer's disease and dementia. Government should therefore pay particular attention to the *UN Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care* in the development of laws and policies relating to nursing care. The principles contain useful guidance for States, including the general principles of least restriction and the requirement for regular review. Therefore, Principle 9(1) states:

[E]very patient shall have the right to be treated in the least restrictive environment and with the least restrictive or intrusive treatment appropriate to [their] health needs and the need to protect the safety of others.

Principle 9(2) requires that the treatment and care be based on an individually prescribed plan that is regularly reviewed.

Many of the principles apply specifically to mental health facilities, which are defined as "any establishment, or any unit of an establishment, which as its primary function provides mental health care". Clearly, not all nursing homes fall within this definition. However, it is likely to include Elderly Mentally Infirm (EMI) homes, or EMI units within general homes. The principles relating to mental health facilities set out, among other matters, specific guidance on recording (Principle 11(10)), the use of physical restraint or involuntary seclusion (Principle 11(11)) and the provision of medication (Principle 10), which are considered further in relevant chapters of this report.

Madrid International Plan of Action on Ageing[59]

The Second World Assembly on Ageing took place in April 2002, launching the *Madrid International Plan of Action on Ageing* which is intended to ensure that ageing is mainstreamed into national and global agendas.[60] The action plan identified three priority directions: older people and development, advancing health and wellbeing into old age and ensuring, enabling and supportive environments. The actions are intended to improve older people's quality of life in the community and in short or long-term care environments. While many of the actions under 'health and wellbeing' are significant for those in nursing homes, especially the requirement for appropriate and adequate provision of accessible nutrition and food in hospitals and other care settings (para 68(i)), other pertinent actions include:

Encourage health and social care providers to fully include older persons in decision making related to their own care (para 77(b).

Promote self-care in older persons and maximize their strengths and abilities within health and social services (para 77(c)).

Provide mental health services to older persons residing in long-term care facilities (para 86(i)).

Establish and apply standards and mechanisms to ensure quality care in formal settings (para 105(g)).

58 Adopted by General Assembly Resolution 46/119, 17 December 1991.

59 United Nations (2002) *Report of the Second World Assembly on Ageing (Madrid International Plan of Action on Ageing).*

60 The First World Assembly on Ageing took place in Vienna in 1982 resulting in the Vienna International Plan of Action on Ageing.

Council of Europe Recommendation (2004)10 concerning the protection of the human rights and dignity of persons with mental disorder

The Explanatory Notes to Council of Europe Recommendation (2004)10 state that it includes mental disorders that occur predominantly in older age, such as dementia.[61] Many of its provisions are therefore relevant to older people in nursing homes. As with the UN principles discussed above, while the general provisions of the Recommendation apply to the treatment and health service provision to all people with mental disorder, certain of the standards, such as Article 9 on environment and living conditions, apply only in the context of facilities designed for the placement of people with mental disorder. However, again, it is probable that EMI homes or EMI units within nursing homes that provide general categories of care can be included within this meaning.

Similar to the UN principles, Article 8 contains the principle of least restriction. Importantly, the Recommendation also sets out general standards relating to the training of staff involved in the provision of mental health services (Article 11) and general principles regarding treatment, including the requirement for regular review (Article 12). Article 27 sets out standards for the use of restraint and seclusion, which is supplemented by detailed guidance in the Explanatory Notes (discussed in greater detail in Chapter 7 of this report).

Concluding remarks

At the time of writing, calls for an international treaty for the rights of older people are increasing.[62] Experts submit that in the absence of a specific international treaty there is no systematic mechanism to protect the rights of older people.[63] As a consequence, national legislation and policies tend to prioritise what others think older people need rather than the human rights to which they are entitled. The recent report by the UN Human Rights Advisory Council states:

> States have taken measures to provide legislative protection and policy provisions for the enjoyment of elderly rights. […] These policy structures focus on health, nutrition, long-term care, social security, and welfare programmes that benefit the elderly from a welfare-based approach. Such measures do not take into account the other United Nations principles such as independence, participation, care, self-fulfilment, and dignity.[64]

While recognising the benefits of a treaty that would set out and consolidate within one text the binding international human rights of older people, the Commission finds that, even in the absence of a specific international treaty, existing human rights standards can, and should, provide the overarching framework for the provision of all aspects of care to older people in nursing homes. The previous sections provided a brief overview of these existing standards and the following chapters will consider their applicability to specific situations that arise for older people in nursing homes.

61 Recommendation (2004)10, Explanatory Notes, para 20.

62 See for example: UN Human Rights Council Advisory Committee (2010) *The Necessity of a Human Rights Approach and Effective United Nations Mechanisms for the Human Rights of Older Persons*, Human Rights Council Advisory Committee, Fourth Session, 25-29 January 2010; Megret F (2011) 'The human rights of older persons: A growing challenge' in 11(1) *Human Rights Law Review*, 37-66.

63 UN Human Rights Council Advisory Committee (2010) *The Necessity of a Human Rights Approach and Effective United Nations Mechanisms for the Human Rights of Older Persons*, Human Rights Council Advisory Committee, Fourth Session, 25-29 January 2010, para 45.

64 Above, para 46.

3 Quality of life

"What do you enjoy most about your work?"
"The chance to be able to sit with them, talk with them and laugh with them and stuff. I love that; that is great." (Interview with care assistant)

Introduction

'Quality of life' means different things to different people. For older people living in nursing homes it is likely to encompass all aspects of their medical and personal care as well as the daily experience of living there. Those who live in nursing homes are often there 24 hours a day and the investigation evidence suggests that their quality of life can depend largely on how they are able to spend that day. In particular, the availability of activities and opportunities for social and emotional stimulation all impact residents' quality of life.[1]

The jurisprudence of the European Court of Human Rights has established that where individuals are in the care of the State, opportunities for social contact and stimulation are important to ensure the right to private and family life[2] and, in certain circumstances, the right to be free from inhuman and degrading treatment,[3] particularly where an individual is prevented from associating with others, or is unable to associate. Therefore, to investigate the quality of life in nursing homes the Commission sought to understand what residents do each day, focusing on whether planned activities are provided and if, in addition to set activities, there was opportunity for social contact and stimulation.

Human rights law and standards

The potential for older people to participate in recreational, leisure and cultural activities is crucial to their quality of life. Article 15 of the *International Covenant on Economic, Social and Cultural Rights* (ICESCR) recognises "the right of everyone to take part in cultural life". In this context, the idea of "cultural life" is broadly defined to include recreation and leisure. For example, commenting on the effect of Article 15, the UN Committee on Economic, Social and Cultural Rights urges States Parties to ensure that:

> [O]lder persons […] have access to the educational, cultural, spiritual and recreational resources of society.[4]

In the context of people with disabilities, the right to effective participation in cultural life, recreation and leisure is reaffirmed in Article 30 of the *UN Convention on the Rights of Persons with Disabilities* (CRPD). This is also contained in Principle 16 of the *UN Principles for Older Persons*.

In relation to the availability of activities, Council of Europe Recommendation (2004) 10 is also relevant for residents with mental impairment, including dementia. Article 12 sets out general principles for the treatment of mental disorder. The Explanatory Notes for this provision recognises the importance of therapeutic and rehabilitative activities. In particular, the Explanatory Memorandum draws from the jurisprudence of the European Committee for the Prevention of Torture (CPT) to state that treatment plans should include, among other matters, rehabilitative activities relevant to daily living, for example, shopping or cooking, art and drama, music and sports.[5]

In addition, taking reasonable steps to facilitate access to activities and social interaction is an important means of upholding, in particular, the right to a private life. This right is set out in Article 17 of the ICCPR and in Article 8 of the European Convention on Human Rights (ECHR) which provides that "everyone has the right to respect for his private and family life, his home and his correspondence". Although the right to a

1 See for example: Principle 13 of the *UN Principles for Older Persons* which states that "Older persons should be able to utilize appropriate levels of institutional care providing […] social and mental stimulation […]".

2 *McFeeley v UK* (15 May 1980) 20 DR 44.

3 See: *Mathew v Netherlands* (29 September 2005) 43 EHRR 444 and *Van der Ven v Netherlands* (4 May 2003) 38 EHRR 967.

4 UN Committee on Economic, Social and Cultural Rights (1995) *General Comment No 6: The Economic, Social and Cultural Rights of Older Persons, 8 December 1995*, UN Doc HRI/GEN/1/Rev 9 (Vol I) para 39.

5 Council of Europe Recommendation (2004)10, *Concerning the Protection of the Human Rights and Dignity of persons with Mental Disorder*, *Explanatory Memorandum*, para 91.

private life protects an individual's right to privacy, other interests are also protected including the entitlement to develop one's personality through establishing and maintaining relationships with others. The European Court of Human Rights has affirmed that private life includes "a zone of interaction … with others, even in a public context […]".[6] In *McFeeley v UK*, the European Commission on Human Rights underlined the importance of relationships with others, finding that the right to a private life required the State to facilitate a degree of association for those in its care.[7]

Access to recreational activities and social stimulation is also an important aspect of physical and psychological integrity as part of the right to private life in Article 8 of the ECHR. As explained in the following case relating to the application of a local authority's 'moving and handling' policy:[8]

> The other important concept embraced in the "physical and psychological integrity" protected by article 8 is the right of the disabled to participate in the life of the community and to have what has been described […] as "access to essential economic and social activities and to an appropriate range of recreational and cultural activities". This is matched by the positive obligation of the State to take appropriate measures designed to ensure to the greatest extent feasible that a disabled person is not "so circumscribed and so isolated as to be deprived of the possibility of developing his personality".

In addition, for those who are unable to interact with others without assistance, the right to be free from inhuman and degrading treatment may be engaged particularly where failure by the nursing home to facilitate social interaction results in complete social isolation. Therefore, the European Court has held that, in certain circumstances, conditions of detention amounting to social isolation constitute inhuman treatment within the meaning of Article 3 of the ECHR.[9]

Even where not amounting to inhuman treatment, leaving an individual for significant periods without meaningful human contact may violate their right to dignity as set out in Article 1 of the EU *Charter of Fundamental Rights*. Moreover, the importance of social stimulation is also emphasised by the *UN Principles for Older Persons*, Principle 13 of which states:

> Older persons should be able to utilize appropriate levels of institutional care providing […] social and mental stimulation in a humane and secure environment.[10]

Minimum standards and home policies

The *Nursing Homes Minimum Standards* require every nursing home to offer "a structured programme of various activities and events". Standard 13 sets out the purpose of activities, how these should be planned, conducted, recorded and reviewed. The standards also require each home to have a policy on its "programme of activities and events". In terms of social contact, Standard 2 states that "contact with family, friends and the local community is facilitated for patients". Among other matters, Standard 2 details the importance of maintaining links with family, friends and the local community and facilitating visitors to the home.

Each of the nursing homes visited for the Commission's investigation provided a copy of its policy relating to activities. The content and length of each policy varied greatly, although each referred in some manner to the importance of activity and stimulation for residents' quality of life. The centrality of activity is conveyed in one policy which states that activity "contributes significantly to meeting the aims and objectives of the home". In addition, policies from two of the homes state

6 *Peck v UK* (28 April 2003) 36 EHRR 719, para 57.

7 *McFeeley v UK* (15 May 1980) 20 DR 44, para 91.

8 Munby J in R *(on the application of A, B, X and Y) v East Sussex County Council and the Disability Rights Commission* [2003] EWHC 167, para 99 (referring to the concurring opinion of (the then) Bratza N in the case of *Botta v Italy* (1998) 26 EHRR 241).

9 See: *Mathew v Netherlands* (29 September 2005) 43 EHRR 444 and *Van der Ven v Netherlands* (4 May 2003) 38 EHRR 967.

10 Above.

explicitly that nursing home staff as well as activity staff are involved in ensuring that activity is available in the home.

Providing an appropriate programme of activities and events is an important part of ensuring a better quality of life for residents. However, it is also important to recognise the benefits of unscheduled daily activity, for example, listening to music or reading a newspaper with staff. While the *Nursing Homes Minimum Standards* emphasise the need for structured activity, the importance of daily activity beyond that which is scheduled is not conveyed. In addition, although Standard 2 refers to different types of social contact there is no reference to staff who are, or should be, a fundamental part of the daily social life in nursing homes. Perhaps because this holistic approach (the importance of set activities, unscheduled daily activity, and the role of staff) is not communicated by the *Nursing Homes Minimum Standards*, it is not always apparent in the relevant policies provided by the homes to the investigation.

Activities and events

Programmes of activity and events

All of the homes provided a programme of activities and events. These included various activities such as exercise, arts and crafts, bingo, baking, jigsaw making, cards, playing music and doing residents' hair and nails. In one home that offered a greater variety of activity, options also included movement to music, gardening, short stories where staff would read stories to residents, and aromatherapy. A number of the homes also invited people into the home to provide entertainment. In one home, local community members attended regularly to play the organ and sing. In another, school and community groups attended to sing or perform drama for special events such as Christmas.

However, in one home staff reported that although residents and family members are promised different activities and events, in practice they do not take place. As one staff member explained:

"[…] sometimes I think they are very depressed because, in their handbook downstairs they give to families, they have this great list of activities and in our unit, especially, there [are] only activities maybe once a week, and they get a beach ball thrown about to them, you know. They don't get proper activities to stimulate them."

This was a concern reported during the Commission's call for evidence. A number of relatives reported that the level of activity promised when they first researched the home never occurred or that, although a programme of activity was displayed in the home, the activity never took place. One caller reported that he had noted discrepancies in the home's recording of activity, explaining that in some instances he had visited the home at 1.00pm to find an entry in the activity book that his mother had taken part in an activity at 2.00pm.

It is important to recognise that not all residents like to take part in organised activities, as one resident stated, "I am not really activity minded". However, it is equally important to offer a flexible and varied programme of activity and for residents to be engaged in deciding what the activities should be. In this way, if residents do wish to take part in activities, nursing homes should maximise their opportunity to do so.

One-to-one activity

In each home, and particularly in homes providing specialist care for residents with dementia, it was recognised that some residents are unable, or prefer not, to participate in group activities. In this case, 'one-to-one' activity was offered where the activities staff would provide activity or therapy for residents who were unable to get out of bed or who preferred to stay in their room. One of the activities staff explained what this would involve:

"Some of them, as I say, are bed patients and what we do with them is cream their hands, talk to them, put music on for them, show them pictures, you know, rub their arms. You know, and you do get it back sometimes off them; the expressions in their face change. You can see somebody has just taken time to sit with them for, should it be, 15 minutes."

However, across each of the four homes visited by investigators the availability of one-to-one activity varied. Therefore, in one home it was stated that residents receive one-to-one activity twice and at times three times each week; in another, the activities staff member indicated that while she "would love to have the time to do more", due to the size of the home one-to-one activity could only be provided once per week. More broadly, a lack of one-to-one activity was reported by callers to the call for evidence and, in two instances, callers stated that they were required to pay for one-to-one activity because it was not provided by the home.

Where group activity is not appropriate one-to-one activity should be offered, even for a short period in the day. In particular, one-to-one activity and stimulation should be available for residents who are unable to get out of bed. Indeed, where individuals in nursing homes are of limited mobility failure to facilitate this type of social interaction may violate their right to a private life. In certain circumstances, it is possible that, for residents who are bed bound, and therefore unable to leave their room without assistance, significant periods without any opportunity for social interaction may engage the right to be free from inhuman treatment.[11]

Devoted activities staff

All of the homes visited for the investigation employed at least one part-time member of staff whose role was devoted to providing activity and events (the 'activities staff'). However, there was a broader range of activity and stimulation available in one of the homes. The manager of this home explained that over time they had increased the staffing level for activity so that the home employed two full-time members of activities staff.

Following interviews with the activities staff and the manager and owner in each of the four homes, the investigators identified the following factors that are important if activity is to become integral to the care provided by nursing homes:

- Activity is prioritised if it forms a key part of the nursing home's ethos. In the home that was found to provide greater levels of activity, the policy referred to activity as "an important adjunct to the provision of holistic care", that is, "given a high profile in meeting the individual needs of residents". In addition, in interview with the home's manager and owner the extent to which activity and the activities staff are valued by the home was apparent: "She is an absolute asset to the home […] She is constantly, constantly striving to come up with new ideas".
- Communication about activities with managers and with the nursing and care staff ensures that all those working in the home prioritise activity. In one home where staff and residents reported a lack of activity, the activities staff did not have meetings with the manager or other staff in the home.
- In one of the homes visited, it was reported that uncertainties about funding had contributed to activities staff leaving their job. However, in another home, the activities staff member was provided with an annual budget and, in consultation with the manager, permitted to control this for the provision of activities and one-to-one therapy. It would appear from the evidence provided to the investigation that protected funding for activity is important.

11 See: *Mathew v Netherlands* (29 September 2005) 43 EHRR 444 and *Van der Ven v Netherlands* (4 May 2003) 38 EHRR 967 (each relating to conditions of detention in which the applicants were held in social isolation).

From the primary fieldwork for this investigation, it is apparent that the provision of devoted activities staff helps to ensure that activity is treated as a central part of daily life for residents. However, activity is prioritised only if those responsible for its delivery are treated as key members of staff responsible for an essential aspect of the care provided by the home.

During the call for evidence, callers reported that the provision of activities staff was often limited; for example, one caller reported that the activities staff member had left the post and had not been replaced. In another case, it was reported that the home provided devoted activities staff only once a fortnight with the result that care staff were working 'out of hours' to ensure some level of activity for residents. One caller explained that although the activities staff member was 'very good', she was too often involved in helping with other care related duties in the home.

Going outside

The investigation also explored how often residents are able to go outside, whether on trips away from the home or outside into the nursing home grounds. Three of the homes visited provided more opportunities for residents to go on trips outside of the home. In one home, a number of the residents attended Boccia (a recreational sport) and a yearly 'memories tour' of Belfast (a bus tour of different parts of Belfast). In another home, if the activities staff had another member of staff to help, she would take residents in pairs to the local café or shops. A bus was organised by a third home to take residents to local community groups, although in practice only one resident would regularly attend.

In one of the homes, although trips had been promised they had not taken place, as one staff member explained:

"[…] they were telling all their families and everybody else they were sitting with, and everybody thought they were going, and they never did."

Similarly, although there was an outdoor space within the nursing home grounds, this was not accessible to all residents in the home. As a result, residents in a particular part of the home had not been taken outside, as one interviewee explained:

"They were sitting looking out at that lovely weather and all they were saying was 'it is awful we are stuck in here'."

This is a serious concern given the obligation in Article 9 of the CRPD to ensure access to the physical environment for people with disabilities.

In two of the homes visited by investigators, residents with dementia were accommodated in a specialist Elderly Mentally Infirm (EMI) unit and it was noted that few of the residents from this unit could participate in day trips. This was due to the level of health care required or because, at times, even though trips outside had been organised when it came to the day residents preferred not to leave the home. However, during the summer months the staff explained that residents would sit outside in the garden area of the home. As the activities staff from one of the homes stated:

"Outside in the garden, in the summer, we would take them out, sit them on the seats and then have the umbrella and things, and they could have lollies or a soft drink, and we have balls like beach balls."

As regards evidence gathered during the Commission's call for evidence, when asked about activity outside of the home, few callers stated that residents went outside unless they had a medical appointment or were going out with relatives, noting that it was rare for residents to go on trips outside. One of the residents who provided written evidence to the call for evidence stated that he was no longer taken outside to visit local shops. As he explained, "It has been impossible for me to visit retail establishments and shops for cash purchases".

Opportunities to go outside can provide an important source of recreation and stimulation

for residents. While it may not be possible for all residents to take part in day trips away from the home, it is important for nursing homes to explore ways in which they can ensure access to the external physical environment for all residents, including those who are more dependent on staff for their medical and personal care. For instance, it may be possible to spend time outside in the grounds of the home or to visit a local shop with one-to-one support from staff. In this respect, nursing homes should have outdoor spaces that are accessible to people with disabilities.

Social contact and stimulation

Daily activity

Aside from set activity, it is important that residents have an opportunity to have an active and meaningful daily routine that does not focus solely on being passive recipients of medical and personal care. In one of the homes visited by investigators, the activity staff had been involved in educating the nursing and care staff about the importance of activity. As the manager explained:

"[The activities staff] is limited to what she can do during the day, so we are focusing on training staff up in expanding the delivery of dementia care, so that, hopefully, if [she] is there for a certain length of time during the day they can emulate that on through the rest of the day or at the weekends."

During interviews, the day and night staff in this home they explained how they would sit with residents to comfort them by holding their hand or, for those who are more active, play music and dance together:

"We would have the music on; we will try and get some of them up, you know what I mean; we would be having a bit of a dance and try and get them up to dance, just to get a bit of movement, just to get them moving."

However, one of the relatives of a resident living in another home visited by investigators explained that although staff "are very caring" the daily routine centres on personal care rather than stimulation. As she explained, "I think the day seems to revolve particularly around meals and toilet and that's the biggest part". Similarly, in another home, staff reported that residents are "moved from watching TV for their dinner, to the toilet, in to watch TV again".

This was a concern reported frequently to the Commission's call for evidence. When asked what residents do in a typical day, there was a sense that interaction with residents revolved around 'getting things done'. One caller explained that social contact is limited to daily tasks such as administering medication; another stated that "interaction is all about toileting". In two instances, callers reported that "changing pads" was recorded as an activity in the resident's activity book.

Unfortunately for many callers, when asked what there is to do in a typical day, the response was that there is simply "nothing". Residents were described as being "parked" in the same place each day, "herded" into the lounge or left in their bedroom. Others reported that the residents were frequently left in the lounge with the television "blaring" even though they were not watching it. Even small differences such as changing the television channel might enhance how residents spend their day. One caller told how her mother loved to listen to the radio and although she bought a radio for her, the staff never switched it on.

From a number of the homes visited, and particularly from the call for evidence, investigators found that outside of set activities, daily activity is often limited or peripheral to the medical and personal care provided by nursing homes. In addition, based particularly on the the call for evidence, there appears to be an over reliance on television when often residents are not interested in watching it.

Finding time to chat

As discussed above, the *Nursing Homes Minimum Standards* require nursing homes to facilitate visits by family and friends and by the local community. This is an important means of social contact for residents. However, people living in nursing homes do not always receive regular visits from relatives and friends. It is therefore important for staff and residents to interact. In seeking to understand how residents spend their day, investigators were interested to learn if there is opportunity for residents and staff to chat.

When asked about the most enjoyable part of their work, staff often referred to the opportunities they have to talk with residents. In one of the homes visited, staff felt that they were provided with time to talk with residents during the day. In this case, social interaction and stimulation were viewed as a key a part of the nursing staff and care assistants' jobs, as the nurse in charge explained:

"[S]taff spend quite a lot of time especially in EMI talking to residents […] because it is a different nature of unit, but they need that."

However, in the other three homes a number of staff stated that while they do chat with residents they would like more time to do so. Staff expressed frustration because they do not get time to speak with residents during the day:

"You go off a wee bit frustrated sometimes because you think you haven't given your best. I haven't spent long enough talking to somebody and then I thought, 'there is a lady there I haven't spoken to all day hardly because I hadn't time'. I think that is terrible but it happens and there you are."

"We don't even have time to talk to the residents or anything. You would love to sit down and have a yarn with them and find out about their past and what they did, what they worked as – and I couldn't even tell you… You don't have time to have a conversation with them to find out."

"[…] at the moment before you are doing your teas you get about five minutes to be able to sit and have a little chat with them, but it doesn't happen. I actually have one of the residents coming up to me; she followed me last night, I told you, she followed me last night and said, 'I am just following you for I am that lonely'."

The residents who spoke with investigators were aware that staff had limited time to spend with them, as a few revealed when asked about their contact with staff:

Q: "And do the staff get much time to chat to you during the day?"
A: "Well, they do their best."

Q: "Do they get much time to just sit and chat and talk to you?"
A: "Not really now; they are always busy but they will chat now and again, you know, all over, you know, to sort of everyone that is there and they are good fun […]."

Q: "Do staff chat to you?"
A: "They don't chat long enough."

Callers to the call for evidence reported that staff rarely had time to chat to residents. One caller explained that although the activity staff would provide massage and aromatherapy, her mother would really like someone to read a newspaper to her or talk about her day. She felt that due to staff ratios "there's not time to chat". One member of the public, who submitted a written response to the call for evidence, stated:

"My Mum was in the home for nearly two years and the RQIA [Regulation and Quality Improvement Authority] rep was doing an inspection and questioned my Mum. She was accompanied by the nurse in charge. Later the nurse said to me she couldn't believe it, the way mother answered the questions, as she thought Mum could only say 'yes' or 'no'."

When living in a nursing home it is important that staff are provided with time to interact and socialise with residents, whether one-to-one or in a group setting. For some residents, the staff are the only source of human contact they have each day and therefore their social and emotional wellbeing depends on it. The Commission finds that staffing levels are rarely at a level that would allow residents and staff to spend significant amounts of time talking together. However, even with limited staff, the evidence gathered for this investigation shows that the quality of interactions can be improved if staff chat with residents while providing other aspects of their medical and personal care.

Concluding remarks

Human rights principles require a holistic approach to nursing care so that older people are treated in a manner that is person-centred, recognising their emotional and social wellbeing as well as medical and personal care needs.[12] While the clinical needs of residents must be attended to, the Commission finds that residents' quality of life also depends on their day-to-day life within the nursing home. The availability of set activities and events and opportunities to go outdoors are each important aspects of residents' quality of life. From the evidence provided to the Commission it is also clear that unscheduled daily activity and regular interaction with staff contribute significantly to the quality of life in nursing homes. With the exception of one of the homes visited, the Commission finds that not enough emphasis is placed on this aspect of care within nursing homes.

The investigation findings suggest that more work is required to ensure that activity is an integral aspect of nursing home care. This should include a particular focus on appropriate and varied programmes of activity that are informed by the views of residents (including group and one-to-one activity), and include the provision of unscheduled daily activity and opportunities for more meaningful interaction between staff and residents.

12 See for example: Principle 13 of the *UN Principles for Older Persons* which states that "Older persons should be able to utilise appropriate levels of institutional care providing […] social and mental stimulation […]."

4

Personal care

"Every time I go up she's the same old jacket maybe on her. Now, I said to her, 'Do they not change these for you?' Says I, 'You're not the sister that I know'." (Interview with resident's brother)

Introduction

Older people living in nursing homes are entitled to help with their personal care and it is crucial for nursing homes to ensure that this help is provided in an appropriate and respectful manner. Where a person requires assistance with personal care, providing it is necessary in order to preserve their dignity and promote respect for their human rights. However, requiring this type of help also represents potentially one of the greatest threats to an individual's sense of dignity and self-worth. As part of its investigation, the Commission sought to understand how the personal care needs of residents are met, including the extent to which residents are enabled to exercise choice in relation to this aspect of their care.

Human rights law and standards

According to Principle 14 of the *UN Principles for Older Persons*:

> Older persons should be able to enjoy human rights and fundamental freedoms when residing in any […] care or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for their right to make decisions about their care and the quality of their lives.[1]

These aspirations are, in large measure, given legal effect in a number of the international treaties. As regards the provision of personal care in nursing homes, of particular significance is the right to private life and to respect for dignity, the prohibition on inhuman and degrading treatment as well as a number of obligations imposed by the *UN Convention on the Rights of Persons with Disabilities* (CRPD).

Article 9 of the CPRD states that in order to "enable persons with disabilities to live independently", States Parties shall take appropriate measures, including the identification and elimination of obstacles and barriers to accessibility. Article 19(a) clarifies that such measures must be taken in respect of *inter alia* housing and medical facilities. Alongside the obligation of accessibility is an obligation, contained in Article 20, requiring States Parties to:

> [T]ake effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities.

In relation to the provision of personal care in nursing homes, these obligations mean that appropriate assistance should be available where older people are unable to access washing or toilet facilities unaided.

The CRPD also requires States Parties to promote the independence of people with disabilities through rehabilitation. Article 26 requires states to "take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence [and] full physical, mental, social and vocational ability". Also relevant is paragraph 77(c) of the *Madrid International Plan of Action on Ageing*, which requires States to "promote self-care in older persons and maximize their strengths and abilities within health and social services". Examples of enabling independence in the context of personal care include facilitating independence in washing, dressing and in the use of toilet facilities.

In addition, the right to respect for private life is enshrined in Article 8 of the European Convention on Human Rights (ECHR) and Article 17 of the *International Covenant on Civil and Political Rights* (ICCPR). Although, as discussed previously, the right to a private life includes a right to privacy, it is much broader than this. It also addresses the infringement of an individual's moral and physical integrity,[2] their dignity interests,[3] the

1 UN General Assembly Resolution 46/91 on the Implementation of the International Plan of Action on ageing and related activities, 16 December 1991, A/Res/46/91 (incorporating UN Principles for Older Persons) (available: http://www.un.org/documents/ga/res/46/a46r091.htm; and http://www.un.org/ageing/un_principles.html).

2 *X and Y v Netherlands* (26 March 1985) 8 EHRR 235, para 22.

3 *R (on the application of A, B, X and Y) v East Sussex County Council and the Disability Rights Commission* [2003] EWHC 167.

circumstances in which it is permissible to provide personal care or medical treatment without an individual's consent,[4] the power of an individual to make decisions as to personal risk[5] and protections to safeguard respect for aspects of an individual's personal identity, including matters such as personal choice as to mode of dress.[6] All of these elements of the right to private life may be engaged by different forms of personal care, including help with dressing, washing and continence needs.

The prohibition on inhuman and degrading treatment is also potentially relevant to the provision of personal care (Article 7, ICCPR and Article 3, ECHR). Article 3 of the ECHR imposes a positive obligation on public authorities, including nursing homes, to take reasonable steps to ensure that individuals are not subjected to inhuman and degrading treatment or torture.[7] Where an older person has difficulty with daily tasks such as washing or dressing, failure by a nursing home to assist, resulting in discomfort or unsanitary living conditions may potentially contravene the prohibition on inhuman and degrading treatment. Indeed, in considering the relevance of Article 3 to the application of a local authority's moving and handling policy, the High Court has stated that human dignity (as part of the right to be free from inhuman and degrading treatment) entails an enhanced degree of protection for those who are "[…] so disabled as to be critically dependent on the help of others for even the simplest and most basic tasks of day to day living".[8] Referring in particular to the provision of assistance with continence needs, Munby J stated:

> Article 3 might well be engaged, for example, in circumstances where the consequences of failing to lift [the applicants] manually might result in them remaining sitting in bodily waste or on the lavatory for hours, unable to be moved.[9]

In less serious cases, failure to assist with personal care needs is likely to be inconsistent with the right to dignity of the older person, affirmed in Article 25 of the *EU Charter of Fundamental Rights* (EU Charter) to which all members of the European Union, including the UK, have committed. Article 25 "recognises and respects the rights of the elderly to lead a life of dignity and independence".

Minimum standards and home policies

In relation to personal care, Standard 19 of the *Nursing Homes Minimum Standards* (2008) refers to "continence management" and requires that residents "receive individual continence management and support". The standards require nursing homes to have a policy on 'continence management' and each of the four homes visited provided a copy of this to investigators. All four policies address the various matters required by Standard 19, that is, assessment and care planning, how to promote continence, and rules regarding the use of catheters. However, the policies from all of the homes go somewhat further to include references to the dignity and privacy of residents in relation to continence needs. For instance, one policy states that the residents care plan on continence will "include resident choice and preferences" and "promote maintenance of resident dignity".

In addition, two of the homes provided policies relating to other personal care needs. These polices refer to bathing and showering and require staff to discuss with residents their preferences for a bath or a shower. One home's policy on 'Quality of Life' refers to 'hygiene and appearance', stating that "residents are groomed as they wish" and "dressed in their own clothes appropriate to the time of day and individual preferences".

4 *Storck v Germany* (16 June 2005) 43 EHRR 96.

5 *X v Belgium* (6 February 1968) 18 DR 225.

6 *McFeeley v UK* (15 May 1980) 20 DR 44.

7 *Watts v UK* (4 May 2010) Unreported, Application No 53586/09 (dealing with the potential harm caused to an older person through the closure of her care home).

8 *Munby J in R (on the application of A, B, X and Y) v East Sussex County Council and the Disability Rights Commission* [2003] EWHC 167, para 93.

9 Above, para 114.

Nursing homes' approach to promoting continence for residents is a significant aspect of the care that homes provide. However, the *Nursing Homes Minimum Standards* focus exclusively on 'continence management'. There is no reference to the importance of promoting the dignity and privacy of people who need help with this aspect of their personal care. The Standards also fail to mention the importance of other personal care needs such as washing, showering, bathing and dressing. It is welcome that the policies provided by each of the four homes go further than the Minimum Standards. However, it would be helpful if nursing home policies included more practical detail on how to respect dignity and privacy in relation to continence and other personal care needs.

Responding to continence needs

Many residents in nursing homes require support from staff to either maintain or regain continence and it is essential that this support is provided in a sensitive and timely manner. During interviews, staff described how residents are offered help to go to the toilet according to a set routine. However, it was stated that residents can also request help outside of these times. One interviewee explained the routine as follows:

"Well, there is a routine. You know the ones that wouldn't know to ask. They are taken when they get up in the morning and then in between breakfast and lunch again, and then between lunch and tea there is a toileting time, and then before bed; but anybody in between that wants to go [can] but there are those times when everybody is definitely offered or, if they don't know to ask, they are taken at those times."

Nevertheless, interviewees from the same home revealed that they cannot always respond to residents' requests between these set times. They explained that there is often a delay in responding during meal times when staff are helping other residents to eat. One interviewee stated:

"You are having to say, 'I can't take you, there is nobody here to help me', you know; and it is maybe taking somebody 20 minutes, half an hour to get back so that they can [help] but by that time it is too late, you know that way. There is not enough staff to meet their needs at times."

Numerous callers to the Commission's call for evidence reported that residents are not taken to use the toilet other than at set "toileting" times and that requests for help often go unanswered. One caller explained how at times when visiting her mother, she is "in tears" and "hammering" on the cupboard for someone to take her to the toilet. It was often reported that it might be up to 45 minutes before a resident's calls for help are answered, by which time it is too late.

Moreover, several callers were concerned that at times due to staffing pressures residents are asked to use incontinence pads even though, with some assistance, they are able to use the toilet themselves. In addition, at least six callers stated that the resident's alarm bell is switched off or placed out of reach so that they are unable to 'buzz' for help to go to the toilet. One caller explained how her mother used to call from a mobile phone in distress because she could not access the alarm bell.

It is difficult to imagine how distressing it must be for a person who is continent to wait for help or to be asked to "go in a pad". This experience impacts on a person's physical and moral integrity and can have adverse psychological effects.[10] It may be acceptable if there is a delay in providing assistance on a very rare occasion, due perhaps to unexpected demands on staff time. However, where it happens more often or to the extent that a person becomes incontinent or reliant on incontinence pads, it may engage their right to private life and, in more severe cases, possibly even their right to be free from inhuman or

10 See for example: the recent national audit of continence care, which states that incontinence is associated with depression (Royal College of Physicians (2010) *National Audit of Continence Care 2010*, Royal College of Physicians, London, p8).

degrading treatment.[11] It is essential that nursing homes respond to residents' requests for help with their continence needs appropriately and in a timely manner.

Individual choice and personal care

Decisions about intimate personal care

Personal care is often an extremely private and intimate matter and it can be difficult to agree to this type of help. In considering the provision of medical treatment, the European Court of Human Rights has stated:

> [E]ven a minor interference with the physical integrity of an individual must be regarded as an interference with the right to respect for private life under Article 8 if it is carried out against the individual's will.[12]

It follows that the provision of personal care against the wishes of a person who has capacity to make this decision may also interfere with their right to private life under Article 8 of the ECHR. Whether this interference results in a breach of Article 8 would depend on the circumstances of the case, including the purpose and necessity of the personal care in question.

The provision of personal care against a person's will may also potentially engage the right to be free from inhuman and degrading treatment under Article 3 of the ECHR. Assessing the provision of medical treatment under Article 3, the court has held:

> [A] measure which is of therapeutic necessity from the point of view of established principles of medicine cannot in principle be regarded as inhuman and degrading.[13]

It is therefore likely that the provision of personal care against a person's will in circumstances where it is demonstrated to be of therapeutic necessity would, in principle, not be incompatible with their ECHR rights.

During the investigation, staff were asked what they would do if a resident refused assistance with personal care. For the most part, staff indicated that it was up to the resident to decide. One of the homeowners explained that personal care is "not done onto" residents, rather they are always asked and approached. However, where a person lacks capacity to consent to different forms of personal care the situation may be different. Here, if a resident refuses help, assistance may be provided if nursing staff determine that the care is in their "best interests". It is well established that a person's best interests is not confined to their best medical interests.[14] As the relevant guidance by the Department of Health, Social Services and Public Safety (DHSSPS) states:[15]

> […] other factors which may need to be taken into account include the individual's values and preferences when competent, their psychological health, well-being, quality of life, relationships with family or other carers, spiritual and religious welfare and their own financial interests.

At times, staff explained a difficult balancing exercise between respecting a person's decision to refuse personal care and ensuring respect for right to health and their dignity. The following member of staff described this:

> Q: "If someone indicated that they didn't want help or they didn't want assistance, what would you do?"

11 See: *Tyrer v UK* (25 April 1978) Application No 5856/72, para 33, where the Court stated that the right to be free from degrading treatment in Article 3 ECHR protects a person's dignity and physical integrity. See also: the dicta of Munby J referring to the potential application of Article 3 ECHR in relation to the provision of assistance with continence needs (Munby J in R *(on the application of A, B, X and Y) v East Sussex County Council and the Disability Rights Commission* [2003] EWHC 167, para 114).

12 *Storck v Germany* (16 June 2005) 43 EHRR 96, para 143.

13 For example: *Jalloh v Germany* (11 July 2006) 44 EHRR 667, para 69.

14 See: *Re MB* (1997) 38 BMLR 175.

15 Department of Health, Social Services and Public Safety (2003) *The Reference Guide to Consent for Examination, Treatment or Care*, DHSSPS, Belfast, para 1.4.

A: "Well, that would depend on the situation really. If you have got somebody that is… maybe, that has had an accident, for example, and they are saying [no], do they understand what has happened to them? You know, what is going to be the best in their interests? Are you going to leave somebody that has soiled themselves even if they are saying 'no'? They mightn't understand that is what has happened to them. So, in order to preserve their dignity you would have to, especially in a communal area – maybe where they are sitting in the lounge […] So, in that situation, no – I wouldn't possibly – I wouldn't be saying, 'oh, that is okay'. […]"

The European Court has held that the application of a "best interests" test is, in principle, not incompatible with the ECHR.[16] Indeed, the Commission acknowledges the difficult balance for staff involved; it is about assessing "best interests" and recognising that, in certain circumstances, failure to provide personal care can become a medical concern. Where an older person lacks capacity and requires help with personal care, such as in the circumstances described, providing appropriate assistance is likely to be consistent with human rights obligations.

If personal care is determined to be in the best interests of a resident who objects, the proposed care should be consistent with their right to dignity. In particular, care should be provided sensitively and in a way that causes least distress. In one home caring for residents with dementia, staff described how they help residents who are at times reluctant to accept assistance. For instance, showers are provided in the evening instead of the morning because this helps to reduce agitation; for some residents, a bath is offered instead of a shower because, as one interviewee explained, "They are afraid of the shower […] because they were never used to it".

In contrast, staff in another home revealed that they require more information about how to help residents who refuse personal care when it is determined to be in their "best interests", as one interviewee stated:

"She does refuse and we are still told to take her into that shower and get her showered, whether she is refusing or not and, okay, she may have dementia but we are having to put her through something she doesn't want to go through, and if she is dirty, is there not something else we can do? I just think there [are] a few things that need to be looked at a bit closer and then staff to be informed a bit better because that is not fair. I wouldn't want somebody grabbing hold of me and shoving me under a hose I don't want to be under."

If a resident lacks capacity and refuses help with personal care, it is important that staff provide care in a sensitive manner and limited to that which is in their best interests.

Not set in stone?

As part of the investigation, the Commission sought to determine how flexible staff are when responding to personal care needs. Overwhelmingly, when staff were asked what they do if a resident does not want to get dressed or washed at a particular time, the response was that although they have a routine it is not fixed. As one interviewee explained, "Nobody has to do anything at a particular time". For example, the staff interviewed in each of the homes talked about a weekly rota, according to which residents are offered a bath or shower. However, where possible this is flexible so that if a resident wishes to have a bath or shower more than once a week, or a wash on a different day, this may be accommodated. One member of staff explained this in the following terms:

16 *Glass v UK* (9 March 2004) 29 EHRR 15, para 75.

"It sounds very institutionalised but […] again, it is not set in stone. But, you know we have – I don't like this word but – a bath list. So yes, there are showers and baths every day. Again, that doesn't have to happen first thing in the morning. Somebody might say, 'I don't want to have a shower. I am only out of bed, will have it later on'. […]"

During the call for evidence, the information received from callers differed. The view of the majority of callers who gave evidence in relation to personal care was that residents' preferences are rarely respected. It was reported that residents are required to get dressed at set times, that they are offered showers only once per week or that, for those who prefer a bath, this is never offered. In addition, a number of callers stated that personal care is provided in a manner that is rushed or "perfunctory" because staff are in a "hurry to get things done". One caller described how her mother was not given time to help herself and as a result her "last wee bit of independence" was taken away.

It is apparent that a routine exists for the provision of personal care within nursing homes. Nevertheless, staff in the homes visited by investigators stated that this is not fixed and where possible there is flexibility so that residents can exercise choice in relation to their personal care. By contrast, information provided to the call for evidence suggests that this is not the case in all nursing homes. Often the home's routine is prioritised and personal care is not provided at the resident's own pace. It is understandable that nursing homes will require some form of routine; however, flexibility is crucial to ensure respect for residents' individual choice and independence.

Failure to provide personal care

During the call for evidence, callers often reported that residents are left wet or soiled or that other personal hygiene needs are not met. A number of callers described instances where their mother or father was "soaking"; other callers, notably upset, informed investigators that at times they found their family member soiled with faeces on different parts of their body. One caller described how she helped change her mother's clothes because she found her "soaked right through" to the extent that her shoes were wet.

As well as failures to change wet or soiled clothing, evidence was received from callers that other personal hygiene needs had not been met for some residents. Several callers stated that their relatives had not been washed, that their nails were dirty or uncut, or that their teeth had not been cleaned. In a number of instances, it was reported that residents had not been provided with their hearing aid or glasses. For example, one caller explained that because staff lost her mother's hearing aid, she was "unable to communicate for the last three days of her life".

Failure to provide personal care for older people who are unable to attend to their own needs may engage various human rights protections including the right to private life and, in more serious cases, where lack of personal care results in neglect or humiliation, possibly the right to be free from inhuman and degrading treatment.[17] From visits to the nursing homes it is apparent that there are times during the day when staff are pressured, particularly at meal times or during staff breaks. This means that residents' personal care needs are not being met at all times.

Privacy and personal care

When interviewing nursing home staff, a number referred to providing personal care in a manner that respects residents' privacy, including closing the door when helping residents to dress or to go to the toilet. However, callers to the call for evidence were concerned that at times privacy is not valued. One caller stated that her mother was often upset because staff had left the door open when she was going to the toilet. Several callers referred

17 See in particular: the dicta of Munby J in *R (on the application of A, B, X and Y) v East Sussex County Council and the Disability Rights Commission* [2003] EWHC 167, para 93, discussing the "enhanced degree of protection" which may be required under Article 8 ECHR in relation to those who are dependent on the help of others for the basic tasks of day-to-day living; and para 114 referring to the potential application of Article 3 ECHR in relation to continence needs.

to the use of a hoist. Indeed, the High Court has noted that "[h]oisting can facilitate dignity, comfort, safety, and independence"; however, "it all depends on the context".[18] Although callers to the call for evidence recognised that the hoist is intended to protect residents' safety, they felt it was used in an undignified manner. Three callers described how their relative was left in a hoist "swinging" or "dangling in the air" in view of other people.

Where staff are involved in helping residents with intimate personal care, gender can often constitute an important aspect of privacy. In one home visited by investigators, a carer explained that, for female residents, a female member of staff could provide intimate personal care:

"We have to explain to the resident that he or she will be going for a bath or a shower and then we make sure that the water temperature is okay, and keep her dignity and keep the door closed. And, if it is a woman [who] doesn't want a man assisting her, then it has to be with a female member of staff […]."

However, at least six callers to the call for evidence stated that male members of staff regularly provided intimate personal care to female residents even though this caused the resident considerable distress.

It is important that residents are afforded privacy when staff are helping with their personal care needs. It is crucial that personal care is provided in privacy, particularly during the daytime when nursing homes receive a large number of visitors, whether from family members or health care professionals. It is also important that nursing homes accommodate choice as to the gender of the staff helping with residents' intimate personal care insofar as this is possible.[19]

Personal identity and personal care

Personal care includes help with washing and more intimate matters such as continence needs. It is also about dressing and the 'smaller things' that help a person feel confident about their appearance. Indeed, in other contexts, such as psychiatric establishments, individualisation of clothing has been recognised as crucial for personal identity, self-esteem and the therapeutic process.[20]

In each of the homes visited, investigators asked staff about dressing and, in particular, whether residents are able to choose what to wear. Staff stated that residents do select their own clothes but, in certain circumstances, and often if the resident has dementia, the staff make the choice. Even in such circumstances, however, staff described how they try to involve residents. As the following interviewee explained, "We will say, 'is this one alright?' and try and get them to engage in us doing it".

A number of callers to the Commission's call for evidence stated that they were content with this aspect of residents' care. However, others described how residents' clothing is often mismatched or damaged, or that their clothes had been lost. In addition, it was reported that in some homes residents are frequently dressed in other people's clothing. In a few instances, callers stated that although they bought new "outfits" for their relative, these were never worn. As the following interviewee explained:

"Every time I go up she's the same old jacket maybe on her. Now, I said to her, 'Do they not change these for you?' Says I, 'You're not the sister that I know'. The same old jacket on her again and I don't know what the rest of her is like […]. The thing is, I brought plenty of stuff up. I brought her tights up – different colours. I brought her the short ones to

18 Above, para 122.

19 See in particular: the UN Committee on the Elimination of All Forms of Discrimination Against Women (1999) *General Recommendation No. 24 on Women and Health*, which states that for women health care services should be delivered in a way that "[…] respects her dignity, guarantees her confidentiality and is sensitive to her needs and perspectives" (para 22).

20 European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) (2002) *CPT Standards*, Council of Europe, Strasbourg [Revised 2010] para 34 (available: http://www.cpt.coe.int/en/documents/eng-standards.pdf).

her knees and I brought her heavy ones that go up to the ball of your leg, and two pair of slippers, and she said she wants a pair of shoes. I brought her a new pair of shoes up and they're lying there. And tops – I brought her more tops up. I've never seen one of them on her yet."

Often the clothes that a person wears and the way in which they present themselves form an important part of their personal identity. The evidence provided to the Commission demonstrates that it is distressing for residents and family members when they are dressed in other people's clothes or when little attention is paid to their appearance. The right to private life includes respect for personal identity, which encompasses an individual's choice about how to dress[21] and it is vital that nursing homes recognise this as a key part of residents' personal care. In addition, Article 1 of Protocol 1 to the ECHR sets out the right of individuals to peaceful enjoyment of their possessions, which is potentially relevant if residents' clothes or other items, such as hearing aids, are regularly lost.

Concluding remarks

Every day, staff in nursing homes help residents with the most intimate and deeply private aspects of their personal care. The findings in this chapter show how failure to attend to this aspect of care, or providing care in a manner that is inappropriate or disrespectful, can engage various human rights. Human rights standards require that personal care is provided in a manner that respects residents' physical and moral integrity[22] as well as their emotional wellbeing. The principle of independence is also central to various human rights instruments, including, most recently, the CRPD. In the context of personal care, this requires that residents' choice and independence is facilitated in relation to washing, dressing and continence needs.

21 *Mc Feeley v UK* (15 May 1980) 20 DR 44.

22 See generally: *R (on the application of A, B, X and Y) v East Sussex County Council and the Disability Rights Commission* [2003] EWHC 167.

5

Eating and drinking

"Sometimes when I go up I will give Mummy her own juice and she will drink two or three glasses all at a go some days, so I know she is so thirsty." (Interview with resident's daughter)

Introduction

Older people living in nursing homes often require help with eating and some are dependent entirely on staff for their nutrition, hydration and general dietary care. As well as being vital for sustenance, eating and drinking in almost all societies have an important social function and can therefore also impact on a person's quality of life. However, for nursing home residents, there is a risk that pressures of time or resources may compromise their eating and mealtime experience, particularly for those who require greater levels of help with eating and drinking. A key part of the Commission's investigation was therefore concerned with this aspect of residents' care. The investigation explored residents' experiences of eating and drinking, including the availability of food and drinks and the extent to which residents can exercise choice about the types of meals offered by the home. Importantly, the investigation considered whether the dignity and privacy of residents is respected during mealtimes.

Human rights law and standards

The right to adequate food, set out in Article 11 of the *International Covenant on Economic, Social and Cultural Rights* (ICESCR) as one of the elements of the wider right to an adequate standard of living, has been elaborated upon by the UN Committee on Economic, Social and Cultural Rights in its *General Comment No 12*. The Committee notes that an important aspect of the right to food is that of accessibility, observing:

> [A]ccessibility implies that adequate food must be accessible to everyone, including physically vulnerable individuals, such as […] elderly people, the physically disabled, the terminally ill and persons with persistent medical problems, including the mentally ill.[1]

Water and fluids are also essential requirements for daily sustenance. As a consequence, although not expressly mentioned in Article 11, the Committee has interpreted it to include the right to water. In its *General Comment No 15* on the right to water the Committee observed:

> The right to water clearly falls within the category of guarantees [contained in Article 11] essential for securing an adequate standard of living, particularly since it is one of the most fundamental conditions for survival.[2]

To fulfil this right, States Parties must provide access to water when individuals are "[…] unable, for reasons beyond their control, to realise this right themselves by the means at their disposal".[3] As well as referring to situations of poverty, this may be understood as referring to physical accessibility, including where individuals are dependent on others for access to water due to physical or mental impairment. The rights to food and water are significant in the context of nursing care. People with dementia may, for instance, find it difficult to ensure that they maintain a healthy and balanced diet and protecting their human rights will often require that they receive assistance with, and monitoring of, their food intake to ensure that they receive sufficient food for their wellbeing.

A body of international standards and guidance also supplements these rights. Access to food and adequate nutrition for all older people forms a key objective in the *Madrid International Plan of Action on Ageing* agreed in 2002. As part of the Plan, States, including the UK, have endorsed measures including the following:

> [The inclusion of] specific nutritional needs of older persons into curricula of training programmes for all health and relevant care workers and professionals; and

1 UN Committee on Economic, Social and Economic Rights (1999) *General Comment No 12: The Right to Adequate Food*, 12 May 1999, UN Doc E/C 12/1999/5, para 13.

2 UN Committee on Economic, Social and Economic Rights (2003) *General Comment No 15: The Right to Water*, 20 January 2003, UN Doc E/C 12/2002/11, para 3.

3 Above, para 25.

> Ensuring appropriate and adequate provision of accessible nutrition and food for older persons in hospital and other care settings.[4]

The Committee of Ministers of the Council of Europe has also passed a resolution dealing with food and nutrition in care settings. *Resolution ResAP(2003)3 on Food and Nutritional Care in Hospitals* (the Resolution) provides guidance which, although specifically directed at hospitals, is also applicable in other care settings. The Resolution provides detailed guidance on, among other matters, including nutritional screening, risk assessment, staff training, monitoring of food intakes and food patterns.

The rights to food and water are not the only rights engaged with regard to nutrition and mealtimes in nursing homes. For those who require help with eating and drinking, it is important that the mealtime experience affords protection for their dignity. Eating, drinking and choice about types of food are also an important aspect of independence. The UN *Convention on the Rights of Persons with Disabilities* (CRPD) is relevant for older people who, as a result of long-term physical or mental impairment, need assistance with eating and drinking. Article 26 of the CRPD requires states to:

> [T]ake effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence [and] full physical, mental, social and vocational ability.

Thus, although assistance is often necessary, the emphasis should be on facilitating older people to provide for their own nutritional needs to the greatest extent of their ability.

In UK domestic law, although there is no "right to food" as such, several of the rights contained in the European Convention on Human Rights (ECHR) are important. Therefore, for instance, the right to private life in Article 8 of the ECHR is potentially relevant to residents' dining experiences and mealtime preferences. In addition, provision of food in a manner that is capable of humiliating, or causing feelings of fear or inferiority, may engage the right to be free from inhuman and degrading treatment under Article 3.[5] In its standards for the prevention of inhuman and degrading treatment in psychiatric establishments, the European Committee for the Prevention of Torture (CPT) notes the significance of eating arrangements for the right to be free from inhuman and degrading treatment:[6]

> […] eating arrangements should be decent; in this regard it should be stressed that enabling patients to accomplish acts of daily life such as eating with proper utensils whilst seated at a table represent an integral part of programmes for the psycho-social rehabilitation of patients. Similarly, food presentation is a factor, which should not be overlooked.

Access to food and water may engage the right to life, (Article 2 ECHR; Article 6 of the *International Covenant on Civil and Political Rights* (ICCPR)). As explained in Chapter 1, the right to life places an obligation on public authorities to refrain from the intentional and unlawful taking of life and it also places a positive obligation on a state and its public authorities "to take appropriate steps to safeguard the lives of those within its jurisdiction".[7] Thus, where an individual lacks physical or mental capacity and is unable to eat without assistance, failure to provide adequate nutrition may engage Article 2, where death is attributable to dehydration or malnutrition.[8]

4 United Nations (2002) *Report of the Second World Assembly on Ageing (Madrid International Plan of Action on Ageing)*, para 68 (available: http://www.un.org/ageing/madrid_declaration02.html).

5 *Kudla v Poland* (26 October 2000) 35 EHRR 198.

6 European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) (2002) *CPT Standards*, Strasbourg: Council of Europe [Revised 2010] para 35 (available: http://www.cpt.coe.int/en/documents/eng-standards.pdf).

7 *LCB v UK* (9 June 1998) 27 EHRR 212, para 36.

8 *R (on the application of Oliver Leslie Burke) v General Medical Council* [2005] EWCA Civ 1003.

Minimum standards and home policies

The *Nursing Homes Minimum Standards* (2008) require nursing homes to have a policy on 'meals and mealtimes' and on 'nutrition'. Each of the four homes visited by investigators provided a written policy covering this aspect of residents' care. In addition, policies and procedures relating to tube and Peri-Percutaneous Endoscopic Gastrostomy (PEG) feeding were supplied by all homes. The policies cover the medical and dietary aspects of nutrition, including matters such as nutritional intake and nutritional assessment. However, only one policy addresses in detail the importance of the dining experience for residents. As part of its policy on nutrition, this home makes explicit the connection between the dining experience and promoting residents' dignity and independence, noting that "staff must be ready to offer assistance where necessary discreetly, sensitively and individually although independent eating is to be encouraged".

Although the policies of the other homes refer to dignity, this is either not as detailed or is contained in another policy and not repeated or cross-referenced with the policy on nutrition. Notably, a 2007 study by the Healthcare Commission in England and Wales on the dignity of older people in hospital found that of the NHS Trusts assessed, many claimed that policies relating to dignity and nutrition were embedded within other documents.[9] If policies are not clearly set out, it is difficult to demonstrate that the dignity aspects of nutrition have been considered.

The *Nursing Homes Minimum Standards* should provide more direction to nursing homes on how to promote residents' independence and dignity during mealtimes. At present, it is not clear from the standards that this should be outlined within homes' policies and procedures on nutrition.

At the departmental level, the launch of *Promoting Good Nutrition*, a Department of Health, Social Services and Public Safety (DHSSPS) policy document designed to implement the Council of Europe's *Resolution ResAP(2003)3 on Food and Nutritional Care in Hospitals* in all care settings, is a welcome development.[10] This provides a number of useful recommendations for homes on how the dining experience can be improved for residents. Nevertheless, greater detail is required on how independence can best be facilitated during mealtimes and, more generally, how the mealtime experience can be enhanced for those who require help with eating.

Choice

Evidence shows that for older people in nursing homes meals and mealtimes form a fundamental part of the day.[11] It is therefore all the more important that residents are provided with the opportunity to exercise choice in relation to the meals provided by the home. The findings from this investigation show that choice in this respect is about two broad themes: the first is about selecting the types of food that an individual would prefer to eat; and the second is about the experience of eating and being able to exercise choice over when and where to eat.

Choice about types of food

Providing a written menu is perhaps one of the most obvious starting points to ensuring that residents can have some degree of choice about the food they eat. All of the homes visited by investigators provided a menu to residents, which generally contained two choices for the afternoon and evening meal. By contrast, a number of callers to the call for evidence reported that the home did not have a menu and there was therefore no opportunity for the resident to choose their meal. As one caller explained, there was one set meal and no alternative available.

9 Healthcare Commission (2007) *Caring for Dignity: A national report on dignity in care for older people while in hospital*, Commission for Healthcare Audit and Inspection, London, p8.

10 Department of Health, Social Services and Public Safety (2011) *Promoting Good Nutrition: A Strategy for Good Nutritional Care for Adults in All Care Settings in Northern Ireland*, DHSSPS, Belfast (available: http://www.dhsspsni.gov.uk/promoting_good_nutrition.pdf).

11 Commission for Social Care Inspection (2006) *Highlight of the Day? Improving meals for older people in care homes*, Commission for Social Care Inspection, Newcastle.

However, the existence of a menu is not a guarantee that residents will be involved in decisions about their meals and simply offering a choice of meals is not sufficient to ensure residents' preferences are catered for. From the primary fieldwork it is apparent that the usefulness of a menu depends not only on when it is provided but also the degree to which residents, family members and staff are involved in its preparation. This includes the need for staff to make concerted efforts to ensure the choices reflect the preferences of the residents. In one of the homes visited, the menu was provided one week in advance, with residents required to select their meals for the week ahead. As the week progressed this proved problematic as residents could not recall what they had ordered. If the resident did not like the alternative choice on the menu, toast appeared to be the only other option. It is important that nursing homes cater for the possibility that residents might change their choice of food and have appropriate, nutritious alternatives available.

In many instances, particularly if an individual has dementia, nursing homes will need to do more than devise a menu to help residents indicate their mealtime preferences. According to information provided to the investigators during visits to the homes and the call for evidence, a number of methods are used by nursing homes to help ascertain residents' wishes about food. For example, questionnaires were used to ask residents about personal likes and dislikes, and portion sizes. In one home, where all of the residents had been diagniosed with dementia, the activities staff member spent time with each resident to help them take part in the questionnaire. In addition, during the call for evidence one caller reported that the home was planning to use photographs to help residents choose their meal.

Nevertheless, not all methods were deemed to be a success. A number of callers to the call for evidence and some interviewees from the primary fieldwork noted that although information about residents' likes and dislikes had been provided, this was not always translated into practice. One caller stated that even though she communicated that her mother did not like fish, within a three-week period fish was served at least five times. Similarly, both from the call for evidence and primary fieldwork, it was reported that despite residents' preferences for 'traditional' food, 'modern' food was routinely served. As one member of staff explained, "there [are] things on the menu like curry and it is not really to their taste".

It is understandable if mealtime preferences cannot be accommodated all of the time. However, as far as possible, residents' likes should be reflected in the menus provided by the home. To ensure this, there should be meaningful opportunities for residents to be involved in decisions about meals. Innovative methods should be used to help residents make decisions about their food. In addition, residents' decisions should be recorded and communicated to staff so that their choices are reflected in practice.

The dining experience

To promote respect for dignity, the dining experience should be an enjoyable and comfortable one. Research has found that residents do not always enjoy eating their meal in shared dining rooms and, particularly for those who require assistance, may prefer to eat in private.[12] It is therefore important for nursing homes to be flexible in their approach to dining.

During the investigation, staff reported that residents can have meals in their own rooms. However, this was generally only if assistance or observation was not required, if the resident was too unwell to go to the dining area, or if they expressed a wish to sleep late in the morning in which case breakfast might be brought to their room.

12 Voices (1998) *Eating Well for Older People with Dementia: Good Practice Guide*, The Caroline Walker Trust, Herts; Kofod J and Birkemose A (2004) 'Meals in nursing homes', 18 *Scandinavian Journal of Caring Science*, 128-134.

As one staff member explained, while they try to accommodate residents' preferences to eat in private this is not always practicable due to staffing levels and the home's routine:

"If I had five people that said, 'I don't want to eat in the dining room' and just in their rooms, that would just be crazy because I couldn't observe that. I can't have five people in individual rooms. So, there are two areas where the residents can eat their [meals]."

In certain circumstances, it may be important for nursing home staff to observe mealtimes so that residents' progress can be monitored. However, if a resident indicates a wish to eat in private, the home should consider ways to accommodate this.

Help with eating

Article 26 of the CRPD requires States Parties to take effective and appropriate measures to enable people with disabilities to attain and maintain maximum independence. Therefore, if a resident requires help with eating, appropriate assistance can ensure that their independence is maintained. Indeed, failure to offer appropriate assistance risks deterioration in health with the result that greater levels of help are required. Assistance must not, however, be provided in a way that is degrading or humiliating for an individual, or which violates their right to privacy.

Devoting staff and time

Some residents may require minimal help with eating; for example, they may need help with cutting up food. The investigation findings show that, where greater levels of assistance are required, time is essential to ensure that residents receive appropriate help. During interview with investigators, a member of staff described taking time to assist residents, which included social interaction as well as physical help with eating:

"While we are assisting them we talk to them, asking them questions – if they are enjoying their meal – because they would just really nod. Or if you sort of ensure that they are enjoying it. You just don't give them the food [...], give them time to chew and offer them milk or juice in between."

However, interviewees from the other homes reported that staffing levels do not always allow sufficient time to help residents with eating. This tended to be a problem during breakfast when care assistants are also helping residents to get dressed for the day. As one resident noted, "Breakfast can be late. You know, they are short staffed here, frankly". When staffing levels are low there is a risk that residents are helped in a less sensitive and sometimes undignified manner. For example, one interviewee reported that although four care assistants are generally required at mealtimes there are days when only three carers would be on duty. To cope with this she would assist two residents at a time, "[...] if there are two residents sitting beside each other that need feeding you can do it alternatively that way".

During the call for evidence, callers provided examples of residents being hurried, referring to food being "shovelled" by staff helping residents to eat. It was also reported that, on some occasions, nursing home staff had not devoted any time to helping residents eat. For example, one caller explained how she observed food being left for residents who could not feed themselves. The meal would be collected again without the food having been eaten. It is essential that in all homes sufficient levels of staff are provided so that assistance can be provided during mealtimes. There should be adequate time available so that residents who need help receive this in a dignified and sensitive manner.

Aiding dependence?

Assistance is generally viewed as a positive measure, that is, something that is provided in order to help residents. However, there is a risk that older people can be provided with inappropriate forms of support that undermine

rather than enhance their ability to eat. For example, a resident may be capable of eating unassisted but this may take longer and therefore be discouraged because of the nursing home's routine. This was a concern reflected in the findings from the call for evidence rather than from the primary fieldwork. Indeed, the manager from one of the homes visited by investigators recognised the risks of inappropriate assistance:

"I think there is only one lady that's actually on a purée diet which I am delighted about because years ago you would see purée, purée, purée, but it didn't need to be – soft would be adequate."

During the call for evidence callers reported their concerns that relatives had been placed on puréed diets for the home's convenience or because an assessment by the dentist or speech and language therapist was delayed or not carried out. One caller explained that after dentures were mislaid there was no attempt to replace them, with the result that the resident was placed on a pureed diet. Similarly, other callers indicated that the home had provided a pureed or soft diet for "handiness" to avoid the one-to-one support that would otherwise be required to help the resident eat.

It is important that staff properly and regularly assess whether a puréed diet is actually required or whether, with more support, the resident can be helped to eat a soft or even more solid meal.

Accessibility

Often residents are reliant on the nursing home for the provision of food and it is essential that staff facilitate residents' access to food. This means ensuring that residents have the means available to them to request food when they would like it. If residents have difficulty communicating their wishes directly to staff, the home should ensure an appropriate system to ascertain if they require food and also fluids in between meal times. As a staff member from one home explained:

"But there is, as I say, certain people who wouldn't be able to ring us […] but we would be checking them and asking them if they want a drink or whatever at that time."

Accessibility appeared to be a problem, more so in relation to fluids than with meals or snacks. Other studies have reported that dehydration is a serious risk for those who are unable to communicate that they need a drink[13] and, in some cases, callers to the Commission's call for evidence stated that dehydration was a reason for hospitalisation of residents (see Chapter 6). Here, it is important to note that in some of the homes visited by investigators this was reported as a concern, as one interviewee explained:

"There is supposed to be a juice round about 11 o'clock. They are supposed to get offered a cold or hot drink but they never get the choice of a hot drink because the dishes are never back up from the kitchen in time. [...] But then, as I say, again sometimes we are that busy there is nobody there to give them their juice [...]. There is sometimes at 11 o'clock, it's just forgot[en] about unless somebody specifically asks."

Even in the one home regarded by investigators as performing particularly well in terms of menu choices and assistance at mealtimes, a family member reported that on occasions her mother appeared dehydrated and quenching for fluids.

Dehydration can have serious consequences for residents' health. As well as providing access to food, staff must ensure that residents have access to water or other fluids throughout the day and night in order to avoid dehydration.

Involvement of family members

In general, input from family members was welcomed particularly when the home was gathering background information about residents' eating likes and dislikes. However, one of the

13 Above, Voices (1998).

homes visited by investigators reported that the dining area is preserved as a private space where family members are generally not allowed. The reason is to ensure that residents' dignity and privacy is maintained. However, it should be possible to include family members during mealtimes while maintaining respect for the dignity of residents who are eating in the dining room. Therefore, if appropriate, family members might assist with meals in the resident's own room. During the call for evidence, more so than in the primary fieldwork, family members reported a sense of exclusion from this aspect of residents' care. One caller described how the home had a 'blanket policy' of asking relatives to leave at mealtimes. This approach of excluding relatives contributed to anxiety among some family members who were not confident that the resident was being helped to eat.

Interestingly, a number of other callers to the call for evidence reported that the attitude of some homes toward family members at mealtimes was one of over-reliance. Far from discouraging family members to visit during mealtimes, the home relied on them to help residents with eating. One caller reported that because of poor staffing levels in the home, relatives were regularly needed to help residents with food. This meant that the food for residents who did not have relatives was often cold by the time a member of staff was available to help.

It is difficult to understand how a home can monitor whether it is discharging its obligations if it routinely relies on family members to provide aspects of residents' care. There is also a risk of different standards whereby residents with family members experience different levels of care to those without. However, involvement is different to 'reliance' and should be encouraged if it is the resident's preference or, for residents who lack decision making capacity, if it is assessed to be in their best interests. Homes should consider ways to maintain dignity in dining areas while also facilitating family members to help residents to eat.

Spacing meals

There was a strong sense from participants in the primary fieldwork and in the call for evidence that decisions about the spacing of meals are geared toward the nursing home routine rather than residents' preferences. It was reported that meals are provided too closely together so that by dinnertime residents are not sufficiently hungry to eat their evening meal. From the primary fieldwork, it is apparent that meals are generally provided at the following times:

- breakfast between 9.00am and 10.00am
- lunch between 12.00 noon and 12.30pm, and
- dinner between 4.30pm and 5.00pm.

Snacks and cold or hot drinks are offered between meals.

Meals and snacks can therefore arrive in quick succession particularly if residents require help and may need 30 to 45 minutes to eat any given meal. As one family member explained:

"They get their breakfast in the morning and, by the time he has eaten it – he enjoys his breakfast – but by the time they get him up, get his breakfast and he gets sitting down for a wee while, the next thing then it is 12 o'clock, their dinner is put in front of them."

Unlike the nursing homes visited by investigators where generally residents could eat at a later stage if they refused their evening meal, a number of callers to the call for evidence reported that after the main evening meal there was no opportunity for the resident to have food. A caller reported that dinner was served at 4.30pm after which time there was no opportunity for the resident to eat until breakfast was served at 10.00am the next morning.

Concluding remarks

Human rights principles require that as well as the nutritional aspects of eating and drinking, dignity is central to the provision of food in nursing homes. The experience and enjoyment of eating is an integral aspect of nutrition and mealtimes. Therefore, if residents require help with eating or drinking, this should be provided in a dignified manner and in a way that enables enjoyment. It is also important that any assistance provided promotes rather than undermines independence, in accordance with Article 26 of the CRPD. In addition, accessibility of food, as part of the overall right to food, should require that older people are facilitated to make choices about their meals. While it is understandable that some form of routine is required, there should also be flexibility to consider residents' preferences about timing and frequency of meals. It is also important that food and water are available throughout the day and night.

6 Medication and health care

"I was so used to monitoring Mummy, to tell the doctor. I got used to doing that and then all of a sudden it was like, 'It's nothing to do with you now dear'." (Interview with resident's daughter)

Introduction

Residents are usually in nursing homes because they have complex medical needs. Their right to the highest possible standard of physical and mental health therefore requires particular attention in the nursing home context. However, it is equally important that residents' rights in all areas of life are not compromised in order to provide health care. Medication and health care must be seen as not just about prolonging life but also enhancing its quality. It is also important to note that health care does not always necessitate medication but might also involve restricting or altering a person's diet or mobility. Therefore, the provision of appropriate medical treatment is important for upholding residents' right to life and ensuring that residents' are able to participate effectively in the life of the home, including everyday activity and its social and cultural life.

To explore residents' right to health, the investigation focused on the provision of medication and health care in nursing homes. The extent to which residents have access to General Practitioners (GPs), other health care professionals and emergency hospital treatment is considered. The Commission also examined nursing home and GP records to assess how residents' medication and health care is reviewed. For this purpose, 25 residents or, where appropriate, their relatives gave consent for their records to be reviewed. As discussed in Chapter 1 of this report, two qualified clinical experts undertook the review.

Human rights law and standards

Article 12 of the *International Covenant on Economic, Social and Cultural Rights* (ICESCR) guarantees the right to the "highest attainable standard of physical and mental health". The right to health is also recognised in other international human rights instruments, such as the *Convention on the Rights of Persons with Disabilities* (CPRD, Article 25) and the UN *Convention for the Elimination of All Forms of Discrimination against Women* (CEDAW, Article 11).

In 2000, the UN Committee on Economic, Social and Cultural Rights provided an extensive commentary on the right to health under the ICESCR.[1] In it, the Committee stresses that health is a fundamental human right, indispensable for the exercise of other rights. The Committee is also clear that "Every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life of dignity".[2] The Committee's *General Comment No 14* outlines the various elements of the right to the highest attainable standard of health, as well as measures States Parties are obliged to take in order to achieve the realisation of this right. The right to health includes:

> [A] wide range of socio-economic factors that promote conditions in which people can lead a healthy life, and extends to the underlying determinants of health, such as food and nutrition, housing, access to safe and potable water and adequate sanitation […] and a healthy environment.[3]

According to the Committee, the right to health includes the right to control one's health and body as well as the right to be free from interference, for example, from non-consensual medical treatment. It also includes the right to health care that is timely and appropriate.[4] Specifically in relation to the realisation of the right to health for older people, the Committee emphasises the importance of an integrated approach, combining elements of preventative, curative and rehabilitative health treatment. Health interventions should be based on periodic check-ups and physical, as well as

1 UN Committee of Economic, Social and Cultural Rights (2000) *General Comment 14: The Right to the Highest Attainable Standard of Health*, 11 August 2000, UN Doc E/C 12/2000/4.

2 Above, para 1.

3 Above, para 4.

4 Above, para 11.

psychological measures, should be aimed at maintaining the functionality and autonomy of older people.[5]

For older people with long-term physical or mental impairment the CRPD contains obligations relevant to their health care. In particular, Article 25 requires States Parties to recognise the right to the highest attainable standard of health without discrimination on the basis of disability. This includes a requirement to prevent discriminatory denial of health care or food and fluids on the basis of disability (Article 25(f)). Article 25 is therefore particularly relevant to older people who are unable to access food and water without assistance from nursing home staff.

The right to health, understood as a social and economic right, is not explicitly included in the European Convention on Human Rights (ECHR). However, the development of the European Court of Human Rights' jurisprudence in relation to certain Convention rights, for example, the right to be free from inhuman and degrading treatment (Article 3), has clear implications for the right to health. For example, the Court has held that the provision of appropriate medical assistance is relevant to an assessment of the overall conditions of a person's detention under Article 3.[6] In addition, access to health care may arise as part of the right to life if it is shown that authorities put a person's life at risk through the denial of health care, which the State has undertaken to make available to the population generally.[7] Human rights standards may also be engaged where medical treatment is provided in the absence of appropriately informed consent. Providing treatment in such circumstances may amount to a violation of the right to physical and moral integrity as an aspect of the right to a private life (Article 8)[8] and may even contravene the prohibition on inhuman or degrading treatment.[9]

Finally, there are important 'soft law' standards relevant to the provision of health care for older people in nursing homes with mental ill health or mental impairment, including dementia. Therefore, Council of Europe Recommendation (2004) 10 concerning the protection of the human rights and dignity of people with mental disorder[10] and the UN *Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care* applies. Principle 9 requires, among other matters, that treatment and care is based on an individual plan that is discussed with the person concerned and regularly reviewed. In relation to medication, Principle 10 states that it:

> [S]hall meet the best health needs of the patient, shall be given to a patient only for therapeutic or diagnostic purposes and shall never be administered as a punishment or for the convenience of others.

As for the maintenance of records, Principle 10 requires that:

> [A]ll treatment shall be immediately recorded in the patient's medical records, with an indication of whether involuntary or voluntary.

Minimum standards and home policies

The provision of medication and health care in nursing homes is regulated by various policies and guidelines, including those from the Department of Health, Social Services and Public Safety (DHSSPS), the Nursing and Midwifery Council (NMC) and other professional regulatory bodies such as the British Medical Association (BMA). For the general management and provision of medicines in nursing homes in Northern Ireland, the *Nursing Homes Minimum Standards* (2008) also apply. Standards 37 to 40 relate to medicines and how these should be managed in the nursing home, including the recording, storage and administration

5 Above, para 25. For more detail see: Chapter 1.

6 *Kudla v Poland* (26 October 2000) 35 EHRR 198, para 94; *Melnik v Ukraine* (26 June 2006) Unreported, Application No 72286/01.

7 *Cyprus v Turkey* (10 May 2001) Application No 25781/94, para 219.

8 See: *MAK v RK v UK* (23 March 2010) Unreported, Application No 45901/05 (relating to the taking of intimate photos of a child by hospital staff without the parents' consent) para 79. See also: *Glass v UK* (9 March 2004) 39 EHRR 341 and *X and Y v Netherlands* (26 March 1985) 8 EHRR 235, para 70.

9 *Jalloh v Germany* (11 July 2006) 44 EHRR 667.

10 Recommendation (2004)10.

of medication. In addition, the standards require all nursing homes to have a policy on the management of medicines.

Each of the four homes visited by investigators provided a copy of the relevant medicines policy. As with other nursing home policies, the content of each varied considerably. Two of the homes provided detailed policies covering procedures for the administration and management of prescribed medication as well as 'home remedies'. One of these policies sets out overarching "goals" for drug and medication management, including that "each resident receives only those medications that are clinically necessary […] and supported by an appropriate diagnosis".

While it is crucial that nursing homes use appropriate and transparent systems for the management of medication, the *Nursing Homes Minimum Standards* should provide guidance for homes on the overall aims of medication, that is, to ensure the highest possible health and social wellbeing for residents. Perhaps due to this absence in the standards, only one nursing home policy reviewed by the Commission states the overall purpose for the use of drugs and medication in the home.

Access to health care

Contact with general practitioners

Staff in the nursing homes visited by investigators reported different experiences of contact with GPs. In two of the homes, nursing staff reported that they had "very good contact" with GPs and that generally GPs visit the home whenever requested. However, in the other two homes it was stated that at times GPs are reluctant to visit, as one interviewee explained:

"Some GPs – it is difficult to get them to come out and see a resident when they are not well. They would rather just send an ambulance and you are fighting with them because you don't need an ambulance."

During the call for evidence, a number of callers stated that GPs do visit residents when requested by nursing home staff. However, others reported that they never see residents face-to-face and, instead, contact nursing home staff by telephone. Perhaps of greater concern is that in a small number of cases, callers stated that nursing home staff contact the GP only if family members insist upon it. If nursing staff are medically trained to help then, in some cases, they may have determined it unnecessary to contact a GP. However, at least six callers stated that, on visiting, the GP diagnosed an illness that required further treatment. In three instances, it was reported that the resident required an antibiotic for a chest infection, and in two instances that the resident required hospital admission, in one case for pneumonia and the other because of a stroke.

The UN Committee on Economic Social and Cultural Rights has observed that health facilities and services should be within physical reach for all people but particularly those who are vulnerable including for older people.[11] Therefore, primary health care, including that provided by GPs should be available to residents in nursing homes without discrimination and in a manner that is timely and appropriate to their needs. The evidence from the Commission's primary fieldwork suggests that often GPs are accessible, although at times nursing staff reported it is difficult to ensure that GPs visit residents face-to-face. However, of greater concern is the evidence from the call for evidence that in a small number of cases nursing home staff failed to contact a GP when further medical help was required.

11 UN Committee on Economic, Social and Cultural Rights (2000) *General Comment No 14 on the Right to the Highest Attainable Standard of Health*, 11 August 2000, UN Doc E/C 12/2000/4.

Contact with other health care professionals

In the homes visited by the investigators, a number of relatives explained that despite their requests, other health care professionals had not visited residents. Difficulties were reported in accessing chiropodists, dieticians, opticians and dentists. Physiotherapy which may be a key part of a resident's rehabilitation was also reported as being difficult to access. One relative noted difficulties finding a dentist for her mother who required replacement dentures. As a result, her mother was on a soft diet for two months. Another relative explained that on discharge from hospital there was a delay in physiotherapy services for her mother. In her view, it was only because she "pushed it" that the service was provided in a timely manner.

Similar evidence was provided from a number of callers to the call for evidence. Most often, callers' concerns related to chiropody services. However, one caller reported that her mother had been losing weight due to problems with her teeth and had difficulty accessing a dentist. In addition, a resident who submitted written evidence to the call for evidence stated that despite his offers to pay for treatment, the home had not arranged for a dentist to visit his wife.

International human rights standards require an integrated approach to care for older people, which combines elements of preventative, curative and rehabilitative health treatment.[12] Residents should be able to access health care professionals other than GPs in all instances where this is required.

Going to hospital

Due to the fact that medically trained staff in nursing homes provide care, hospitalisation may not be required in the same way that it would if a person lived at home. Staff interviewed for the investigation explained that hospital admission is often distressing for residents, particularly if they have dementia. They felt it important to minimise admission where possible, as one interviewee explained:

"In the past, it has been if there is a problem, 'send her to hospital' […] [But] is it best to keep them in an environment where they are familiar, that we can provide a certain level of nursing and they are less at risk?"

However, it was reported to the call for evidence that on occasion staff failed to contact emergency services when, in the caller's view, immediate help was required.

In a small number of cases, evidence was provided that, on occasion, staff asked relatives to take residents to hospital, for example, by taxi, even when relatives expressed serious concerns about whether they could react appropriately should the situation deteriorate on the way to hospital. In certain circumstances, it may be acceptable for family to provide transport to hospital, particularly if this helps a resident to feel less anxious and it is what the family and resident prefer. However, it is not appropriate if immediate medical assistance is required or if the family is concerned about their ability to care for the resident on the way to hospital.

Finally, of further concern from the call for evidence were 15 reports that residents were admitted to hospital for dehydration. In eight of these cases, it was the caller's view that this was because the home failed to provide residents with enough to drink. As reported in Chapter 5, dehydration is a serious risk for residents who are unable to communicate that they need a drink. It is crucial that residents receive regular fluids. Lack of fluid can have consequences for residents' health and wellbeing and in serious cases may even impact on their right to life.

12 UN Committee on Economic, Social and Cultural Rights (1995) *General Comment No 6 on the Economic, Social and Cultural Rights of Older Persons*, 8 December 1995, HRI/GEN/1/Rev 9 (Vol I).

Review of nursing home and GP records

Review of medication and health care

Under current regulations it is required that GPs undertake yearly reviews of medication.[13] When providing care, doctors should prescribe drugs and treatment, including 'repeat prescriptions', only when they have adequate knowledge of a person's health and are satisfied that the drugs and treatment serve their needs.[14] Where a person has capacity to make decisions in relation to their health care, this knowledge should be gained from discussion with him or her, taking into account their medical history and views. Where a person lacks capacity, decisions regarding medication should be taken in their "best interests".

There was evidence of yearly medication reviews by a GP for 22 out of the 25 residents who gave consent for their GP records to be examined by the Commission. The quality of the reviews and the documentary evidence varied substantially. In ten instances, the review was undertaken in a face-to-face meeting with the resident. In nine cases, it would appear that it was undertaken by reviewing computer notes. In the remaining six cases, it would appear that the review occurred by telephone discussion with the nursing home. In one case, where the resident had late stage dementia, there was evidence of discussion with family members.

There was a distinct lack of evidence to show whether the mental health of residents with dementia had been reviewed by GPs. For residents with dementia, there was little evidence of a reassessment of mental capacity,[15] which would help determine if dementia medications are still advisable and therefore should continue to be used. For residents receiving anti-depressants, there was no evidence that their depression had been reassessed using recognised assessment methods.[16] Lack of reassessment for depression may lead to unnecessary use of medication.

Only four of the 25 nursing records examined contained written evidence of the reasons why a GP had either prescribed or changed medication. It was not recorded in any of the nursing records examined whether the GP had completed an individual's medication review. Any reviews by the GP were only apparent from changes made to the prescription chart when medication was either discontinued or commenced. In addition, it was unclear from the records whether there had been regular meetings between nursing home staff and GPs to discuss the overall welfare of residents, or whether this occurred only when a change in the resident's condition warranted such a discussion.

The lack of a uniform approach to the review of residents' medication is of concern. As recommended by the BMA, GPs should complete annual reviews of residents' medication. In addition, in order to ensure the highest possible standard of health, it is essential that GPs review residents' mental health and overall welfare. A review of mental health is particularly important for residents who have dementia. Where possible, reviews should be carried out in person with residents.

Physical and mental health assessments

All of the nursing home records examined showed evidence of physical health assessments. For example, they contained assessments of nutritional needs, instances of falls, moving and handling, and bowel and bladder control. Additionally, the care plans identified actions required to provide nursing care with appropriate regular reviews so that any changes required could be addressed. The daily evaluation record for each resident gave a brief summary of the care carried out and the physical health care given appeared adequate and relevant to the residents' assessed needs.

13 *Health and Personal Social Services (General Medical Services Contracts) Regulations (Northern Ireland)* 2004, section 6.

14 General Medical Council (2006) *Good Medical Practice*, GMC, London.

15 For example: the 'Mental Status Questionnaire'.

16 For example: the 'Patient Health Questionnaire PHQ-9'.

However, two of the nursing homes were caring for residents with an Elderly Mentally Infirm (EMI) illness and it was of concern that assessment of mental health or evidence of care plans to address identified mental health needs appeared insufficient. For example, one of the nursing homes had a comprehensive assessment system across the physical and mental health activities, that is, 'sleep', 'communication', 'orientation', 'anxiety' and 'consent and capacity', with a further section for an assessment of the resident's 'ability level'. The aim of this assessment process is to identify the resident's potential health risks, indicate their mental health and wellbeing score and give clear indicators for an appropriate care plan. The records analysed for this investigation show evidence of the relevant 'ability score' having been recorded but there was no information on whether any of the assessments had been carried out. There was also a lack of information documenting changes or reviews. Only three records of the nine reviewed in this particular home contained any details in the section that assessed 'consent and capacity'.

It is of serious concern if there is a lack or inadequacy of mental health assessments, particularly for residents with dementia. The progressive nature of dementia means that the support required will differ over time both in terms of mental wellbeing and the physical adjustments that may be required in relation to, for example, walking or eating. Assessment of mental health is also linked to the prescribing of medication and a lack or inadequacy of assessments may lead potentially to overuse of medication, including sedation. It is therefore important that regular assessments are conducted by a qualified medical practitioner and that these are appropriately recorded in nursing home records. This should be translated to care plans to ensure the provision of appropriate daily care.

Responding to falls

It was apparent from the analysis of the nursing home records that one home referred residents who had fallen to the local Accident and Emergency department for examination, to ensure that the fall had not resulted in a fracture. The other three homes contacted the GP or 'out of hours' service after a resident had experienced a fall. However, there did not appear to be reports of any discussion between the nursing staff and the GP after repeated falls by residents. This would have given an opportunity to discuss, within a multi-disciplinary team, the potential reasons for falling and any possible changes in care or treatment that might be considered. There was little or no evidence within the written records that the GP or nursing home considered whether medication, particularly sedatives, may have been a contributory factor in such falls. Likewise, in the records of residents with dementia, there was no mention of any review or consideration of behaviour patterns following a fall.

Again, as with mental health assessment, it is of concern if nursing staff and GPs do not take the opportunity to review the reasons for falls and the potential impact of medication such as sedatives. In all instances, where a review takes place it should be recorded. While the physical consequences of a fall appear to have been addressed in an appropriate manner, a review of the reasons for a fall can result in adjustment of, for example, preventative measures or medication. It is important that the changing needs of residents, including changes in their physical condition, are carefully reviewed following any incidents of this nature. In this way, nursing homes can ensure that residents receive the most appropriate care and, where necessary, access to preventative and rehabilitative help.

Record keeping

Professional guidelines for nursing staff require that nurses must:

> [M]ake a clear, accurate and immediate record of all medicines administered, intentionally withheld or refused by the patient, ensuring that any written entries and the signature are clear and eligible.[17]

In relation to care records, nursing staff are required to exercise their best judgment as to what is necessary and relevant to record.[18]

All nursing home records analysed for this investigation included prescription charts where the GP would mark each medication to be given to the resident. A separate daily medication record was used to record the prescribed medication, its dosage, frequency and daily administration. In some of the records, the prescription charts were several years old and contained numerous discontinued drugs. This appeared confusing and it was not apparent why the chart was not rewritten each year to ensure that it was easier to read. All records contained a 'daily evaluation record', which includes information about the care provided to residents each day. However, there was no detailed information within the 'daily evaluation records' explaining the reasons for changes to medication. This would only be indicated on the prescription chart by the written changes to medication made by the GP.

In one of the homes the medication record was not the universally used record. Instead of using the full name, each medication was coded on the prescription chart with an alphabetical letter to indicate the drug administered, for example, 'A=Diazepam'. Potentially, this can introduce high risk for error because, for each drug to be administered, staff are required to cross-reference with the prescription chart. As this is not the universally accepted practice, any new bank or agency nursing staff might be unclear about how to use this coded system and may require considerable time to become familiar with it.

Each nursing home used a contact record, which indicated the date and time a contact was made with a GP, other health service (for example, optician, dietician, and chiropodist) or relatives. However, the contact record did not include details of the outcome or context of the contact. Neither was this information recorded within the 'daily evaluation record'. It is possible that this detail is provided verbally to other nurses when a shift 'handover' is taking place. Nevertheless, it is good practice to record adequate detail so that staff involved with the care of residents are kept well informed.

In addition, keeping accurate and clear records of the medicine and care provided to residents in nursing homes is important to ensure that staff are accountable. It also helps professional staff, residents and their families to assess whether the care provided corresponds to that which an individual is entitled to.

Involvement of family members

It was difficult to determine from the nursing home records examined the extent to which relatives were involved and informed about the ongoing care of the resident. Although there was a record showing entries of contact with relatives, there was no detail on the context or outcome of this communication. Only two of the 25 residents' records included written evidence that relatives were informed of the reasons for medication prescribed to the resident. Two of the nursing homes provided care for less dependent residents, and relatives would probably not have been informed as the resident was capable of understanding their medication. In the case of homes providing care to people with dementia, a lack of involvement of family members is a concern.

While a number of relatives who participated in

17 Nursing and Midwifery Council (2008) *Standards for Medicines Management*, p7, (available: http://www.nmc-k.org/Documents/Standards/nmcStandardsForMedicinesManagementBooklet.pdf).

18 Nursing and Midwifery Council (2009) *Record Keeping: Guidance for Nurses and Midwives*, pp3-4 (available: http://www.nmcuk.org/Documents/Guidance/nmcGidanceRecordKeepingGuidanceforNursesandMidwives.pdf). GuidanceRecordKeepingGuidanceforNursesandMidwives.pdf).

interviews with investigators stated that they are informed about their relative's medication, two felt that they had been excluded from this aspect of the care. It can be difficult for family members if they are not informed, especially if they were previously involved with their relative's health care. As one relative explained, "Well, I used to know everything Mummy was on when she came in here and then, that is one thing, you don't get much feedback".

Where the resident lacks decision-making capacity, nursing homes should maintain communication with relatives regarding the resident's health care to the extent that this is in their best interests. If the resident does have decision-making capacity, communication with relatives regarding health care should be decided by the resident.

Concluding remarks

The right to the highest attainable standard of health is essential for the enjoyment of other human rights and is central to the lives of older people living in nursing homes.[19] The fulfilment of the right to health requires not only medical care to sustain life but also other measures to promote residents' physical and mental wellbeing and provide opportunities to enjoy the highest possible quality of life. In addition, older people, regardless of where they live, have the right to health care that is accessible and of a quality equal to that available to the general population.

This chapter has revealed the importance of access to appropriate and timely health care, including contact with GPs and referrals to emergency hospital services. In addition, contact with other health care services such as physiotherapy and dentistry is an essential part of ensuring an integrated approach to the health care of older people.

Based on a review of the nursing home and GP records of 25 residents, the findings also show a lack of uniform approach by GPs to the review of residents' medication and insufficient evidence within the records to show that mental health needs are regularly reassessed. The findings emphasise the importance of keeping accurate and clear records of the medicine and care provided to residents in nursing homes.

19 See: UN Committee on Economic, Social and Cultural Rights (2000) *General Comment No 14 on the Right to the Highest Attainable Standard of Health*, 11 August 2000, E/C 12/2000/4, para 1, "Health is a fundamental human rights indispensible for the enjoyment of other human rights".

7

Restraint

"There is nothing worse than somebody who wants to get up and do something for somebody to try and make them not do it [...]. You're trying to make someone do something they don't want to do." (Interview with nursing home staff)

Introduction

The use of restraint can interfere substantially with residents' human rights, particularly their right to be free from inhuman and degrading treatment,[1] and possibly the right to liberty.[2] At times, different forms of restraint are required in nursing homes, the main purpose of which is to ensure the safety of a resident or others. However, it is important to note that as part of the right to private life in Article 8 of the European Convention on Human Rights (ECHR), individuals are entitled to take decisions as to personal risk.[3] Whether or not a person has capacity to understand the dangers posed to themselves or to others by their own actions, restricting movement through the use of restraining techniques is unlikely to be in keeping with human rights standards, unless it is a matter of "therapeutic necessity".[4]

This investigation examined how restraint is used and understood in nursing homes. In particular, the Commission considered the extent to which different activities that take place in nursing homes are recognised as restraint, including chemical restraint, that is, the administration of sedating medication, and other direct and indirect forms of restraint. As part of this, the nursing home and GP records of 25 residents were examined to assess the use and review of sedation and dementia and anti-psychotic medication. Two qualified clinical experts undertook this assessment (as discussed in more detail in Chapter 1).

Human rights law and standards

International human rights bodies have assessed methods of restraint in institutional environments, such as psychiatric hospitals and social care establishments, against State Parties' obligations to ensure that no one is subjected to cruel, inhuman or degrading treatment (Article 9 of *International Covenant on Civil and Political Rights* (ICCPR); Article 16 of the *Convention against Torture* (CAT)). Therefore, for example, in its examinations of States Parties, the Human Rights Committee and the Committee against Torture have been clear that the persistent use of enclosed restraint beds, that is, net and cage beds is considered inhuman and degrading.[5] In considering whether other methods of physical restraint are inhuman and degrading, they have examined the extent to which restraint is regulated by law,[6] regularly reviewed,[7] governed by appropriate guidelines[8] and appropriately recorded.[9] Referring specifically to children and young people, the Committee on the Rights of the Child has also established that restraints should be used only as a last resort, exclusively to prevent harm, and never for disciplinary purposes.[10]

Traditionally, physical integrity has been considered integral to the right to be free from cruel, inhuman or degrading treatment. Therefore, for instance, the Human Rights Committee has examined the use of restraint methods against the State's

1 For example: *Henaf v France* (27 November 2003) 40 EHRR 990 (shackling to a bed amounted to degrading treatment); *Mouisel v France* (14 November 2002) 38 EHRR 735 (handcuffing of ill prisoner in hospital amounted to degrading treatment).

2 See: Article 9 ICCPR and Article 5 ECHR. For relevant case law see: *Storck v Germany* (16 June 2005) 43 EHRR 96; *Novotka v Slovakia* (4 November 2003) Unreported, Application No 47244/99.

3 *X v Belgium* (6 February 1968) 18 DR 225.

4 *Herczegfalfy v Austria* (24 September 1992) 15 EHRR 437.

5 UN Human Rights Committee (2009) *Concluding Observations: Croatia*, 4 November 2009, CCPR/C/HRV/CO/2, para 12; UN Human Rights Committee (2007) *Czech Republic: Concluding Observations*, 9 August 2007, CCPR/C/CZE/CO/2, para 13; UN Committee against Torture (2010) *Concluding Observations: Austria*, 20 May 2010, CAT/C/AUT/CO/4-5, para 25.

6 For example: UN Human Rights Committee (2007) *Concluding Observations: Czech Republic*, 9 August 2007, CCPR/C/HRV/CO/2, para 5.

7 Above, para 5.

8 For example: UN Committee against Torture (2008) *Concluding Observations: Latvia*, 19 February 2008, CAT/C/LVA/CO/2, para 15.

9 For example: UN Committee against Torture (2001) *Concluding Observations: Australia*, 21 November 2000, A/56/44, para 53(d).

10 UN Committee on the Rights of the Child (2008) *Concluding Observations: United Kingdom of Great Britain and Northern Ireland*, 20 October 2008, CRC/C/GBR/CO/4, para 39.

responsibility to protect the individual's physical integrity under Article 7 of the ICCPR.[11]

More recently, however, Article 17 of the *Convention on the Rights of Persons with Disabilities* (CRPD) has provided explicitly for the right of people with disabilities to respect for their physical and mental integrity. Early indications suggest that the use of methods of restraint by States Parties will be examined under this provision. Therefore, the Committee has requested information about the legal and regularity framework concerning the use of restraining equipment under Article 17 of the CRPD.[12] Potentially, therefore, the jurisprudence of the Committee will provide further details on the level of regulation required where particular methods of restraint are used.

The European Court of Human Rights has considered methods of restraint mostly in relation to people deprived of their liberty. It has found that the use of measures restricting physical movement, such as shackling to a bed,[13] or the use of handcuffs on a prisoner who required hospital treatment,[14] may violate the prohibition on inhuman and degrading treatment under Article 3 of the ECHR. However, the court has consistently held that a measure, which is of therapeutic necessity from the point of view of the ordinary principles of medicine, cannot in principle be regarded as inhuman and degrading.[15] Nevertheless, the medical necessity must be convincingly demonstrated, which requires adherence to appropriate procedural safeguards.[16] In relation to procedural safeguards, the European Committee for the Prevention of Torture (CPT) provides specific direction. While the CPT's country reports refer to restraint in various care settings, including nursing homes, it is important to note that the most recent CPT standards address the use of restraint in psychiatric establishments.[17] Nevertheless, the standards contain comprehensive guidance based on a clear human rights framework and, therefore, in the Commission's view, should inform the use of restraint in the context of health and social care in Northern Ireland.

The CPT's standards set out the following requirements:[18]

- that restraint is subject to a clearly defined policy
- initial attempts of restraint should as far as possible be non-physical
- physical restraint should in principle be limited to manual control
- staff should receive training on the use of non-physical and manual restraint, and
- all instances of physical restraint should be recorded in a specific register and in the person's file.

In addition, the CPT is clear that the use of physical restraint as a punishment or for a period of days is likely to constitute ill treatment.[19] The CPT also requires that the use of "chemical restraint", that is, sedating medication, should be governed by clear rules and subject to the same oversight as regards any other means of restraint.[20]

11 UN Human Rights Committee (2001) *Concluding Observations: Switzerland*, 12 November 2001, CCPR/CO/73/CH, para 13.

12 UN Committee on the Rights of Persons with Disabilities (2010) *List of Issues: Tunisia*, 10 November 2010, CRPD/C/TUN/Q/1, para 17.

13 *Henaf v France* (27 November 2003) 40 EHRR 990.

14 *Mouisel v France* (14 November 2002) 38 EHRR 735.

15 *Herczegfalfy v Austria* (24 September 1992) 15 EHRR 437; Jalloh v Germany (11 July 2006) 44 EHRR 667.

16 *Nevmerzhitsky v Ukraine* (5 April 2005) Application No 54825/00.

17 European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) (2002) *CPT Standards*, Council of Europe, Strasbourg [Revised 2010] (available: http://www.cpt.coe.int/en/documents/eng-standards.pdf). See also: European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, (CPT) (2005) *Standards of the CPT on the Use of Restraints*, Strasbourg: Council of Europe, a working document which refers to the use of restraints in hospital, nursing home or social welfare institutions (available: http://www.cpt.coe.int/en/working-documents/cpt-2005-24-eng.pdf).

18 Above.

19 Above, para 48.

20 European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) (2011) *Report to the Government of Ireland*, CPT/Inf (2011)3, para 132.

The use of physical, chemical or environmental restraints may, in principle, give rise to concerns regarding the right to liberty and security of the person enshrined in Article 5 of the ECHR. The European Court of Human Rights has defined a deprivation of liberty as the "confinement in a particular restricted space for a not negligible length of time" combined with the absence of valid consent of the individual in question.[21] For rights under Article 5 to be engaged it is not necessary for an individual to be held under locked conditions. Preventing their movement for a period of time[22] or significantly restricting their daily activities without their valid consent[23] could equally engage an individual's right to liberty. However, in practice, methods of restraint will more often constitute a restriction rather than a deprivation of liberty and therefore fall to be considered under the right to be free from inhuman and degrading treatment, or the right to physical and moral integrity as part of the right to private life under Article 8 the ECHR.

In extreme circumstances, the use of restraints may lead to injury and death, engaging the right to life under Article 2 of the ECHR and Article 6 of the ICCPR. The Human Rights Committee has at times examined the use of restraints under Article 6.[24] Research related to the use of physical restraint finds that the use of mechanical devices may lead to sudden death, for example, by asphyxiation.[25] Deaths have been reported in connection with, for example, the use of wheelchair straps in nursing homes.[26] Incidents of death relating to the use of restraints are not, however, limited to the use of physical devices. Describing the consequences of prescribing chemical restraints, Hughes and Lapane argue that older people are "more sensitive to drugs which act on the central nervous system, with chemical restraints exemplifying such agents […]".[27] They go on to state:

> Effects such as sedation and confusion may increase the risk of falls and, in frail nursing home residents, injuries sustained through falls can lead to further complications and death […].[28]

It is therefore clear that inappropriate use of sedating medication also has the potential to violate the individual's right to life.

A number of soft law standards are relevant to the use of restraint in health care settings.[29] Article 27 of Council of Europe Recommendation (2004)10 requires that restraint should only be used in compliance with the principle of least restriction, to prevent imminent harm to the person concerned or others, and in proportion to the risks entailed. Measures of restraint should only be used under medical supervision and appropriately documented. In addition, the reasons for and duration of restraint should be recorded in the person's records. All instances of physical restraint should also be recorded in a register so that the use of restraint can be appropriately monitored.[30] The Explanatory Memorandum notes that there may be higher levels of risk for older people where restraint is used and therefore additional safeguards may be advisable.[31]

21 *Storck v Germany* (16 June 2005) 43 EHRR 96, para 74.

22 *Novotka v Slovakia* (4 November 2003) Unreported, Application No 47244/99.

23 *Ashingdane v UK* (28 May 1985) 40 EHRR 761.

24 UN Human Rights Committee (2001) *Concluding Observations: Switzerland*, 12 November 2001, CCPR/CO/73/CH, para 13.

25 Evans D, Wood J and Lambert L (2003) 'Patient injury and physical restraint devices: a systemic review' in 41(3) *Journal of Advanced Nursing*, 274-282.

26 See for example: http://www.birminghampost.net/news/west-midlands-news/2011/01/19/bupa-fined-over-edgbaston-care-home-death-97319-28015303/.

27 Hughes CM and Lapane KL (2010) 'Covert medication and chemical restraint' in Hughes R (ed) (2010) *Rights, Risks and Restraint-free Care of Older People*, Jessica Kingsley Publishers, London/Philadelphia, p46.

28 Above.

29 See in particular: Articles 8, 11 and 27 of Council of Europe Recommendation R(2004)10; and Principles 9 and 11 of the UN *Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care*.

30 Above, Article 27(3) (ii) and para 203 of the Explanatory Memorandum.

31 Above, para 194 of the Explanatory Memorandum.

Article 27 of the Recommendation does not apply to instances of "momentary restraint". This is an important distinction; momentary restraint is intended to cover "only very brief physical holding of a person, for example, by placing a hand on the person's arm".[32] However, the Explanatory Memorandum is clear that the use of momentary restraint on a regular basis requires careful monitoring:

> If momentary restraint were necessary on a regular basis it would be good practice for the need for such restraint to be recorded and to be subject to medical supervision in the context of the patient's treatment plan. (para. 193)

> […] it is good practice for the doctor to be aware of the frequency with which momentary restraint is being used in order to review its appropriateness and consider whether any less restrictive intervention might be used as an alternative. (para. 198)

As explained below, there may be subtle ways in which the movement of nursing home residents is controlled, for instance, by verbal communication or gesturing. It is important that nursing homes are sensitive to this so that behaviours or actions not traditionally considered as restraint are nevertheless recognised for their potential to constitute momentary restraint, which should prompt further monitoring if used frequently or as a matter of routine.

Minimum standards and nursing home policies

There is no statutory definition of "restraint" in Northern Ireland.[33] However, various policies and regulations address the question of when restraint may or may not be used. For example, the *Nursing Homes Regulations (Northern Ireland)* (2005) (the 2005 Regulations) require that restraint is not used unless it is "the only practicable means of securing the welfare of that or any other patient and there are exceptional circumstances".[34] In addition, while the *Nursing Homes Minimum Standards* (2008) do not include a standalone standard on restraint, it is referred to in Standard 10 on "responding to patients' behaviour" and Standard 23 "meeting patients' safety needs".

Criterion 10.7 states that restraint should only ever be used:

> […] as a last resort by appropriately trained staff to protect the patient or other persons when other less restrictive strategies have been unsuccessful.

The way in which Standard 10 is phrased suggests that this criterion applies to the use of restraint to manage aggressive or "challenging" behaviour. In contrast, Standard 23 refers to the use of restraint in the context of ensuring residents' safety. Criterion 23.3 states that restraint is only used following a multi-disciplinary team decision, in accordance with good practice guidelines, is time limited and regularly reviewed. While it would appear that Standard 10 and Standard 23 are designed for different reasons, it is not clear why the criteria on the use of restraint in each instance differ. In addition, the absence from each of any reference to international human rights standards is of serious concern.

The review of policies supplied by the four homes examined by investigators reveals a considerable amount of variation in the content and detail of nursing policies on restraint. For example, one home's policy on the use of restraint states that physical restraint should be used only as a last resort where alternative options have failed. The policy refers to "acceptable" and "unacceptable" forms of restraint, including inappropriate use of

32 Above, para 192 of the Explanatory Memorandum.

33 This is in contrast to England and Wales where Section 6(4) of the *Mental Capacity Act 2005* states that restraint occurs if a person uses force or the threat of force to make another individual do something that they are resisting or if they restrict a person's liberty whether or not they resist.

34 Regulation 14 (5), *Nursing Homes Regulations (NI) 2005*.

wheelchair straps as an example of the latter. In contrast, in another home, the 'Procedure for introducing restraint' refers to three forms of restraint, the use of bedrails, tab monitors, and straps on chairs, and is supplemented by a more general policy on the meaning of restraint. Other related policies supplied by each home also refer to restraint, including policies on the protection of vulnerable adults and managing challenging behaviour.

The analysis of nursing home policies, the *Nursing Homes Minimum Standards* and the 2005 regulations reveals that, on a policy level at least, there is no uniform approach to restraint in nursing homes in Northern Ireland. It is important that formal guidance be put in place, drawing consistently on international human rights standards to set out what constitutes restraint, the circumstances where measures of restraint may lawfully be used, and appropriate and acceptable alternatives to the use of physical measures of restraint.[35]

Recognising restraint

To ensure that restraint is used as a last resort and in a proportionate manner, nursing home staff should recognise how their actions can restrict residents' movement. A number of recent studies have identified different types of restraint in health and social care settings.[36] From these and from its primary fieldwork and call for evidence, the Commission finds that the different types of restraint used in nursing homes may be summarised as follows:

- **chemical:** medication, such as sedation, that impacts a person's ability to move freely
- **electronic:** 'wandering' technology such as 'tag' monitors or alarm mats
- **environmental:** locked doors; restricted space; crowded rooms
- **mechanical:** straps on a wheelchair or other chair; bedrails; reclining chairs, and
- **physical:** laying hands on another person; using a table or chair to discourage or prevent movement.

As well as these more obvious or concrete forms of restraint, there may be more subtle ways in which residents' movement is controlled. Therefore, for instance, verbal or non-verbal cues may be used to tell or gesture to a person that they should sit down. Likewise, movement can be restricted in ways that are indirect by, for example, not providing a walking aid such as a Zimmer frame.

There has been no case specific guidance from the European Court of Human Rights or jurisprudence from the international human rights bodies relating to these types of non-physical and indirect actions. The CPT does state that where restraint is necessary, oral persuasion is preferred wherever possible as the least restrictive method.[37] However, drawing on the body of jurisprudence that does exist in relation to physical restraint, it is clear that the purpose, duration, frequency and practical effect of any verbal or indirect methods must always be borne in mind. Therefore, for example, ordering a person continually to sit down, or refusing to provide a walking aid for reasons that are not medically necessary, is likely to have serious implications for a person's physical and moral integrity under the right to private life or their right to be free from inhuman and degrading treatment. Indeed, in the case of *Price v UK*,

35 The Commission is aware that there exists guidance on the use of restraint and seclusion, which is applicable in various health and social care settings. However, it is not specific to nursing homes and the DHSSPS website notes that "it does not constitute formal guidance issued by the Department" (see: Department of Health Social Services and Public Safety (2005) *Guidance on Restraint and Seclusion in Health and Personal Social Services*, DHSSPS, Belfast (available: http://www.dhsspsni.gov.uk/eq-humanrights).

36 Mental Welfare Commission for Scotland (2006) *Rights, risks and limits to freedom: Principles and good practice guidance for practitioners considering restraint in residential care settings*, June 2006, Mental Welfare Commission for Scotland, Edinburgh; Qureshi H (2009) *Restraint in Care Homes for Older People: A Review of Selected Literature*, Social Care Institute for Excellence, London; Hughes R (ed) (2010) *Rights, Risk and Restraint-Free Care of Older People*, Jessica Kingsley Publishers, London.

37 European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) (2006) *16th General Report of the CPT's Activities*, para 39 (available: http://www.cpt.coe.int/en/annual/rep-16.pdf).

involving the detention in custody of a woman with disabilities, Judge Greve in her separate opinion considered that it was a violation of the applicant's right to physical integrity under Article 3 of the ECHR to prevent her from bringing with her the battery charger for her wheelchair.[38]

During the Commission's call for evidence, several callers reported that tables had been used to "barricade" residents or that measures such as reclining chairs were used beyond the time assessed necessary. Callers described residents being told repeatedly to "sit down" or being "shooed" back into their room. In these instances, based on the callers' views, it would appear that restraint was intended.

However, the findings from the primary fieldwork show that rather than any negative intent, nursing home staff had different understandings about what constitutes restraint. In a few instances, staff expressed a broad understanding of the various ways in which residents' liberty might be restricted, as one interviewee explained:

"[…] We were talking yesterday about forms of restraint and one of the girls said to me, 'use of tables', and I said, 'yes absolutely, use of tables' […]. It is only a table but it could be deemed as trying to encourage somebody not to get up, and if they can't move that table themselves, then it is a restraint [or], like, if you had someone in a wheelchair that could also use their Zimmer, but you don't bring their Zimmer with them. You're restraining them because they can't go anywhere without that Zimmer frame."

At other times when asked directly about its use, staff replied that they do not use restraint even though bedrails and other equipment such as 'wandering' technology were available in the home. In a number of instances, measures taken with the intention of benefiting a resident were not recognised as a form of restraint. For example, one interviewee referred to placing a table in front of a resident because he was at risk of falling; another referred to using a wheelchair and safety belt for residents if staff are not available to observe in the lounge.

As explained at the beginning of this chapter, there is no statutory definition of restraint in Northern Ireland and little guidance within the *Nursing Homes Minimum Standards* explaining restraint. Unfortunately, the findings of the investigation reveal that this difficulty translates into practice. Therefore, at times, staff are often uncertain about when a measure or action constitutes restraint. Recognising restraint is extremely important if nursing home staff are to make informed decisions about its use. It is important that staff receive adequate guidance, based on international human rights standards, including examples of how their own actions can impact on residents' movement.

Human rights and restraint: Achieving balance

A number of relatives who took part in the Commission's call for evidence reported that when they requested bedrails for a resident they were informed that this was "against their human rights". However, as outlined in the beginning of this chapter, human rights standards do not prevent all forms of restraint in all circumstances. Certain forms of restraint may be lawful if subject to appropriate procedural safeguards. Therefore, for example, bedrails may be advisable if they are assessed as therapeutically necessary, and constitute the least restrictive measure to prevent a person from falling. Bedrails are not recommended, however, if a resident is likely to climb over the rail and fall from a greater height. Similarly, using the safety belt on a wheelchair to ensure the safety of a resident while being transported is likely to be lawful. However, strapping a person into a wheelchair beyond the time necessary for transport, for example, while the resident is sitting in the lounge or eating dinner is not acceptable.

38 *Price v UK* (10 July 2001) Application No 33394/96. The applicant, who had been detained in a police cell and subsequently prison, had disabilities due to thalidomide.

In all instances where restraint is planned or more than momentary, an assessment is required to determine if it is therapeutically necessary.[39] All instances of mechanical, electronic or chemical restraint should be assessed by a medically qualified doctor.[40] In making an appropriate assessment, the following should always be considered:

- Is restraint proposed in pursuance of a legitimate aim? Is the main purpose to prevent imminent harm to the resident or to others? It is not permissible to use restraint for the convenience of staff, or for punishment or coercion.
- Is the method of restraint the least restrictive method available and a last resort, that is, have all other less restrictive approaches been considered?
- Will it be used for the shortest possible period and subject to regular review?
- Has the resident consented to this form of restraint? If the resident does not have capacity to make this decision, the nursing home should consult with his or her relatives or carers.

A number of callers to the call for evidence suspected that restraint was used in the absence of an assessment and more for the home's convenience rather than for the safety of residents. In contrast, interviews with nursing home staff during the Commission's primary fieldwork suggested that staff understood the importance of completing an assessment for all planned instances of restraint. As one interviewee explained:

"You involve the GP and you involve the family and you get occupational health; they have to come out and do an assessment […]."

However, difficulties tended to arise in relation to less obvious forms of restraint, for example, where a table is used to discourage movement. The interviewee who referred to using a table explained the difficult dilemma between respecting residents' liberty and ensuring safety:

"What do you do? Do you just walk away? Do your duties up and down the corridor? You don't watch him anymore and you know he is restless and leave him in the chair and the next thing he is up walking about and he is on the floor. You don't want to have another break, you know, it is difficult."

Nevertheless, staff should understand that in a circumstance such as this any form of restriction on the resident's liberty requires an appropriate assessment, as set out above. In this respect, it is important to note that Article 11 of Council of Europe Recommendation (2004)10 requires that staff involved in mental health services receive appropriate training on measures to avoid the use of restraint and the limited circumstances in which different methods of restraint may be justified. The Explanatory Memorandum states that this training should also include the benefits and risks of different methods of restraint.[41] The evidence for this investigation suggests that, at present, training for staff in this respect is insufficient.

Chemical restraint

The European Committee for the Prevention of Torture (CPT) has recognised the need for specific standards in respect of the use of restraint in care settings.[42] In particular, the CPT recommends that the use of chemical restraint, that is, sedating medication, should be governed by clear rules and subject to the same oversight as any other means of restraint.[43] Investigating the state of human rights of older people in health care in 2006,

39 *Herczegfalfy v Austria* (24 September 1992) 15 EHRR 437.

40 Above, CPT Standards (2002) [Revised 2010].

41 Above, para 87 of the Explanatory Memorandum.

42 See: European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) (2005) *Standards of the CPT on the Use of Restraints*, Council of Europe, Strasbourg, working document (available: http://www.cpt.coe.int/en/working-documents/cpt-2005-24-eng.pdf).

43 European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) (2011) *Report to the Government of Ireland*, CPT/Inf (2011)3, para 132.

the Parliamentary Joint Committee on Human Rights (JCHR) noted that a number of witnesses expressed concern about the use of medication as a means of control.[44] In addition, a report by the All-Party Parliamentary Group on Dementia notes that antipsychotic drugs have limited benefits for people with dementia and there are serious side effects of, in particular, long-term prescribing of such drugs.[45] In this context, the Commission contracted two medical experts to review a sample of GP and nursing home records from the four homes visited during the investigation (see Chapter 1 for details).

Overall, the medical experts considered that GP records gave a clear account of the prescriptions given and the rationale for starting treatment. In the case of residents with a formal diagnosis of dementia, this usually followed the recommendation from a consultant psycho geriatrician and, where the GP initiated a new medication, this was generally well documented in the GP notes. However, a number of concerns were indentified and these findings are presented below.

The use of sedation

Out of 25 residents, 22 were receiving a drug either explicitly for sedation or at high risk of causing sedation, including night sedation, antidepressants, anti-psychotic drugs and dementia medication. All drugs were prescribed at appropriate doses and time intervals with limited use of 'PRN'.[46]

However, in some instances night sedation was used regularly without evidence that there had been a review of the appropriateness of continuing this medication. Thirteen out of the 25 residents were prescribed a form of night sedation; eight were prescribed Temazepam and four, Zopiclone. In the case of one resident, Temazepam was prescribed due to depression following bereavement. An antidepressant was started at the same time and the medical records stated "[…] short term use of Temazepam until A/Dep kicks in". However, the resident was still receiving Temazepam (and the antidepressant) 18 months later. There was no indication in the GP records that the need for Temazepam had ever been reviewed. Moreover, for those residents on long-term prescription of Temazepam or Zopiclone there was a lack of evidence within the records that this had been reviewed.

The long-term use of drugs such as Temazepam and Zopiclone is of serious concern as they are recommended only for the short-term in cases of severe insomnia. In addition, both of these drugs may not be advisable if a person has depression, although the NHS information indicates that they still may be prescribed "with care".[47] Past research finds that drugs such as Temazepam have been prescribed in the absence of a clear clinical indication as to why, and that there is a significantly higher proportion of prescribing this in nursing homes compared to prescribing patterns in the community generally.[48]

It is important to note that in one home where a small number of residents are on long-term sedatives, it was explained that it would be more detrimental to end the prescription. As one interviewee stated:

44 House of Lords, House of Commons Joint Committee on Human Rights (JCHR) (2007) *The Human Rights of Older People in Healthcare: Eighteenth Report of Session 2006-2007, Vol I*, TSO Ltd, London, p14.

45 All-Party Parliamentary Group on Dementia (APPG) (2008) *Always a Last Resort: Inquiry into the prescription of anti-psychotic drugs to people with dementia living in care homes*, Alzheimer's Society, London, p1. The inquiry considered evidence from England and Wales.

46 'PRN' refers to the prescribing of drugs to be used "as and when needed"; it should be used in limited circumstances because it places more responsibility on nursing staff for administration of medication.

47 NHS Choice, available: http://www.nhs.uk/medicine-guides/pages/MedicineOverview. aspx?condition=Insomnia&medicine=Zopiclone&preparationZopicl one%203.75mg%20tablets (regarding Zopiclone) and at: http://www.nhs.uk/medicine-guides/pages/MedicineOverview.aspx? condition=Insomnia&medicine= temazepam&preparation=Temazepam%2010mg%20tablets (regarding Temazepam).

48 Hughes CM and Lapane KL (2010) 'Covert medication and chemical restraint' in Hughes R (ed) (2010) *Rights, Risks and Restraint-free Care of Older People*, Jessica Kingsley Publishers, London/Philadelphia.

"I have got four people on Temazepam […] from they were 30 something [years of age], and you get to a stage in your life if you are 70 something and you have constantly used that, it is actually more detrimental to take that away."

Another home had introduced a new project several months prior to the Commission's investigation, with the aim of monitoring residents' medication and reducing the use of sedatives and psychotropic medication.

The Commission is concerned that regular or long-term use of sedation without appropriate review may lead to residents being over-sedated or sedated for an extended period of time. This impacts on a person's liberty and may affect their ability to participate fully in everyday life. The prescribing of sedating drugs, including those with a high risk of a sedating effect, should be limited to that which is proportionate and their use should be regularly reviewed. In addition, the reasons for, and reviews of, the use of sedation should be clearly documented.

Dementia and anti-psychotic medication

It was apparent from the records that five out of the 25 residents who gave consent for their records to be reviewed had commenced dementia medication, such as Donepizil, Galantamine or Memantine. A consultant psycho geriatrician initially prescribed these drugs, with responsibility for further treatment and review passed to each resident's GP. All of these drugs are usually first prescribed when a person is diagnosed with 'mild to moderate' dementia. However, once dementia is 'moderate to severe', the continued use of the first two drugs is not recommended.[49] Memantine is licensed for moderate-severe dementia and should be regularly monitored and discontinued when evidence of therapeutic effect is no longer present. In addition, these drugs have documented side effects including drowsiness and dizziness and can increase the risk of falling. However, for four out of the five residents on this class of medication, there was no documented evidence in their records that the continued use of these drugs had been reviewed.

In keeping with accepted practice, eleven residents with a history of severe agitation and/or aggression had been prescribed regular anti-psychotics. Again, as with the use of dementia medication, there was a lack of written evidence that a specific review or reconsideration of each resident's ongoing need for treatment with anti-psychotic drugs.

Concluding remarks

Human rights principles emphasise the importance of achieving a balance between ensuring residents' safety and promoting independence. In this regard, the CRPD is relevant, Article 26 of which requires states to:

[T]ake effective and appropriate measures […] to enable persons with disabilities to attain and maintain maximum independence [and] full physical, mental, social and vocational ability.

Moreover, there is increasing evidence of the benefits of 'wandering' for people with dementia.[50] It is therefore important that staff are supported to encourage residents to move freely where possible. Although there may be situations where restraint is medically necessary, its use should be

49 The latest, 2011, guidance from the National Institute for Health and Clinical Excellence (NICE) recommends that Aricept, (Donepezil Hydrochloride), and Reminyl, (Galantamine) are available as part of NHS care for people with mild-to-moderate Alzheimer's disease. These drugs are not licensed in the UK for treatment of severe Alzheimer's disease (see: National Institute for Health and Clinical Excellence (2011) *NICE Technology Appraisal Guidance 217: Donepezil, Galantamine, Rivastigmine and Memantine for the treatment of Alzheimer's disease*, NICE, London, March 2011 (available: http://www.nice.org.uk/nicemedia/live/13419/53619/53619.pdf)). Ebixa (Memantine) is licensed for the treatment of moderate-to-severe Alzheimer's disease; however, the licence requires that the tolerance and dosing of Memantine should be reassessed on a regular basis, preferably within three months after start of treatment and, thereafter, subject to regular reassessment.

50 See for example: Health Scotland (2008) *Facing Dementia: How to Live Well with your Diagnosis*; Health Scotland, Edinburgh; Health Scotland (2008) *Coping with Dementia: A Practical Handbook for Carers,* Health Scotland, Edinburgh.

proportionate and limited to the least restrictive measure. Crucially, nursing homes should ensure that staff recognise restraint and appreciate the ways in which their own actions can limit residents' movement. In Northern Ireland, the absence of a statutory definition of restraint and the lack of appropriate guidance that draws on international human rights standards remains a serious concern.

The Committee on Economic, Social and Cultural Rights states that the right to health requires that medical treatment is "timely and appropriate".[51] To ensure respect for residents' right to health, regular review of medication is necessary, including a review of the appropriateness of continuing with dementia or anti-psychotic drugs. Moreover, for residents who have decision-making capacity, a process of review can ensure that they are aware of the risks and benefits of a particular medication, so that their consent to continue or refuse treatment is properly informed. Indeed, treatment in the absence of consent may amount to violation of a person's physical and moral integrity and, therefore, their right to private life.[52] In extreme cases, it may even breach the right to be free from inhuman and degrading treatment.[53]

51 UN Committee of Economic, Social and Cultural Rights (2000) *General Comment 14: The Right to the Highest Attainable Standard of Health*, 11 August 2000, E/C 12/2000/4, paras 11 and 12(d).

52 See: *MAK and RK v UK* (23 March 2010) Unreported, Application No 45901/05, para 79. See also: *Glass v UK* (9 March 2004) 39 EHRR 341, para 70 and X and Y v Netherlands (26 March 1985) 8 EHRR 235.

53 *Jalloh v Germany* (11 July 2006) 44 EHRR 667.

8 Conclusions and recommendations

"In the current fiscal environment, we must be vigilant in ensuring that the provision of social protection, long-term care and access to public health for the elderly is not undermined." (Ban Ki-Moon, UN Secretary-General)[1]

Introduction

It is apparent in analysing the evidence for this investigation that there are certain matters integral to ensuring respect for the human rights of residents in nursing homes. To ensure that respect, it is vital that there is clarity over what the relevant human rights standards are and how they should be applied in nursing homes. That clarity must be provided, foremost, in the domestic legislative, policy and regulatory framework governing nursing homes. This framework must also be communicated through relevant training programmes for nursing home staff involved in providing everyday care to residents. In addition, the duty-bearers must make the necessary and, if required, additional resources available in order to ensure that human rights standards can be put into practice. Finally, there must be appropriate and effective mechanisms for holding the corresponding duty-bearers to account when rights are denied or cannot be accessed; in particular, avenues for remedy and redress should be available.

This first part of this chapter draws together the main findings and puts forward a number of recommendations that are required for the protection of the human rights of older people in nursing homes. These recommendations are aimed at addressing the systemic concerns identified in the substantive chapters of this report. The second part of this chapter makes recommendations that nursing homes should implement immediately. These are intended to address concerns identified by this investigation in relation to quality of life, personal care, eating and drinking, the use of restraint, and medication and health care. If implemented, the recommendations would enhance the quality of care provided to all residents in nursing homes in Northern Ireland.[2]

Treaty obligations

While government has signed the *Revised European Social Charter*, it has not yet agreed to be legally bound by its provisions. The Revised Charter contains rights additional to those contained in the original Charter of 1961 and a number of its provisions are particularly significant for older people. Notably, the Revised Charter is the only binding human rights treaty that refers explicitly within the text of its articles to the human rights of older people in institutions. Article 23 provides that every older person has the right to social protection, with States Parties undertaking:

> [T]o guarantee elderly persons living in institutions appropriate support, while respecting their privacy, and participation in decisions concerning living conditions in the institution.

Given its particular significance for the human rights of older people in nursing homes, the Commission recommends that:

1. The government ratifies the *Revised European Social Charter* without delay.

Integrating human rights standards: The legal, policy, and regulatory framework

The main legal and policy standards that apply to nursing homes in Northern Ireland are the *Nursing Homes Regulations (NI) 2005* (the 2005 Regulations) and the Nursing *Homes Minimum Standards* (2008) (the Minimum Standards) issued by the Department of Health, Social Services and Public Safety (DHSSPS). The 2005 Regulations

1 Ban Ki-Moon (2011) *UN Secretary-General's Message for 2011: International Day of Older Persons*, 1 October 2011.

2 The Commission is aware of the recent initiatives that are intended to improve care and services for older people; for example: the Northern Ireland Dementia Strategy (see: DHSSPS (2011) *Improving Dementia Services in Northern Ireland: A Regional Strategy*, November 2011) and the Northern Ireland Single Assessment Tool, which was developed to provide a standardised mechanism to assess the health and social care needs of older people (see the Health and Social Care Board (2011) *The Northern Ireland Single Assessment Tool (NISAT): Procedural Guidance*, January 2011 (Version 3). However, the absence of an overarching legal framework underpinned by international human rights standards mean that these still fall short of what is required to ensure the human rights of older people in nursing homes.

are legally binding on all nursing homes and the Minimum Standards are intended to provide more detail on how to comply with the regulations.[3] In Northern Ireland, nursing homes are regulated by the Regulation and Quality Improvement Authority (RQIA) which conducts inspections twice yearly of all homes.[4] When carrying out an inspection, the Minimum Standards state:

> The Regulation and Quality Improvement Authority must take into account the extent to which the minimum standards have been met in determining whether a service provider maintains registration or whether to take action for breach of regulations.[5]

At present, residents' human rights are not referred to in the 2005 Nursing Homes Regulations. Human rights are acknowledged explicitly in the Minimum Standards but only as "underpinning values".[6] The values are not integrated throughout the Minimum Standards and there is little, if any, guidance for nursing homes on how to respect human rights. At present, there is also no clear mechanism for the RQIA to inspect nursing homes using a human rights framework.

In addition, the changes introduced by the *Health and Social Care Act 2008* were not readily understood by the homeowners interviewed for this investigation. During interview with a senior nursing home employee, it was explained to investigators that the new legislation represents "an additional measure" to the existing regulatory standards applicable to nursing homes. This suggests that human rights standards are somehow supplementary when in fact the European Convention on Human Rights (ECHR) contains fundamental human rights and freedoms against which other regulatory standards should be assessed.

The Commission therefore recommends that:

Nursing Homes Regulations (Northern Ireland) 2005

2. The *Nursing Homes Regulations (NI) 2005* are amended to require that nursing homes are conducted so as to promote and protect residents' human rights.

Nursing Homes Minimum Standards (2008)

3. The *Nursing Homes Minimum Standards* should integrate human rights standards so that:

- **nursing homes are provided with guidance on how to apply human rights standards to every day care; and**
- **RQIA inspections are grounded within a clear human rights framework.**

4. Pending this amendment of the Minimum Standards, the RQIA should ensure that its inspections are grounded within a clear human rights framework.

Commissioning of services

5. Human rights should be integrated into the procurement and commissioning of services in nursing home care.

Legislation and guidance

In addition, there remain serious legislative gaps in Northern Ireland around mental capacity and restraint, where the absence of legal clarity leaves too much potential for human rights violations.

3 Department of Health, Social Services, and Public Safety (2008) *Nursing Homes Minimum Standards*, DHSSPS, Belfast, p5.

4 The RQIA conducts inspections twice yearly of all nursing homes in Northern Ireland to assess compliance with the Minimum Standards (see: Section 6 of the *Regulation and Improvement Authority (Fees and Frequency of Inspections) Regulations (NI) 2005)*.

5 Above, p5.

6 "Rights: patients' individual and human rights are safeguarded and actively promoted within the context of services delivered by the home" (Department of Health, Social Services and Public Safety (2008) *Nursing Homes Minimum Standards*, DHSSPS, Belfast, p6).

The Commission therefore recommends that:

Decision-making capacity

6. The Northern Ireland Executive brings forward legislation, as a matter of urgency, on capacity under which there is a "presumption of capacity" and a "decision specific approach".

Restraint

7. The Northern Ireland Executive brings forward a statutory definition of restraint, drawing on the international human rights standards.

8. The Northern Ireland Executive drafts formal guidance on restraint that is applicable in the nursing home context, drawing on international human rights standards and, in particular, on the standards of the Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment. This should also be reflected as a standalone 'standard' on restraint in the *Nursing Homes Minimum Standards.*

Human Rights Act 1998

As identified in Chapter 2, an outstanding concern remains that although all residents are entitled to protection of fundamental human rights under the ECHR, those who are privately funded do not have recourse to the domestic courts under the *Human Rights Act* (HRA) *1998*.

Taking into account the extreme vulnerability of nursing home residents, the Commission therefore recommends that:

9. Legislation is enacted to extend the definition of 'public function' in Article 6(3)(b) of the *Human Rights Act 1998* to include the provision of accommodation together with nursing or personal care for *all* residents in care homes.

Participation and autonomy

Participation in decision-making is not only a means to an end but a human right in itself. Indeed, it is integral to all of the themes identified in this report, from quality of life to personal care, to choices around medication and health care. The nursing home environment should be built around enabling older people to make meaningful decisions about their lives. The ethos of participation by residents and promoting their autonomy are underlying themes in the *Nursing Homes Minimum Standards*. However, the investigation reveals that the failures to make an express link between human rights standards and their applicability in practice means residents are not given adequate opportunity to be involved in making decisions that impact them.

The Commission therefore recommends that:

10. The legislative framework and guiding standards that apply to nursing homes elaborate on how all residents can and should actively participate in, for example:

- **deciding how they choose to spend their day**
- **planning activities and outings**
- **decisions around the physical layout of the nursing home, including surrounding gardens/grounds**
- **decisions around personal care and how and when help is provided**
- **devising menus and the timing and place of meals, and**
- **reviews and decisions around medication and health treatment.**

Particular attention should be given to those with cognitive impairments, including people with dementia. In addition, fundamental to this recommendation is the need for nursing homes to have available adequate resources to ensure that residents' choices can be reflected in practice.

Human rights training

The evidence provided to the Commission shows that, while staff receive training on a range of issues relevant to human rights standards, human rights standards are not at the heart of the training. This means that even among managers and legally responsible people interviewed as part of this investigation, there is a low level of awareness of human rights. When discussing this with senior staff, there appeared at times to be a purely legalistic understanding of human rights. Therefore, when asked why the home did not offer human rights training for staff, one interviewee replied:

"If we felt that there was a failure for us to recognise human rights […] or their rights were compromised in some way, then I think we would be only too willing to do something about that."

Considering that practices in nursing homes now have to comply with the HRA, the reported gaps in awareness of human rights standards and their application in care settings is of particular concern. While professional standards for nursing and care staff, and compulsory training, as well as the *Nursing Homes Minimum Standards* (2008), cover some aspects of human rights standards, these do not provide for a systematic overview of what is required to comply with the relevant domestic legislation or international human rights law.

The Commission therefore recommends that:

11. Nursing home staff, managers and homeowners should receive human rights training developed in collaboration with health care staff and human rights experts. This should include examples of how human rights standards apply to all aspects of care in the home for all residents in the home.

12. Nursing home staff should receive regular training on how to maximise decision-making capacity so that, to the greatest extent possible, residents are enabled to optimise their independence. Training should include guidance for staff on how to assess capacity and the approach that they should adopt when it is determined that a resident does not have capacity to consent to, or refuse, a particular form of care or treatment.

13. Human rights training should also be available to the RQIA so that its inspections take place within a clear human rights framework.

14. All training should be regularly reviewed and updated in light of evolving human rights jurisprudence.

Staffing resources: An accepted indignity?

Although referring specifically to psychiatric establishments, the Committee for the Prevention of Torture (CPT) is clear that the prevention of inhuman or degrading treatment depends largely on the availability of adequate numbers of staff. The CPT notes that deficiencies in staff resources seriously undermine efforts to offer activity and can "lead to high risk situations, notwithstanding the good intentions and genuine efforts of the staff".[7]

The Commission cannot avoid finding that fundamental concerns emerging from this investigation are due to poor staffing levels. Even in those homes in which interviewees spoke positively about the managers and staff, concerns emerged about their ability to respond appropriately to residents everyday needs. In particular, it appears that staffing levels are rarely set at a level that allows for more than minimum essential levels of care. This means that, for the most part, staff do not have time to interact meaningfully with residents and, often, personal care is hurried. As one relative interviewed as part of the investigation explained, the day revolves around getting things done. In the longer term, therefore, it is the Commission's view that staffing levels should

7 European Committee for the Prevention of Torture (CAT) (2002) *CPT Standards*, Council of Europe, Strasbourg [Revised 2010] para 42 (available: http://www.cpt.coe.int/en/documents/eng-standards.pdf).

be raised progressively over time to ensure the delivery of more than minimum essential levels of care.

More immediately, however, there are concerns about staffing that require urgent attention. Based primarily on the evidence provided during the call for evidence, the Commission finds that there has developed an accepted indignity where, due to staffing levels, residents should wait for lengthy periods of time before a member of staff is available to assist with continence needs. As a consequence, residents become wet or soiled or they are asked to use, and potentially become reliant on, incontinence pads. As argued in Chapter 4, where this happens regularly or as a matter of routine, it is likely to violate the individual's right to physical and moral integrity as part of their right to private life and, in certain circumstances, their right to be free from inhuman and degrading treatment.

The Commission therefore recommends that:

15. The RQIA guidelines for determining the ratio of staff to residents are reviewed as a matter of urgency.[8]

The right to an effective remedy

Effective and efficient complaints procedures are not merely good management practice, they provide an essential means of ensuring compliance with human rights guarantees. What an "effective remedy" entails in a specific instance is very much dependent on the facts of the case. Whichever means are used to provide redress, a remedy must be effective in practice as well as in theory and law.[9]

The findings from this investigation reveal that, in practice, there are significant barriers for older people and their families in raising complaints. In particular, many older people in nursing homes have fluctuating capacity due to, for instance, dementia and this may prevent them from making a complaint. While family members or other interested people can make complaints, the evidence received during the investigation is that many residents do not receive regular visits and therefore do not always have others to make complaints on their behalf.

The Commission therefore recommends that:

16. Independent and appropriately accredited and professional advocacy services should be available for older people in nursing homes. As not all residents are able to contact professional advocacy services to request help by themselves, there should be a regular programme of visits to nursing homes by such services.

17. Advocates should receive regular human rights training and be familiar with the internal and external complaints systems, and receive training on how to work alongside people with dementia.

Implementation of the above recommendations would constitute an important step towards ensuring that nursing home care is in compliance with international human rights standards.

8 Regulation and Quality Improvement Authority (2009) *Staffing Guidance for Nursing Homes*, June 2009, RQIA, Belfast.

9 *Kudla v Poland* (26 October 2000) 35 EHRR 198, para 157.

Care provision

Effective human rights protection requires action from many actors. Nursing homes themselves have a crucial role to play in this regard. In order to ensure that care delivery respects the human rights of older people, the following recommendations are proposed for immediate action by nursing homes to the extent they are not already in place:

Quality of life

18. Residents should be offered opportunities and enabled to go outside. For those who are unable to participate in trips away from the home, nursing homes should ensure that there is access to the physical environment within the nursing home grounds for all residents including those with disabilities.

Personal care

19. Residents' personal hygiene should not be neglected. In particular, residents should not be left wet or soiled.

20. Residents should be ensured privacy when receiving help with their personal care and, as far as practicable, have their choices respected in relation to the gender of staff helping with intimate personal care.

21. The loss or misplacement of residents' clothes and other belongings should be minimised to ensure respect for personal identity. Where items are lost, these must be replaced promptly.

22. Nursing homes should ensure that older people are not dressed in clothes belonging to other residents.

Eating and drinking

23. Residents should have access to adequate food and water. Nursing homes should ensure this is available at all times of the day and night.

Medication and health care

24. Nursing homes must ensure timely and appropriate health care. In particular, they should:

- **refer residents to a GP or hospital without unnecessary delay;**
- **provide access to other health services such as chiropody, dentistry, optometry and physiotherapy as soon as practicable once it is determined that this is required;**
- **ensure regular mental health assessments and, in any event, at least once each year. This should be recorded in the nursing home records and translated into care plans to ensure appropriate care; and**
- **if immediate medical treatment is required, or if there are concerns that the resident's health will deteriorate on the way to hospital, relatives should not be asked to provide transport to hospital.**

Restraint

25. Nursing homes should maintain a register in which all instances of physical restraint are recorded.

26. Nursing home staff should receive appropriate training in measures to avoid the use of restraint and the limited circumstances in which methods of restraint may be justified.

27. Methods of restraint must never used to compensate for a lack of staff.

28. The use of medication causing sedation should be subject to compulsory review by a qualified medical practitioner at regular intervals and at least twice a year. This review must be evidenced in the GP records and the resident's nursing home file.

Concluding remarks

This investigation has uncovered significant structural barriers to the implementation of the human rights of older people in nursing homes. Therefore, specific failings in relation to, for instance, the provision of help with personal care or eating and drinking are often matched by gaps and shortcomings in the overarching legal framework and policy guidance, which is, at best, weak in its commitment to mainstream residents' human rights.

All this is not to say that individual nursing home staff are not committed to ensuring the human rights of older people. On the contrary, the primary fieldwork for this investigation reveals that many staff are devoted to working with older people in an environment that is often challenging with significant time and resource constraints. In many instances, staff care for older people not merely as part of their job but as a personal commitment.

For example, during interviews a number of staff stated that they often visit residents on their days off. Residents who spoke positively about their care also described how the staff had been central to their experience.

As one interviewee explained:

"I must admit, if you want me to be perfectly honest, when I first came in I thought it was like a prison. I had never been in a home in my life before and the main nurse that was on used to come down and I used to sit and cry […] and I got through that with a lot of help from the carers and the nurse."

While it is wrong to rely solely on the personal commitment of individual members of staff as a safeguard to protect and promote residents' human rights, that personal commitment is an essential element of a human rights compliant care package. The Commission is heartened by the fact that many of the staff interviewed displayed devotion to their work and a belief in the inherent dignity of those they cared for. It is now of paramount importance that government, the ultimate duty-bearer, ensures that the necessary structures and resources are in place to enable the staff to carry out their work in compliance with the international human rights standards.

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Appendix 1: Terms of reference

Background

In the UK, the fastest growing age group is those aged 80 and over.[1] It is also accepted that increased longevity has meant that the likelihood of needing some form of residential care is much greater today than in the past. In light of the changing demographics, the Northern Ireland Human Rights Commission has been exploring the vulnerabilities and problems that older people face and the responsibilities of government to this group of people.

Having undertaken an extensive scoping exercise from May 2009, drawing on the expertise of academics, non-governmental organisations and other statutory bodies, the Commission has decided to conduct an investigation into the rights of older people in nursing care. Residents in nursing homes require 24-hour care and the Commission has identified a group of people that are likely to have complex medical needs and vulnerabilities. It wishes to explore the extent to which those medical needs are met along with the rights and entitlements residents share with any other member of the population living in their private residence. The investigation will therefore focus on the following areas in respect of nursing home care in Northern Ireland:

- **sedation:** appropriate prescription and use of sedatives
- **review of medication:** appropriate use of medication
- **nutrition:** including malnutrition and methods of feeding
- **dignity:** focusing on the day to day experiences of residents in relation to, for example, autonomy in decision making, access to outdoor spaces, clothing, stimulation, finances and such other matters as the residents, family members and/or staff may identify, and
- **non-discrimination:** exploring the extent to which older people face discrimination in the enjoyment of rights because of their age as well as for example, gender or ethnicity.

Investigation remit

The investigation aims to identify:

- the international and regional human rights standards to which the UK is a party, relating in particular to accommodation, health care, dignity, nutrition, non discrimination and disability
- relevant international and regional 'soft law' standards relating to health, dignity, disability and elder care
- the extent to which existing legislation, guidance, and practice in relation to older people in nursing care complies with international human rights standards, and
- the extent to which the rights of older people are met in the nursing home environment.

Methodology of investigation

It is envisaged that fieldwork will commence in November 2009 and will continue until the summer of 2010. The Commission has devised criteria in order to select four homes for the purposes of primary evidence gathering. The homes will not be named in the report. The homes identified consist of a mixture of rural and urban locations from across Northern Ireland and will include a range of bed sizes and specialist care.

A primary aspect of the fieldwork will involve access to individual residents for interview and to their medical and nursing home records. The Commission will seek written consent from the individuals concerned before proceeding with these aspects of the investigation. Where an issue may arise (as identified by nursing home staff) as to the individual's mental capacity to provide consent, written consent will be sought

1 Available: http://www.statistics.gov.uk.

from their next-of-kin. It is envisaged that the final report will be published by the end of 2010, with a series of recommendations to nursing homes. As with all investigations reports, the Commission plans to monitor the extent to which those recommendations are implemented and report on this through its statutory functions and annual report.

The investigation will be carried out by the means of:

- review of literature and relevant human rights standards and case law
- review of legislation and policy
- analysis of available statistical material on the issue of nursing home or elder care
- interviews with relevant Department of Health and Trust employees
- interviews with management and staff from each of the nursing homes selected for investigation
- review of relevant policies and other documentation (including that relating to complaints) from each of the nursing homes selected for investigation
- analysis of the information necessary (e.g. gender, length of time in nursing home) to identify a sample of residents from each of the nursing homes selected for investigation. The Commission particularly wishes to speak to people with dementia
- interviews with the sample of residents from each of the nursing homes selected for investigation
- analysis of the nursing home notes/ records and medical records of the sample of residents for the purpose of assessing appropriateness of care and medication provided by the nursing home. This review will be conducted with the assistance of a suitably qualified medical expert
- Analysis of nursing home records for the purpose of reviewing the care and medication of residents. This review will be conducted with the assistance of a suitably qualified medical expert.
- interviews with family members and friends of nursing home residents where appropriate
- meetings with non-governmental organisations in order to participate in interviews and provide case studies of people in nursing care and to help in establishing contacts with residents and their families
- interviews with other professionals actually or potentially involved with this issue including elder care social workers, geriatricians and social care workers, and pharmacists, and
- call for evidence and analysis of data received (see further below).

Call for evidence

In gathering evidence for this investigation, the Commission wishes to include a public call for evidence. Members of the public are asked to contact the Commission with any relevant experiences of the issues under investigation, whether experienced firsthand or by family members. The evidence will be gathered over the phone for an initial two-week period from 15 to 26 February, Monday to Friday. After that period, any callers will be given a time-limited opportunity to input via a questionnaire on the Commission's website or by post. Evidence gathered in this way will be used to:

- ascertain the extent to which the issues identified through first hand observations and interviews represent systemic problems across nursing home establishments in Northern Ireland
- produce anonymous case studies for the report

- assess arising areas of systemic concern that the Commission could potentially address by way of public interest litigation, and
- identify areas of good practice in nursing homes and opportunities for shared learning.

Individual cases may, in certain circumstances raise concerns of sufficient gravity that might lead, with the callers consent, to referral to the Commission's legal team. The legal team, having assessed the evidence further may offer assistance to reach informal resolution/advocacy. There will be the possibility of the call for evidence revealing a pattern of concerning calls about a particular home not already subject to this investigation. The Commission intends to deal with this through formal contact with the nursing home manager and may also discuss the concerns raised in the final investigation report, while not naming the nursing home.

Appendix 2: Methodology

Literature review and documentary analysis

To set the findings of the investigation within the broader context of available research into the situation of older people in nursing homes, a wide-ranging review of available literature was completed, both in preparation for the commencement of the fieldwork and at the report drafting stage.

The documentary analysis undertaken for this investigation also included a detailed review of human rights standards pertaining to the situation of older people in care, and relevant legislation and policy documents.

Primary fieldwork

The primary fieldwork for this investigation commenced in November 2009 and continued until September 2010.

The Commission devised criteria in order to select four homes for the purposes of primary evidence gathering. The four homes selected had the following characteristics:

a) four Trust areas were represented in the selection

b) two homes were in urban and two in rural areas

c) one home was small (30 residents or fewer), one large (61 residents or more) and two medium (between 31 and 60 residents)

d) one home was run by a charity, two homes were owned privately by single owner, one was owned privately by a larger corporate group

e) one home provided nursing care only and three provided both nursing and residential care, and

f) one home provided dementia care only, two provided dementia and other categories of care and one provided general categories of care, excluding dementia care.

The primary fieldwork included:

a) conducting interviews with management and staff from each of the nursing homes selected for the investigation (63 individuals in total)

b) review of relevant policies and other documentation from each of the nursing homes selected for investigation

c) analysis of the information necessary to identify a sample of residents from each of the nursing homes selected for investigation (e.g. gender, length of time in nursing home); the Commission particularly wished to speak to people with dementia

d) conducting interviews with the sample of residents from each of the nursing homes selected for investigation (17 residents participated in an interview; 10 residents with dementia took part in an informal chat with investigators about their experience in the nursing home)

e) analysis of nursing home and GP records of a sample of residents (25 residents in total) for the purpose of reviewing the care and medication of residents; two qualified medical experts conducted this review (see Appendix II), and

f) conducting interviews with family members and friends of nursing home residents where appropriate (13 individuals in total).

Call for evidence

In gathering evidence for this investigation, the Commission included a public call for evidence during which members of the public were asked to contact the Commission with any relevant experiences of the issues under investigation, whether experienced firsthand or by family members. The call for evidence (facilitated through the provision of a freephone number) was open between 15 and 26 of February 2010 and recorded 163 calls.

Respondents were asked to answer a structured questionnaire of 38 questions in the areas of dignity, dementia care, the use of medication (general) and provision of health care, the use of sedation, nutrition, safety, discrimination, the reasons for transfer to residential nursing care and ideas for alternative support, and contact with homes (complaints and compliments). Each caller was also given an opportunity at the end of the structured interview to raise any other issues of relevance to their personal situation or that of their relatives.

After the call for evidence closed, members of the public were also given a time-limited opportunity to input into the investigation via a shorter questionnaire on the Commission's website. In all, 25 completed questionnaires were received.

The information collected through the call for evidence and the questionnaires was used to:

- ascertain the extent to which the issues identified through the Commission's primary fieldwork in the four selected nursing homes represent systemic issues across nursing homes in Northern Ireland
- provide evidence additional to that gathered by investigators in the four selected nursing homes of the experiences of residents or relatives in relation to nursing homes
- identify areas of good practice in nursing homes and opportunities for shared learning, and
- assess arising areas of systemic concern that the Commission could potentially address by way of public interest litigation.

Ethical considerations

Important ethical considerations had to be addressed before this investigation started. It was clear that the agreed methodology meant that investigators would be entering people's homes and the merits of observing daytime and nighttime routines were explored. While such observation would have provided substantive material on the quality of care provided, it was nonetheless concluded that this approach would have constituted too great an intrusion into the lives of the nursing home residents. Moreover, there was also a concern that such observations might impact the routine of the home itself. The investigation therefore relied on extensive interviews with staff, residents, and family members or friends visiting the home. A close examination of the written policies and procedures of each home and analysis of nursing home and GP records was also completed.

The Commission was aware that many nursing home residents have dementia. Two of the four selected homes were chosen because they specialised in dementia care and the experiences of their residents needed to form a substantive part of the investigation's findings. Given the issue of capacity to consent to interview and access records held by the GP and nursing home, the Commission had to decide on how best to approach residents for consent. A decision was made that consent would be sought from the resident's next-of-kin as identified by the nursing home.

This approach did not carry legal certainty. Where issues of capacity to consent are raised the ability to make decisions such as access to sensitive medical information or to participate in research is not passed automatically to the next-of-kin. The *Mental Capacity Act 2005* (covering England and Wales) and the *Adults with Incapacity (Scotland) Act* offer some regulation for research but there is currently no equivalent legislation for Northern Ireland. In the absence of relevant legislation locally, the Commission decided to seek formal written consent from the next-of-kin with the proviso that a refusal from the resident would override any consents provided.[1] Having

1 For a discussion of the approach to consent, see: Sugarman J, Roter D, Cain C, Wallace R, Schmechel D and Welsh-Bohmer KA (2007) 'Proxies and consent discussions for dementia research' in 55(4) *Journal of the American Geriatrics Society* 556-561; Moore TF and Hollet J (2003) 'Giving voice to persons living with dementia: The researcher's opportunities and challenges' in 16(2) *Nursing Science Quarterly*, 163-167; Hellström I, Nolan M, Nordenfelt L and Lundh U (2007) 'Ethical and methodological issues in interviewing persons with dementia, in 14(5) *Nursing Ethics* 608-619.

considered available research and guidance relating to research involving people with dementia, the Commission concluded that it was the most responsible and inclusive way of proceeding. The next-of-kin was also asked if they wished to participate in an interview with the investigators. GPs and nursing homes did not challenge or question this approach in the event of having to disclose medical records and other sensitive information. The Commission stored, retained and used that information in full compliance with its data protection responsibilities.

The Commission also had to consider the possibility of uncovering abuse or other ill treatment within nursing homes, either in a home in which primary fieldwork was being carried out or through the call for evidence. Discovering a situation in which a resident or staff member was at risk of harm could not be left as a finding to be included in the investigation report. It was decided that where such a situation did arise, it would be reported immediately to the relevant Health and Social Care Trust (HSC Trust). Subsequently, during the investigation, nine referrals were made to the relevant HSC Trust according to the Commission's protocol for responding to suspected or alleged abuse of vulnerable adults.

Appendix 3: Details of clinical reviewers

In the course of the investigation, the Commission contracted two experts to provide it with the analysis of GP and nursing home records of selected residents. The two clinical reviewers were:

Ian MacKenzie, BSc MB ChB MRCGP

Ian has nearly 20 years experience of general practice and was formerly an Associate Medical Director for a PCT – a post in which he was responsible for all aspects of Clinical Governance, GP appraisal and performance systems and the Out of Hours service. He has also been responsible for infection control and reviews of nursing homes and community hospitals. He has been involved in Pharmacy Inspections and chaired the local Area Prescribing Committee. He worked as a Clinical Adviser for the Healthcare Commission.

Pauline Neill, MSc RGN RDN RHV

Pauline had extensive experience both in a clinical and managerial capacity in general, and in the elderly and community nursing (health visiting and district nursing). She had been a nursing director within two NHS trusts for fifteen years. She participated in numerous health service reviews across England and Wales for the Healthcare Commission and Health Inspectorate Wales as a clinical adviser and a peer reviewer/inspector. Her recent work included a two-year review of the National Services Framework for Older People (for the Health Inspectorate Wales). This work looked mainly at the privacy/dignity rights and care of older people within residential institutions with particular focus on patients with dementia.

The Commission was very saddened to learn that Pauline passed away in late February 2011 and before she was able to see the effects of her work for the Commission reflected in this report. We are very grateful for all her work and support for this investigation.

Both clinical experts confirmed that they did not know any of the residents whose records were included in the Commission's review, and that no conflict of interest arose during their work for the Northern Ireland Human Rights Commission.

Northern Ireland Human Rights Commission
Temple Court
39 North Street
Belfast BT1 1NA
Tel: (028) 9024 3987
Fax: (028) 9024 7844
Textphone: (028) 9024 9066
SMS Text: 07786 202075
Email: information@nihrc.org
Website: www.nihrc.org

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