

The background of the cover is a solid blue field with several large, white, five-pointed stars scattered across it, mimicking the design of the European Union flag.

# Dementia in Europe Yearbook 2017

## Standards for residential care facilities in Europe





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## Table of contents

<b>1.</b>	<b>Foreword</b> .....	<b>3</b>
<b>2.</b>	<b>Introduction</b> .....	<b>4</b>
2.1	Background to the report.....	4
2.2	Relevance of the topic and European policy context.....	5
2.3	Prevalence of dementia in residential care settings and regulation to improve the quality of care.....	6
2.4	Areas of interest to this report.....	8
2.5	Structure of the report.....	9
<b>3.</b>	<b>Legislative frameworks for residential care facilities in Europe</b> .....	<b>10</b>
3.1	National Standards.....	14
3.2	Dementia in the regulatory framework.....	15
3.3	Implementation and monitoring of the requirements: inspections.....	17
3.4	Areas addressed by the legislative framework/National Standards.....	21
3.5	Personal account.....	22
<b>4.</b>	<b>The physical environment of the residential care facility</b> .....	<b>23</b>
4.1	Design and layout of the facility.....	23
4.2	Lighting, heating and ventilation.....	24
4.3	Adaptation and equipment to maximise residents' independence, call systems and use of closed circuit television (CCTV).....	26
4.4	Bedrooms, communal and outdoor spaces.....	27
4.5	Personal account.....	31
<b>5.</b>	<b>Workforce</b> .....	<b>32</b>
5.1	The registered manager.....	32
5.2	Staff that should be present in the residential care facility.....	36
5.3	Care assistant-to-resident ratio.....	36
5.4	Nurse-to-resident ratio.....	37
5.5	Qualification and training.....	38
5.6	Personal account.....	39
<b>6.</b>	<b>Provision of care and rights</b> .....	<b>40</b>
6.1	Admission.....	40
6.2	Assessment of needs, care plan and provided care.....	42
6.3	Decision making, participation and involvement.....	51
6.4	Personal account.....	52
<b>7.</b>	<b>End-of-life care</b> .....	<b>53</b>
7.1	General overview.....	53
7.2	Involvement of the resident and family.....	53
7.3	Last moments of life.....	54
7.4	Staff training in end-of-life care.....	55
7.5	Personal account.....	55
<b>8.</b>	<b>Abuse and use of restraint</b> .....	<b>56</b>
8.1	General overview.....	56
8.2	Types of abuse, identification and reporting.....	56
8.3	Restraint.....	57
8.4	Personal account.....	60
<b>9.</b>	<b>Conclusions</b> .....	<b>61</b>
<b>10.</b>	<b>Acknowledgements</b> .....	<b>62</b>
<b>11.</b>	<b>References</b> .....	<b>63</b>
<b>12.</b>	<b>Appendix</b> .....	<b>64</b>

# 1. Foreword



It gives me great pleasure to present this comparative report on standards for residential care facilities in Europe. Most people with dementia live in the community. However, some, may need to move into residential care due to dementia or other conditions. Also, some people

living in residential care facilities may develop dementia at some point of their lives.

Moving into residential care is a significant life event and can be quite challenging for many people and this decision may be even more difficult for a person with dementia. Amongst the questions expressed by older persons are when to make the decision and which care home to choose as well as concerns over more practical aspects of care, such as having to share a room or not being able to decide about meals or when to go to bed.

Every person living in these settings should have the same rights and opportunities to enjoy a meaningful and good quality of life as people living in other settings. This is particularly true for people with dementia who may often have more complex needs than other residents and, as dementia progresses, may be less able to defend their interests and rights, make decisions or communicate preferences.

This report provides an overview of the existing care standards and regulatory requirements that residential care facilities need to meet. The report addresses key areas that have a great impact on the lives of residents, namely, the physical environment, the staff providing care, health and social care and human rights, end-of-life care and abuse and restraint.

We identify some important oversights on how dementia is currently addressed or neglected in frameworks and standards in Europe, but were also able to provide examples

of good practices and standards where the specific needs of residents with dementia have been taken into account.

The report also draws attention to end-of-life care for people living in residential care settings. This is a great concern as many people, with and without dementia, will spend their last days and moments of life in a residential care facility. Abuse, and specifically, the use of restraint, is also an important topic in dementia care. Alzheimer Europe carried out work in 2012 on the area of restrictions of freedom and the use of restraint. The use of restraint, particularly on frail, older people with dementia, is generally considered unethical or harmful and is rarely if ever justifiable.

Some of the key issues that still need to be considered at policy level are the formulation of clear and legally binding standards with specific considerations of the needs of residents with dementia, appropriate training for staff, and awareness raising and the provision of high quality accessible information to residents, families and staff about their rights and what they should be able to expect from care.

In closing, I want to acknowledge the important work of our member associations and other national experts who provided the information for this report, and Ana Diaz, Project Officer, who coordinated this work and carried out this impressive comparison of national care standards. A special mention goes to the members of our European Working Group of People with Dementia and their supporters, who have provided very insightful personal accounts and thoughts on this important topic.

We hope this comparative report will be useful in advancing the understanding of this topic and improving the standards of care and the quality of life of people with dementia in residential care.

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## 2. Introduction

### 2.1 Background to the report

This comparative report has been produced as part of the 2017 Work Plan of Alzheimer Europe (AE)<sup>1</sup>, which has received funding from the European Union in the framework of the Health Programme.

The report looks at the topic of residential care facilities in Europe, and in particular, provides a comparative overview of the requirements that these facilities must comply with when providing care, i.e. the minimum provision below which no provider is expected to operate. In this report, the term residential care facilities includes both care homes and nursing homes (please see appendix for further details).

The report focuses on the following areas:

1. Physical environment,
2. Workforce,
3. Provision of care and rights,
4. Palliative care,
5. Abuse and restraint.

The information for this comparative report has been provided by AE members and other national experts (please see appendix for details on the methodology followed and the acknowledgements section for the list of people who have contributed to the report). Members of the European Working Group of People with Dementia (EWGPWD)<sup>2</sup> were invited to share their experiences with and views on each of the topics addressed in the report by providing a short written testimonial (“personal accounts”). The personal accounts of six people with dementia and three supporters are included at the end of sections 3 to 8.

The report includes information from 29 European countries (please see table 1 for more information). For Belgium and the United Kingdom (UK) separate information is provided for the different parts of the countries (i.e. Wallonia and Flanders in Belgium, and England, Northern Ireland, Wales and Scotland for the UK). For some countries where the requirements are developed at regional level the information is provided for one of the regions (e.g. Germany, Spain, Switzerland) (please see appendix for further details).

Table 1: Participating countries

EU Member States				Non-EU Countries
Austria	France	Luxembourg	Spain	Norway
Belgium (Flanders)	Germany	Malta	Sweden	Switzerland
Belgium (Wallonia)	Greece	Netherlands	UK (England)	Turkey
Bulgaria	Hungary	Poland	UK (Northern Ireland)	
Croatia	Ireland	Portugal	UK (Wales)	
Cyprus	Italy	Romania	UK (Scotland)	
Czech Republic	Latvia	Slovenia		
Finland	Lithuania	Slovakia		

<sup>1</sup> Alzheimer Europe is a non-governmental organisation aiming to raise awareness of all forms of dementia. As of October 2017, Alzheimer Europe has 40 member associations from 35 countries. For further information please visit: <http://www.alzheimer-europe.org>.

<sup>2</sup> In 2012, Alzheimer Europe set up the European Working Group of People with Dementia (EWGPWD), comprised of people with different forms of dementia and of different ages and nationalities, to advise the board of Alzheimer Europe (through the Chair of the EWGPWD) and to participate (either as a group or through individual members) in all activities and projects organised by Alzheimer Europe.

## 2.2 Relevance of the topic and European policy context

Population ageing is a long-term trend which began several decades ago in Europe (Eurostat, 2017). According to current estimations the EU-28's population will continue to age. Another aspect of population ageing is the progressive ageing of the older population itself, the share of people aged + 80 years will double between 2016 and 2080 (Eurostat, 2017). This overall increase in life expectancy across Europe is a very positive trend. However, demographic change is also seen as a challenge for many policy areas, including social protection systems, and health and long-term care<sup>3</sup> in particular. According to the European Commission (2014), the ageing of the population is expected to put pressure on governments to provide more formal long-term care benefits. Long-term care is a broad concept and it encompasses both informal and formal care. Only some aspects of the latter (i.e. long-term care provided in residential care facilities) are addressed in this report.

In the European Union (EU), it is estimated, that the number of people who may potentially need long-term care services will increase by 30% between 2013 and 2060 (Commission Services and Economic Policy Committee, 2016). Whilst, older people are not the only citizens who may need long-term care, they are more likely to need it due to potential frailty and co-morbidities. The growing number of people living with dementia is also another factor that is often mentioned in this context.

Within the EU, the provision of long-term care is a Member State responsibility (Social Protection Committee and the European Commission, 2014). However, the topic of long-term care, as part of the social inclusion and social protection strand<sup>4</sup> is addressed at EU level in different ways.

As part of the political cooperation, the Commission works together with Member States through the Social Protection Committee using the Open Method of Coordination<sup>5</sup> in the areas of social inclusion and social protection. This provides a framework for national strategy development for social

protection and investments, as well as for coordinating policies between EU countries on, among other issues, health and long-term care. In this context, Member States have agreed on three common objectives: (1) guarantee access for all to health and long-term care, (2) promote quality in health and long-term care and adapt care to the changing needs and preferences of society and individuals, notably by establishing quality standards reflecting best international practice and by strengthening the responsibility of health professionals and of patients and care recipients and (3) ensure that health and long-term care remain affordable and sustainable.

The European Semester<sup>6</sup> allows countries to discuss their economic and budget plans and monitor progress throughout the year. As part of this work, the Commission issues an Annual Growth Survey which presents the Commission's view of EU policy priorities for the coming year. The 2017 Annual Growth Survey refers to long-term care and highlights that Member States need to ensure access to quality services including long-term care, and also, in order to slow the rise in expenditure in long-term care services, recommends policy action to enable individuals to stay healthy for longer and make health systems more effective, accessible and resilient. In 2016, 19 Member States referred to challenges linked to long-term care, 11 in their national reports referred to scarce provision and coverage (ENNHRI website<sup>7</sup>).

In 2016, the European Commission introduced the European Pillar of Social Rights. The Pillar reaffirms rights that are already present in the EU and complements them to take account of new realities (European Commission website). The principles and rights enshrined in the Pillar are structured around three categories: (1) equal opportunities and access to the labour market, (2) fair working conditions and (3) social protection and inclusion. Chapter III (article 18) refers to the right to affordable long-term care services of good quality.

<sup>3</sup> Long-term care can be defined as "a range of services and assistance for people who, as a result of mental and/or physical frailty and/or disability over an extended period of time, depend on help with daily living activities and/or are in need of some permanent nursing care".

<sup>4</sup> The European Commission supports and complements the Member States' policies in the fields of social inclusion and social protection.

<sup>5</sup> The Open Method of Coordination on Social Protection and Social Inclusion was launched in 2000 and is a method of soft governance and part of the implementation of the process of coordination of social policies. It is used by Member States to support the definition, implementation and evaluation of their social policies and to develop their mutual cooperation. The method supplements the legislative and financial instruments of social policy (EU website).

<sup>6</sup> In the framework of the "Europe 2020" strategy, the European Commission (EC) put in place a process of economic reforms and surveillance to support Member States in achieving the planned objectives and the targets. This process is known as the European Semester. The European Semester is an annual cycle during which information is exchanged between the EC and the Member States and economic reforms in the fields of employment, education and poverty reduction are planned. In November of each year, the EC sets out its priorities in the Annual Growth Survey. On the basis of these priorities the EU Heads of State issue policy guidance to Member States. This policy guidance is then meant to be reflected in the drawing up of National Reform Programmes and Stability/Convergence Programmes by each Member State. These programmes are assessed by the EC which then draws up a number of Country Specific Recommendations which are considered and finally adopted by the European Council (Azzopardi-Muscat et al., 2015).

<sup>7</sup> <http://ennhri.org/Long-term-Care-in-Europe>.

Despite this work, the cost, sustainability and quality of long-term care systems remain a challenge for most EU Member States (Commission Services and Economic Policy Committee, 2016; Social Protection Committee and the European Commission, 2014). The OECD/European Commission

report concluded that “the measurement of quality in long-term care lags well behind the health sector. More effective monitoring of long-term care quality, and the development of robust, comparable measures, should be a priority for OECD countries” (2013:16).

### Box 1: European projects addressing long-term care

A number of European projects and initiatives have looked at different aspects of long-term care in Europe and have tried to address some of these challenges. Some examples of this work include:

- ANCIEN project: Assessing the needs of Care in European Nations (2009–2012).
- ENNHRI: Human rights of older persons in long-term care project (2015–2017).
- Interlinks: Health systems and long-term care for older people in Europe. Modelling the interfaces and links between prevention, rehabilitation, quality of services and informal care (2008–2011).
- PACE: Palliative Care for Older People in care and nursing homes in Europe (2013–2018).
- WeDO project: European Partnership for the wellbeing and dignity of older people (2010–2012). As part of this work the European Quality framework for long-term care services was developed.

## 2.3 Prevalence of dementia in residential care settings and regulation to improve the quality of care

Current estimates suggest that over 9 million European citizens (EU28) may have dementia (Alzheimer Europe, 2017, unpublished document). In Europe, the majority of people with dementia live at home in the community. However, due to different circumstances, and at different stages of the condition, some people will need or chose to move to a residential care facility. Also, some people may develop dementia after moving to residential care. It is still a challenge to estimate which proportion of people living in residential care facilities have dementia. This varies greatly from country to country, but evidence suggests that this may range from 13.4% in Hungary to some 70–80% in Sweden (Froggatt et al., 2017 – see table 2 for further details and box 2 for an example of prevalence in Switzerland). Also, it has to be borne in mind that, whilst an important number of residents may experience cognitive impairment or dementia, several never receive a diagnosis (Cahill et al., 2009, Froggatt et al., 2017).

There are different types of care facilities providing long-term care to older people in Europe. Froggatt and colleagues (2017) identified three different types of care facilities: type 1: facilities providing care to the most dependent older people with on-site physicians, nurses and care assistants, type 2: facilities with onsite nurses and care assistants which rely on external providers for provision of medical care, and type 3: facilities providing care for older people with lower levels of dependency and where the on-site care is provided by care assistants. They concluded that in the majority of countries included in their study, at least two of these three types of facilities providing care co-exist. Froggatt

and colleagues (2017) highlighted that the situation of the long-term care sector is “continuously evolving with relevant changes happening in funding and organisational models” (Froggatt et al., 2017, p.12).

The assurance and monitoring of quality of residential care for older people is particularly important (O’Dwyer, 2015). Nevertheless, this is a complex endeavour. Measures to assess the quality of care are improving, however they are still in the early stages in many Member States (European Commission, 2008). Among other factors that may have an impact on the quality of the long-term care, increasing patient choice and ensuring the capacity of the workforce in long-term care, have been identified as core factors (European Commission, 2008). Similarly, the Social Protection Committee and the European Commission (2014) highlighted that the provision of long-term care should be attuned and responsive to older people’s wishes and preferences. Other issues that have been identified in Europe as challenges to the quality of long-term care are inadequate accommodation, lack of privacy and excessive use of restraint and force (European Commission, 2008).

The development of minimum standards and the licensure and accreditation of facilities are some of the main instruments to regulate quality of care in institutional settings and can be considered as the “starting point” of quality assurance (OECD/European Commission, 2013). In several countries, accreditation or certification is either compulsory or a condition for reimbursement or contracting (OECD/European Commission, 2013, p.22). These processes



recognise that the facility meets certain basic criteria and is fit to operate. The type and depth of information addressed in the standards and legislation varies, however, common requirements include aspects related to the living environment, workforce (ratios and qualifications needed) and administrative matters of care provision. Other areas such as human rights of residents, individualised care planning, reporting processes for complaints and specific standards for dementia care, also seem to play an important role, and in recent years, more attention has been given to such areas (OECD/European Commission, 2013).

Most countries have indicators of inputs, such as staffing and care environment, but only a limited number of EU countries collect information on quality systematically (Social Protection Committee and the European Commission 2014). The work carried out by O'Dwyer on quality of residential care for older people, indicated the existence of three different regulatory regimes in Europe (O'Dwyer, 2015, p.122–124):

- Self-regulatory approach, typically used in Northern Europe. In this approach, regional and local authorities are tasked with overseeing the quality of care services but the responsibility for the quality

of the service provider is seen to rest primarily with the care providers. In these countries, there is a great focus on quality improvement and assurance and providers themselves are required to collect performance indicators.

- Command and control approach, typically used in mainland Europe, Ireland and the UK, where independent, external bodies are responsible for monitoring the quality of care. In these countries, there are regular inspections and sanctions in case of non-compliance. The focus is on quality assurance and quality or performance indicators are not used.
- Quality assurance with poor or underdeveloped oversight, typically found in Eastern Europe but also in some Mediterranean countries. Several countries fall in this category, and have poorly developed regulatory systems.

Whilst it is still unclear which approach could have better care outcomes, O'Dwyer's work suggests that countries using the first approach (self-regulation) are more likely to have higher average standard of care. However, she argued, other factors may also influence this (e.g. the organisation of long-term care services in each country).

**Table 2: Proportion of residents with dementia in long-term care facilities (LTCFs)**

Country (date of data)	Proportion of residents living in LTCFs with dementia
Austria (2007)	52.5%
Denmark (2013)	66.6%
Finland (2012)	56% (health centres) 68% (nursing homes)
Germany (2007)	61% (60–74 years) 71% (75–84 years) 69% (85+ years)
Hungary (2008)	13.4%
Iceland (2014)	63.2%
Ireland (2012)	64.2%
Italy (2012)	22% (severe dementia in nursing homes) 70% (significant cognitive impairment)
Netherlands (2012)	57% nursing homes 35.6% residential homes
Norway (2007)	81%
Sweden	70–80%
Switzerland (2014)	60%
UK (2011/2013)	47.5% (dementia) 80% (significant memory impairment) 31% (cognitive impairment)

Reprinted with permission from “Palliative Care Systems in Long-Term Care Facilities in Europe”, by Froggatt et al., 2017 p.19.

### Box 2: Prevalence of dementia in nursing homes in Switzerland

Alzheimer Switzerland conducted two pieces of research in 2011 and in 2012 about the prevalence of dementia in nursing homes in Switzerland. For this work, they used the RAI (Resident Assessment Instrument) and PLAISIR (Planification Informatisée des Soins Infirmiers Requis) data in Swiss nursing homes. According to the first of these studies, which involved 26,000 residents from 386 nursing homes in 15 cantons, 47.6% of the residents had a diagnosis of dementia and 16.9% had a CPS  $\geq 3$  (Cognitive Performance Scale), which corresponds to suspected dementia. The study conducted in 2012, in four French-speaking cantons (Genève, Jura, Neuchâtel and Vaud), suggested an even higher prevalence, with 83.3% of the residents having either a diagnosis of dementia or suspected dementia (CPS  $\geq 3$ ).

## 2.4 Areas of interest to this report

The impact of the physical environment on health, wellbeing and quality of life is well established (Nordin et al., 2015). In particular, the layout of the building, the sensory environment and the privacy and autonomy of the residents have received a lot of attention from research (Barnes et al., 2002). A design that promotes independence and supports function is very relevant to residents. This includes for example the existence of handrails and seating along corridors (Potter et al., 2017). Some other elements, that can be particularly relevant to people with dementia, are those related to spatial orientation and wayfinding in the building (Barnes et al., 2002). In relation to stimulation, the existence of specific areas dedicated to sensory stimulation are of great importance, but also, the existence of outdoor spaces (gardens) and the lighting of the building can have an important impact on stimulation. In the 80's, Ulrich's work evidenced that patients with rooms with windows looking at a natural scene had shorter hospital stays (Ulrich, 1984 as referenced by Potter et al., 2017). There is also some research evidence highlighting the significance of artificial and natural light on various behaviours in care setting environments, with some research suggesting a relationship

between appropriate lighting and improved quality of life (Sorensen and Brunstron, 1995 as cited by Barnes et al., 2002). Privacy and control over the environment are also important aspects. Private space and home-like environments can enhance the person's wellbeing (Papoulias et al., 2014). In addition, having control over the environment, (as for example, having (or not) control of heating and ventilation in the resident's bedroom) has been associated with residents' satisfaction.

A well-performing health workforce is described by the World Health Organisation (WHO) as one where "there are sufficient staff, fairly distributed, they are competent, responsive and productive" (2007, p.6). Care workers are crucial to the quality of care and quality of life of residents in long-term care settings (Bowers et al., 2000). However, working in residential care has been described as stressful, and often, staff experience work-related stress and burn-out (Baker et al., 2015) with the level of turnover in these settings being an ongoing concern among scholars and policy makers (Mukamel et al., 2009). Job satisfaction, on the other hand, has been associated with (i) the opportunity

to provide high-quality person-centred care, (ii) effective leadership and teamwork and (iii) resident satisfaction (Schwendimann et al., 2016). In the case of dementia, lack of appropriate training and managing behaviours that challenge can be particularly stressful.

People living in residential care settings should receive care which respects, enhances and protects their human rights. The WHO has recognised the importance of ensuring a human rights-based approach for people with dementia (both living in the community and in residential care settings) and has recommended adopting the PANEL approach, which addresses participation, accountability, non-discrimination, empowerment and legality. People with dementia living in residential care should be able to exercise their human rights in all aspects of their daily lives including respect for dignity, privacy and autonomy, and should be enabled to participate in decisions affecting their lives and in the formulation and implementation of policies that affect them. There is concern that people with dementia may be at particular risk of abuse (Manthorpe, 2014). In

the UK, for example, work carried out by the Alzheimer's Society (2011) has drawn attention to the risks of financial abuse among people with dementia living in the community and in care homes; they are more at risk than others of money management problems, and potentially more vulnerable to financial abuse (2011, p.52).

In sum, the organisation and provision of residential care in Europe is heterogeneous, with relevant differences in the type of facilities providing care, the funding mechanisms and the regulatory systems for the implementation and overseeing of the quality of the care and support provided in these care settings. The environment, workforce and the care provided are key elements of the quality of care provided and are often part of the minimum requirements regulated in Europe. In addition to those, recent evidence suggest that, residents' rights (particularly choice and involvement), end-of-life care and abuse (particularly the unlawful or inappropriate use of restraint) may be also key aspects which are highly relevant to the people receiving the care provided in these care settings (European Commission, 2008).

## 2.5 Structure of the report

This comparative report looks at the topic of residential care facilities and, in particular, at the specific requirements that these facilities must meet when providing care. The report has a particular focus on regulatory requirements and standards that have been developed for or with people with cognitive problems or dementia in mind. People with dementia living in residential care settings often have more complex needs, may experience challenges in communicating these needs and may be less able than others to cope with inadequate care.

The report is structured as follows. It starts with an overview of the existing legislative frameworks for residential care in Europe, how dementia is addressed in this framework and how the requirements are implemented and monitored in the different countries. This is followed with information on whether each of the specific topics of relevance to this report (i.e. physical environment, staffing, care and human rights, end-of-life care and abuse and restraint) have been addressed in the legislation specifically in the context of residential care. The reports describes then in detail the requirements and provisions for each of these topics as written in the legislation and national standards.

### 3. Legislative frameworks for residential care facilities in Europe

Table 3 shows an overview of the regulatory framework for residential care facilities by country. In the majority of the cases, the main responsibility for regulating and monitoring the care provided in these facilities lies in the central government. However, in a number of countries (e.g. Austria, Belgium, Germany, Italy, Switzerland, Spain and Sweden) this function is de-centralised.

In some countries (e.g. Czech Republic, Finland, Latvia, Lithuania, Slovakia, Slovenia and Sweden), the main regulatory requirements that residential care facilities have to meet are covered by legislation for health and social services. Likewise, in the UK (England), the standards apply to all services registered with the Care Quality Commission (CQC)

that carry on regulated activities (e.g. residential care facilities, hospitals, hospices and community support facilities). Nevertheless, in many other countries, there is a regulatory framework which is specific for residential care facilities. Belgium (Wallonia), has different requirements for care homes for older people with lower dependency needs and nursing homes for older people with higher levels of dependency. Likewise, in the UK (Northern Ireland), two different sets of standards exist i.e. Minimum Standards for residential care homes and Care Standards for nursing homes<sup>8</sup>. Both sets of standards in Northern Ireland were written under the provisions of Article 38 of the Health and Personal Social Services (Quality Improvement and Regulation) (Northern Ireland) Order 2003.

Table 3: Regulatory framework by country

Country	Relevant legislative framework and national standards
Austria	<ul style="list-style-type: none"> <li>In Austria, residential care is not under the competence of the Federal Government, but under the competence of the Länder (there are 9 Länder in Austria). Each of them has different pieces of legislation, laws and care standards for residential care facilities. In addition, the Federal Ministry of Health and the Federal Ministry of Social Affairs developed the Austrian Dementia Strategy in 2015.</li> </ul>
Belgium (Flanders)	<ul style="list-style-type: none"> <li>The Special Act of 6 January 2014 provides for the Flemish Community to be given responsibility for various healthcare and welfare services, among other services the provision of residences for older people and long-term care.</li> <li>Residential Care Decree of 13 March 2009.</li> </ul>
Belgium (Wallonia)	<ul style="list-style-type: none"> <li>Code of Wallonia for Social and Health Care.</li> </ul>
Bulgaria	<ul style="list-style-type: none"> <li>Social Assistance Act and its regulation. Currently, a new law about social services is being drafted.</li> </ul>
Croatia	<ul style="list-style-type: none"> <li>People with dementia were mentioned for the first time in documents relating to nursing homes in 2009 (Ordinance NN64/2009 art. 82 to 86). Since 2014, and as stipulated by Law of Social Welfare NN157/13 art. 185, public nursing homes are allowed to take care of people with dementia. In 2015, additional and more concrete descriptions of the conditions for providing social services were developed. These are according to changes and additions to the Rule Book on the minimum conditions for providing social services NN 66/2015 (Ministry of Social Policy and Youth).</li> </ul>
Cyprus	<ul style="list-style-type: none"> <li>Law of 1991 for the operation of residential care facilities for senior citizens and disabled persons, and its 2000 updated regulations. Amended 2011.</li> </ul>

<sup>8</sup> In Northern Ireland, nursing homes are for people who have a disability or illness that means the person needs nursing care on a frequent basis.

Country	Relevant legislative framework and national standards
Czech Republic	<ul style="list-style-type: none"> <li>• Social Services Act. No. 108/2006 Coll. 2006 (effective from 1. 1. 2007).</li> <li>• Health Care Services Act No. 372/2011 Coll.</li> <li>• Decree No. 505/2006 (Quality standards for social services).</li> <li>• Decree No. 398/2009 Coll. on general technical requirements ensuring the barrier-free use of buildings.</li> <li>• Decree No. 6/2003 Coll. which sets the hygienic limits of chemical, physical and biological indicators for the indoor environment of the living rooms of some buildings.</li> <li>• ČSN 73 0802:2009 Fire safety of buildings.</li> <li>• ČSN 73 4301 Residential buildings.</li> </ul>
Finland <sup>9</sup>	<ul style="list-style-type: none"> <li>• Act on Supporting the Functional Capacity of the Older Population and on Social and Health Care Services for Older Persons (2012).</li> <li>• The Recommendations for the Quality of Elderly Services (Ministry of Social Affairs and Health) Social Welfare Act 710/1982, 2013, updated 2017.</li> <li>• Health Care Act 1326/2010.</li> <li>• Act on the Status and Rights of Social Welfare Clients (812/2000).</li> <li>• Act on the Status and Rights of Patients (785/1992).</li> <li>• Act on Private Social Services (922/2011).</li> <li>• Private Health Care Act (152/1990).</li> </ul>
France	<ul style="list-style-type: none"> <li>• Code of Social Action and Families (2017).</li> <li>• Code of public health, code of construction and housing, general code of local authorities (2017).</li> <li>• Law No. 2002–2 renewing social and medico-social activities and implementing decrees.</li> <li>• Law No. 2002–303 on the rights of patients and the quality of the health system.</li> <li>• Law No. 2005–102 for equal rights and opportunities, participation and citizenship of persons with disabilities.</li> <li>• Law No. 879 on hospital reforms and relative to patients, health and territories and implementing decrees (2009).</li> <li>• Law No. 2015–1776 on the adaptation of society to ageing and implementing decrees.</li> <li>• Law No. 2016–87 creating new rights for patients and the end-of-life.</li> </ul>
Germany	<ul style="list-style-type: none"> <li>• Law on Long-Term Care Insurance (LTCI) Code of Social Law XI (1995).</li> <li>• There are institutional care laws and regulations at federal state level regarding construction and staffing.</li> <li>• There are national expert standards for different topics<sup>10</sup>.</li> </ul>
Greece	<ul style="list-style-type: none"> <li>• Law N.2716/99 and FEK n.661/2000 (hospices for people with mental health problems)<sup>11</sup>.</li> <li>• FEK 455/1996 and FEK 1136/2007 (private Care Units for older people).</li> </ul>
Hungary	<ul style="list-style-type: none"> <li>• Act on Social Regulations and Social Assistance (1993/III.)</li> <li>• Act on Health (1997/CLIV).</li> <li>• Act on the informational autonomy and freedom of information (2011/CXII).</li> <li>• Regulation of the Minister for Social and Family Affairs 1/2000 on the tasks of social institutions providing personal care and the conditions of their operation.</li> <li>• National Standards for Physical Environment, Employment in Dementia Care for Residential Facilities for Older People.</li> </ul>
Ireland	<ul style="list-style-type: none"> <li>• S.I. No. 293/2016 Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) (Amendment) Regulations 2016.</li> <li>• National Standards for Residential Care Settings for Older People 2016.</li> <li>• Guidance on Dementia Care for Designated Centres for Older People 2016.</li> </ul>

<sup>9</sup> The Act provides the general requirements, the more specific details are further developed in various acts, norms and guidelines. The Ministry of Social Affairs and Health has published recommendations for the Quality of Elderly Service which are very influential but not mandatory.

<sup>10</sup> An expert group is developing standards for the care of people with dementia. The standards apply to care in general (i.e. not specific for residential care settings).

<sup>11</sup> These laws set the relevant requirements for hospices for people with mental health problems. These type of hospices are few, funded by the state and accept people over 56 who need psychogeriatric assistance. There is an ongoing consultation by the Ministry of Health on making specific additions to these laws for the five new Hospices-Palliative Care Units for people with dementia at the late stages of the condition that are planned to operate in different cities in Greece.

Country	Relevant legislative framework and national standards
Italy	<ul style="list-style-type: none"> <li>• Law 328/2000 Framework Law for the Implementation of the Integrated System of Social Services.</li> <li>• Ministry Decree 308/2001 Minimum Structural and Organizational Requirements for Authorization to Perform Services in residential and semi-residential structures, pursuant to Article 11 of Law No. 328.</li> <li>• This regulation lays the main principles which are then further developed in regional laws.</li> </ul>
Latvia <sup>12</sup>	<ul style="list-style-type: none"> <li>• Law on Medical treatment.</li> <li>• Law on the Rights of Patients.</li> <li>• Law on Social Services and Social Assistance.</li> <li>• Regulation No. 291 of the Cabinet of Ministers on “Requirements for social service providers”.</li> </ul>
Lithuania	<ul style="list-style-type: none"> <li>• Social care norms Order No. A1-46 of the Minister of Social Security and Labour (2007).</li> <li>• Law on Social Services.</li> <li>• Working time standards for social care staff Order No. A1-317 (2006).</li> </ul>
Luxembourg	<ul style="list-style-type: none"> <li>• Grand-ducal regulation concerning the approval for providers of services for older people (1999).</li> <li>• Law 24 July 2014 related to the rights and obligations of patients.</li> <li>• Law 19 June 1998 introducing the dependency insurance. In 2018, a new law on dependency insurance will be in place.</li> </ul>
Malta	<ul style="list-style-type: none"> <li>• Homes for Older Persons (Care Quality Standards) Authority Act, 2016.</li> <li>• National Minimum Standards (Care Homes for older people) 2015.</li> </ul>
Netherlands	<ul style="list-style-type: none"> <li>• Quality Framework for Nursing Home Care (2017)<sup>13</sup>.</li> <li>• Law on Long-Term Care (2014).</li> <li>• Law Quality, Complaints and Disputes in care (2015).</li> <li>• Law Occupations in the Individual Health Care (1993).</li> <li>• Tax regulations.</li> </ul>
Norway	<ul style="list-style-type: none"> <li>• The Act on Municipal Health and Care Services (2011, last updated 2017).</li> <li>• Regulations for nursing homes and special dementia units (1989, last updated 2013).</li> <li>• Patient and Users Rights Act (2001, last updated 2017).</li> </ul>
Poland	<ul style="list-style-type: none"> <li>• Social Assistance Act 2004. Amended in 2012.</li> <li>• Minister of Family, Labour and Social Policy Decrees on social assistance homes 2012 and 2017.</li> <li>• Old Persons Act 2015.</li> <li>• Minister of Health Regulation on guaranteed nursing and care services for long-term care of persons with chronic diseases.</li> </ul>
Portugal	<ul style="list-style-type: none"> <li>• D.L. No. 64/2007 on the legal framework for licensing and supervision of the provision of services.</li> <li>• Order (Portaria) No. 67/2012 on the conditions of organization, operation and installation to which residential establishments for older persons must comply.</li> <li>• Order (Portaria) No. 196-A/2015 on the criteria, rules and forms of the specific model of cooperation between the Social Security Institute and the Private Social Solidarity Institutions.</li> <li>• Order (Portaria) No. 100/2017 creating the “Program to Celebrate or Extend the Cooperation Agreements between the Social Security Institute and the Private Social Solidarity Institutions”.</li> </ul>

<sup>12</sup> These laws address some aspects of the care that should be provided in these facilities, however more specific details can be found in the internal documents and regulations of each residential care facility.

<sup>13</sup> Based on the quality requirements which are in the Law on Long-Term Care.

Country	Relevant legislative framework and national standards
Romania	<ul style="list-style-type: none"> <li>Order No. 2126/05.11.2014 regarding the approval of the minimum quality standards for the accreditation of social services for the elderly, the homeless, young people who have left the child protection system and other categories of adults in need, and for services provided in the community, services provided under the integrated social and Cantonese, published in the Official Gazette of Romania, Part I, No. 874/12.02.2014.</li> <li>Order of MMFPSPV No. 3123/2015 amending the Order of the Ministry of Labour, Family, and Social Protection and the Elderly of Romania No. 2126/2014.</li> <li>Order No. 67/21.01.2015 regarding the approval of minimum quality standards for the accreditation of social services for adults with disabilities.</li> </ul>
Slovakia	<ul style="list-style-type: none"> <li>Act No. 448/2008 Coll. on Social Services and on amending of the consolidated.</li> </ul>
Slovenia	<ul style="list-style-type: none"> <li>Social Security Act 2008 (last updated 2017) No. 540-01/91-5/46</li> <li>Health Care and Health Insurance Act 1992 (last updated 2013) No. 1992-2711-0044.</li> <li>Mental Health Act No. 1999-2711-0006.</li> <li>Health Services Act 1992 (last updated 2013) No. 1992-01-0460.</li> <li>Patient Rights Act 2008 (last updated 2017) No. 2005-2711-0080.</li> </ul>
Spain	<ul style="list-style-type: none"> <li>Law 39/2006 on the promotion of Personal Autonomy and Care for Dependant People.</li> <li>Agreement partially amending the Agreement approved by the Territorial Council of Social Services and the System for Autonomy and Care for Dependency on 2008 on accreditation of centers and services of the System for Autonomy and Attention to Dependency<sup>14</sup> 2015.</li> <li>The above law (2006) and agreement (2015) establish the main principles and minimum standards which are then further developed by regional law (Comunidades Autónomas).</li> </ul>
Sweden	<ul style="list-style-type: none"> <li>Social Services Act 2001.</li> <li>Health and Medical Service Act.</li> <li>Regulations and national guidelines published by the National Board of Health and Welfare.</li> </ul>
Switzerland	<ul style="list-style-type: none"> <li>The main responsibility for health care (Gesundheitsversorgung) lies within the cantons. All cantons have legislation for residential care facilities.</li> </ul>
Turkey	<ul style="list-style-type: none"> <li>There are two separate sets of regulations, i.e. for public residential facilities and for private facilities.</li> </ul>
UK (England)	<ul style="list-style-type: none"> <li>Health and Social Care Act 2008 (Regulated Activities) Regulations 2014<sup>15</sup>.</li> <li>Care Quality Commission (Registration) Regulations (Part 4) 2009.</li> </ul>
UK (Northern Ireland) <sup>16</sup>	<ul style="list-style-type: none"> <li>Health and Personal social services Order (2003).</li> <li>The Residential Care Homes Regulations (Northern Ireland) 2005; Residential Care Homes – Minimum Standards (2011).</li> <li>The Nursing Homes Regulations (Northern Ireland) 2005; Care Standards for Nursing Homes (2015).</li> </ul>
UK (Wales)	<ul style="list-style-type: none"> <li>Current regulation: Care Homes Regulation 2002 (all care homes), Minimum Standards for Care Homes for Older People 2004.</li> <li>Regulation and Inspection of Social Care (Wales) Act 2016.<sup>17</sup></li> </ul>
UK (Scotland)	<ul style="list-style-type: none"> <li>National Care Standards (NCS) (due to be replaced by the National Health and Care Standards (NHCS) from April 2018), deriving from the Public Services Reform (Scotland) Act 2010.</li> </ul>

<sup>14</sup> In addition to this agreement, there are regional laws for each Comunidad Autónoma. For example, in Madrid: Law 11/2002 on the organization of the activity of the centers and services of social action and of improvement of the quality in the provision of social services in the Comunidad Autónoma of Madrid. Order 612/1990 by which Decree 91/1990 is developed, relating to the authorization regime of social action centers and services.

<sup>15</sup> Section 23 of the Health and Social Care Act 2008 (HSCA 2008) stated that the Care Quality Commission (health and social care regulator) must produce guidance to help providers to comply with the regulations made under this Act. The guidance has been in force since April 2015 and was designed to implement Robert Francis's recommendations from his report about Mid Staffordshire NHS Foundation Trust.

<sup>16</sup> In Northern Ireland, "a residential care home provides residential accommodation with both board and personal care for persons in need of personal care by reason of old age and infirmity; disablement; past or present dependence on alcohol or drugs; or past or present mental disorder. They do not provide nursing care. A nursing home is any premises used, or intended to be used for the reception of, and the provision of nursing for persons suffering from any illness or infirmity. Some homes are registered to care for both people in need of residential or nursing care" (RQIA website).

<sup>17</sup> Not yet into force.

### 3.1 National Standards

In addition to the national or regional laws or acts, some countries have a separate document, often referred to as “Minimum Standards” or “National Standards”, which amplifies on the regulations and provides specific details on the different requirements. The following countries have this type of document: Ireland, Malta, Netherlands and the UK (Northern Ireland, Wales and Scotland). As these documents have received different names in each country (e.g. National Standards in Ireland, Minimum Standards in Northern Ireland, National Minimum Standards in Wales), for the purpose of this report, these documents will be referred as the “National Standards”.

The National Standards are in all cases regulated by law and there is a regulatory body or Authority designated to monitor and inspect their implementation (please see table 4 for further details)

The National Care Standards in Scotland (2002) are currently under review. Information on the current and new standards is provided in Box 3. In Norway, the Government is currently working at national level to improve the quality of residential care facilities; this work will inform the national standards.

**Table 4: Regulatory bodies/authorities**

Country	Name of regulatory body/authority
Ireland	Health Information and Quality Authority (HIQA): an independent authority established to drive high-quality and safe care for people using health and social care services in Ireland.
Malta	A Bill to establish the Homes for Older Persons (Care Quality Standards) Authority was drafted for consultation in August 2016. The Bill is still being discussed in Parliament.
Netherlands	The Netherlands Care Authority.
UK (Northern Ireland)	Regulation and Quality Improvement Authority.
UK (Wales)	Healthcare Inspectorate and Care and Social Services Inspectorate Wales.
UK (Scotland)	Care Inspectorate is an executive non departmental public body which carries out regulatory functions on behalf of the Scottish Government.



### Box 3: National Standards

#### Scotland: Current and new standards in Scotland

The current National Care Standards in Scotland (2002) are arranged in three sections: “Services for Adults”, “Services for Children and Young People”, and “Services for Everybody” and apply to regulated care settings. The Standards for care homes for older people describe what each individual person can expect from the service provider. In Scotland, as a result of the Regulation of Care (Scotland) Act 2001 there are no legal differences between residential homes and nursing homes, thus the standards apply to both. Within the existing National Care Standards (NCS), there are no dementia specific standards. However, the national regulatory body, the Care Inspectorate, uses good practice standards and guidance to inform decision making, recommendations and requirements when inspecting services. For dementia this includes the National Dementia Standards and Promoting Excellence’s quality of life indicators.

The National Care Standards in Scotland, have been under a process of review and new standards (National Health and Care Standards) will come into effect from April 2018. The new standards are relevant across all health and social care provision. They are no longer just focused on regulated care settings but for use in health and social care, as well as in early learning and childcare, children’s services, social work and community justice. The new standards reflect a greater focus on human rights and wellbeing. Also, the standards mark a shift in approach, moving from setting out what a provider of a care service must do, to describing what a person should experience as a result of care. This change to outcomes-focus standards means quality will be assessed with reference to the lived experience of a person, not just compliance with a set of minimum standards.

#### Norway

The Norwegian Government, in collaboration with the Minister for Health, has started some work at national level to improve the quality of residential care facilities. The work will be finished by 2020. The process has been called “Safe care facilities” and has involved municipalities, trade unions, professional organisations and patients organizations. So far, three main areas have been identified to work on and for which to develop models of better care quality. These are: (1) leadership and knowledge, (2) activities and (3) nutrition and food. The models will be tested in a number of municipalities before they will become national standards.

Last year, there was a lot debate about the quality of residential care facilities in Norway, in particular: malnutrition, the quality of the food and residents having to eat together were topics which got a lot of attention.

## 3.2 Dementia in the regulatory framework

According to the information provided by the participating countries, overall, dementia is not always sufficiently addressed in the regulatory context for residential care.

In some countries, dementia is addressed in relation to existing facilities (e.g. dementia-specific care units) for the care of people with dementia with behaviours that challenge (e.g. Croatia, France, Italy, Netherlands, Norway, Slovakia, Slovenia). Likewise, in Belgium (Wallonia), the Code of Social Action and Health has specific requirements for facilities with dedicated units for the care of people

with dementia. However, the word dementia itself is not used in the legislation<sup>18</sup>, as in Wallonia, this word is perceived in a negative way.

In some National Standards (e.g. in Ireland, Malta, UK – Northern Ireland and Wales) there are references to the needs of people with dementia (or of people with cognitive problems). For example, in Northern Ireland, in the Standards for Nursing Homes, in recognition of the high numbers of residents in nursing homes who present with some degree of the condition, three standards (i.e. standards

### Box 4: Example from Italy

In Italy, “Nuclei Alzheimer” are nursing and care units for people with dementia with major behavioural disorders.

These units (“Nuclei Alzheimer”) can be found within “RSA” (residential care facilities for people with moderate to severe dementia) and “IDR” (focus on providing rehabilitation, temporary stay).

<sup>18</sup> The term used is “disoriented people”.

24 to 26) are specific to the needs of residents with dementia: (standard 24 “Recognising the signs of dementia and responding to need”; standard 25 “Approach to care for residents with dementia” and standard 26 “Understanding and responding to distressed behaviour in residents with dementia”). Also, standard 10, refers to the use of memory, life story work and reminiscence and requires that staff are trained in effective reminiscence work and use a range of aids to stimulate memory and assist with memory (e.g. diaries and note books, visual stimuli and pictures).

Currently in Greece, there is an ongoing consultation, by the Ministry of Health, about introducing dementia-specific requirements into the existing national legislation for state-funded hospices. These requirements will apply to the new five hospices/palliative care units for people at advanced stages of dementia that are planned to operate in different cities in Greece. The National Observatory for dementia-Alzheimer and the Panhellenic Federation of Alzheimer’s disease and related disorders are involved in this consultation.

Some other examples include:

- A number of countries have developed guidelines on dementia care. In some cases, this guidance is specific for the care provided in residential care facilities, whilst in others, it refers to dementia care in general:
  - In Ireland, the Health Information and Quality Authority (HIQA) developed guidance for dementia care in residential centres for older people to guide service providers in the provision of high quality, safe and effective care for residents with dementia (“Guidance on Dementia Care for Designated Centres for Older People”, 2016).
  - France has guidance documents with recommendations, for example: “Support provided to people with Alzheimer’s disease or related dementias in health and social institutions”, 2009 and “Support for people with a neurodegenerative disease in specialised units”, 2017. Both guidance documents were published by the National Agency for the Evaluation and Quality of Social and Health and Social Institutions and Services (ANESM).
  - In Belgium (Flanders), the Centre of Expertise on Dementia has developed an integral frame of reference for the quality of life and care of people with dementia.
  - Scotland has developed standards for dementia care applicable to care in general (published the Scottish Government).
  - An expert group in Germany is currently developing standards for the care of people with dementia.
- In Belgium (Flanders), additional funding can be granted to residential care facilities with at least 25 residents with ‘dementia category C’ (i.e. who are incontinent and/or require assistance when eating and are physically dependent on others for moving around, going to the toilet and washing and dressing independently). In addition, dementia officers (i.e. professionals who have completed specific training on dementia accredited by the Flemish Government) can provide guidance on care and optimisation measures to residential care facilities providing care to people with dementia.
- In the UK (Scotland), the Care Inspectorate has carried out “dementia-focused inspections” in care homes for older people across Scotland, looking to support improvement by promoting and showcasing best practice and innovation in services which care and support people living with dementia.
- In some countries, there are references to the care that people with dementia should receive in residential care facilities in the National Dementia Strategy or Plan:
  - In Finland, the National Memory Programme (2012–2020) states that: “Local authorities and joint authorities will be responsible for providing 24-hour care to people with dementia according to national guidelines. The objective is to reduce the amount of residential care and to increase the availability of treatment alternatives based on housing and personalised services. The Finnish Ministry of Social Affairs and Health, the Finnish Ministry of the Environment and the Housing Finance and Development Centre of Finland will be responsible for coordinating local authorities and joint authorities in their efforts to ensure the quality of the living environments for people requiring 24-hour care and for promoting the development of alternatives based on housing and personalised services. Local authorities and joint authorities will be responsible for providing 24-hour care, in a manner, that ensures that the rights of people with mild, moderate and severe dementia are guaranteed and that the chosen service providers have the sufficient know-how to provide care to individuals with dementia”.
  - In France, the different national plans for dementia have aimed at increasing the number of beds in long-term care for people with dementia.
  - In Norway, the Dementia Plan 2020 states that “in nursing homes and assisted living facilities with 24-hour care, new buildings and the modernisation of existing buildings, will make residential facilities more dementia-friendly by creating small departments and housing collectives with space for community living and social activities. The grant scheme of the State Housing Bank imposes certain requirements on

the design of living units. They must be based on universal design principles, adapted to people with dementia and cognitive impairment, and

equipped for the use of electronic aids to daily living, communication and alarm technology, and other forms of welfare technology”.

### 3.3 Implementation and monitoring of the requirements: inspections

Residential care facilities have to comply with the regulatory requirements at the time of registration, and are monitored after registration. In Europe, inspections are the most common way of assuring minimum quality standards (Interlinks, 2010).

providers that work in smaller regions apply permits from a local Regional State Administrative Agency (AVI). In addition to the inspections, in Finland, all the service providers have to develop a self-monitoring plan and provide a yearly report to the regulatory body.

In the majority of the cases, the body responsible for such inspections is a national body (e.g. Bulgaria, Croatia, Czech Republic, Netherlands, Ireland, Luxembourg, Malta, Netherlands, Portugal, Slovenia, Turkey and the UK). In Finland, two different bodies exist: Valvira and AVI. Valvira is the national supervisory authority of welfare and health, and provides permissions to health and social care service providers with services in more than one region. The service

In terms of the frequency of inspections, overall in all countries, an inspection would take place if a complaint has been filled. In several countries, no specific time frames are listed in legislation and thus, the visit and inspection can occur at any time. In some countries (e.g. Croatia, Ireland, UK – Scotland), facilities which give raise to concern are inspected more frequently. Table 5 shows examples of provisions regarding the frequency of inspections.

#### Box 5: Examples of registration

##### Cyprus<sup>19</sup>

Residential care homes have to be registered (Law 222/91 on Long-term care residential facilities for the elderly and the disabled and the Regulatory amended Law 213/2006). In order to be registered, residential care homes have to pass a Social Welfare Services (SWS) notified inspection, which will prove that the facility complies with the law regulations. After registration, these facilities undergo unannounced inspections by an SWS officer at 6 months intervals. The inspector gives a report using an inspection tool, which was developed based on the law regulations and which is divided into the following requirements: personnel qualifications, level of care, facilities, comfort, security, level of health care, quality of foods and nutrition, behavioural treatment of the residents and their families, indoor and outdoor cleanliness, furnishings and infrastructure sufficiency, amusement and occupational therapy, contacts with relatives and the community, general atmosphere in the premises and compliance with the regulations (e.g. fire, hygiene etc.).

##### Luxembourg<sup>20</sup>

In Luxembourg, the provision of private residential services is restricted to organisations approved by the Ministry of Family Affairs based on the fulfilment of certain quality standards and after adhesion to a framework contract with the National Health Insurance, which determines the rights and obligations for executing the nursing care services. By the end of 2014, 52 nursing homes and integrated homes for older people with a mix of dependent and less-dependent residents were registered.

##### UK – England

When registering care providers, the Care Quality Commission (CQC) checks whether they meet a number of legal requirements including the fundamental standards of quality and safety. They also assess and make judgments about whether the services look suitable, whether there are enough staff with the right skills, qualifications and experience, the size, layout and design of the place they intend to provide care, their policies, systems and how effective they will be and how they are run and how they plan to make decision. After a service is registered, they are continuously monitored with reference to five key questions: are they safe; are they effective; are they caring; are they responsive to people’s needs and are they well-led.

<sup>19</sup> This text has been reproduced from Loizou C, 2010.

<sup>20</sup> This text is an excerpt from the Joint Report on Health Care and Long-Term Care Systems & Fiscal Sustainability, 2016, National report for Luxembourg.

Table 5: Frequency of inspections

Country	Minimum frequency of inspections
Belgium (Wallonia)	Annually.
Bulgaria	According to the plan adopted by the executive director of Social Assistance Agency.
Croatia	1–2 inspections per year.
Cyprus	Every 6 months.
Czech Republic	Inspections for quality standards every 3–5 years. <sup>21</sup>
Germany	Annually.
Ireland	At least once in a three-year cycle. Inspections can also be carried out at other times as informed by the centre's risk profile.
Luxembourg	At least once per year.
Portugal	Every two years ("extra" visits may occur if necessary).
Romania	Every 6 months.
Slovenia	At least once every three years.
Turkey	Annual visits and online grading on e-BHKS system (Quality Standards Care Services Online System).
UK (Wales)	Every year.
UK (Scotland)	At least once every year, but using a risk basis, so services which give rise to concern are inspected more frequently.

In some countries, (e.g. Czech Republic, Ireland, UK), in addition to reviewing the relevant paperwork and records and visiting the care facility, inspectors talk to different stakeholders including: people using the service, their representatives and families, staff and managers. In England, users or interested parties can report examples of poor care,

abuse and/or neglect they have experienced (or know about) in health and social care services. This can be done directly to Care Quality Commission (CQC) or through the 'share your experience' or the Healthwatch tools. In Scotland, anyone can make a complaint, anonymously if needed, to the Care Inspectorate which has the powers to investigate.

<sup>21</sup> This is not included in the law, this was described in the 2008 Recommendations.

## Box 6: Examples of monitoring quality and inspections

### Belgium – Flanders

#### Flemish Indicator Project

The Flemish Indicator Project measures the quality of care at Flemish residential care facilities.

The aim is to:

- Help residential care facilities to assess themselves and to improve their quality policy.
- Inform the residents or general public.
- Allow the government to use the results for inspections and accreditation assessments.
- Compare various facilities (benchmarking).

The residential care facilities measure indicators of care, safety, care providers and the organisation all year round. They provide the data to the Flemish Care and Health Agency twice a year.

#### The Residential Care Helpline

The Residential Care Helpline provides information and handles complaints about care services for older people

### Belgium – Wallonia

In Wallonia, nursing and residential care homes must be accredited before opening. Then, approximately once a year, they receive an inspection (specific or global). They have to meet a series of requirements relating to the building, safety, health care as well as the quality of their support for people who are 60 years or older.

The implementation of, and the compliance with, the requirements are monitored in a special program (only available to the public administration) which is used to prepare a biennial report where the results of this sector are analysed.

If an institution does not meet one of the standards, an inspector designated by the Government and working for the public service, will inform the management during the visit and give the manager a warning. If too many standards are not met, or if there concerns regarding the security and dignity of the residents, a proposal can be made to the Ministry of Health to close the institution.

### Germany<sup>22</sup>

In Germany, residential care facilities have to ensure the quality of the care they provide. In the contracts between the Federation of providers and the regional branches of the LTC insurance, it is stipulated that care providers are expected to meet the requirements and federal provisions (type of services provided, staff ratios and skills etc.), use a quality management system and use existing expert standards (e.g. related to medical and nursing care).

The Medical Advisory Boards of long-term care insurance funds, carry out the external monitoring/auditing of residential care facilities. In addition, the Local Residential Home Authorities ensure compliance with Land regulations. This includes inspections of the physical environment (e.g. rooms, living area, etc.), relevant activities and the care status of the residents.

If inspections are not successful, the Medical Advisory Board of sickness funds (MDK) may cut payments or exclude the provider from funding entirely.

<sup>22</sup> Summary from OECD/European Commission report, 2013.

In several countries, support to implement the regulated requirements and/or standards is provided to residential care facilities. However, differences are found in the type and intensity of such support. Some examples of the support provided include:

- Development of guidance documents on a number of relevant topics to support providers in the implementation of the regulated requirements (Finland, Ireland, Portugal, UK). Interestingly, in Northern Ireland, guidance documents have been developed also for members of the public.
- Provision of advice to the residential care facility at request (Germany, Finland, Ireland)
- Training on implementing of the requirements (Netherlands, Portugal and Slovenia).
- In the Czech Republic, when the national standards were launched (in 2006) some regional authorities provided support to social care facilities (e.g. onsite visits, support with methodological aspects etc.).
- In Malta, some standards will be phased in gradually for existing homes.

After an inspection, care facilities have to remedy any deficiencies identified. In some cases, there can be financial consequences for the facility if requirements are not addressed, as for example in Belgium (Flanders), Greece, Italy or Turkey where the facility may not receive funding from the health system, or in the Czech Republic, Malta, Romania, Poland and Portugal where the facility can be fined if the facility does not meet or comply with the regulated requirements and standards.

In England, after an inspection, the CQC produces a report which also includes a rating to show the overall judgment of the quality of care (outstanding, good, requires improvement or inadequate). By law, care providers must display the ratings the CQC gives them in the places they provide care, so that the people who use the services can see them, as well as on their website if they have one. In Belgium (Wallonia), the Government has developed a charter about

quality of care according to which, and in order to improve the quality of life of the residents, facilities for older people should focus on the needs and expectations of the residents and respect them. Care facilities that adhere to the charter are included in a list published by the Government and are given a “quality label”. Residents are informed about this.

In Scotland, in recent years, the Care Inspectorate has shifted the focus of its work on social care and social work services, from one based on an approach primarily concerned with compliance and inputs, to an improvement-focused approach which provides assurance about care quality and looks to improve the experience and outcomes for people who use care services. Quality is assessed by the extent to which care supports positive outcomes, not compliance. Scrutiny becomes a diagnostic tool which evidences what is working well and what needs to improve. An example of this change lies in changing inspection approaches. For example, where managers of services may have previously identified improvement needs within their services, (and there are robust plans to address the shortcoming), this would now be considered a management strength, rather than necessarily a service failure. Whilst inputs are not being removed completely, significantly more emphasis is being placed on the experience of the person using the service. This form of scrutiny does not mandate how improvement must take place – that is owned by local care leaders. The model provides independent evidence on whether improvement activity has been successful. In exceptional circumstances where services refuse to comply or do not improve, the Care Inspectorate can take legal action through the courts to have a service closed down, however, this is a measure of last resort.

In Wales, while the standards included in the National Standards are qualitative (i.e. they provide a tool for judging the quality of life of service users) they are also measurable. Regulators look for evidence that the requirements are being met and a good quality of life is enjoyed by service users. The involvement of lay assessors in inspections helps ensure a focus on outcomes for and quality of life of service users.

### 3.4 Areas addressed by the legislative framework/National Standards

Participating countries were asked to provide details of the specific regulated requirements or standards for the following areas:

1. Physical environment.
2. Workforce.
3. Care and human rights.
4. End-of-life care.
5. Abuse and restraint.

Table 6 shows whether each of the five key topics is addressed in the relevant legislation or National Standards in each country. Typically, requirements for the physical environment, staffing and care are well addressed. In the case of rights, very often this is covered through legislation on patients' rights, as the provisions in such legislation can also apply to residential care facilities. Likewise, the topic of abuse is often addressed not specifically in the context of residential care but as a societal issue. Gaps can be observed regarding end-of-life care and the use of restraint.

Table 6: Areas covered by legislative framework/National Standards

Country	Physical environment	Workforce	Care and rights		End-of-life care	Abuse	
			Health & social care	Human rights		Abuse	Restraint
Austria	•	•	•	•	•	•	•
Belgium (Wallonia)	•	•	•	•	•	•	
Belgium (Flanders)	•	•	•	•	•	•	•
Bulgaria	•	•	•				
Croatia	•	•	•	•	•	NP	
Cyprus	•	•	•				
Czech Republic	•	•	•	•	•	•	•
Finland	•	•	•	•	•		•
France	•	•	•	•	•	•	•
Germany	•	•	•	•	•	•	•
Greece	•	•	•			•	
Hungary	•	•	•	•	•		•
Ireland	•	•	•	•	•	•	•
Italy	•	•	•	•		•	•
Latvia	NP	•	NP	•			
Lithuania	•	•	•	•	•	•	
Luxembourg	•	•	NP	•	•	•	•
Malta	•	•	•	•	•	•	•
Netherlands	•	•	•	•	•	•	•
Norway	•	•	•	•	•	•	•
Poland	•	•	•	•	•	•	•
Portugal	•	•	•	•	•	•	•
Romania	•	•	•	•	•	•	
Slovakia	•	•	•	•	•	•	•
Slovenia	•	•	•	•	•	•	•
Spain	•	•	NP	NP	NP	NP	NP
Sweden	•	•	•	•	•	•	•
Switzerland	•	•	•	•	•	•	•
Turkey	•	•	•	•	•	•	•
UK	•	•	•	•	•	•	•

NP: Information not provided.

### 3.5 Personal account



**(Alv):** I was diagnosed with vascular dementia 7 years ago. I currently live with my wife Berit in a small village in Norway. To me, the most important issue in residential care facilities is how to provide a stable and peaceful environment i.e. no sudden changes in routines or personnel. If changes have to be made, they should have a slow progress and be peacefully explained. The person should be supported by staff-members well-known to him/her.

**(Berit):** It will be a very sad loss if, or when, the time comes when you have to assign your husband to other people's care. As a wife, I would wish the nursing home to provide calm and predictable surroundings, and a homely atmosphere where I, or other family members, could visit freely. I would also want it to be a place where meaningful activities are provided, and where all kinds of assistance are offered with respect and thoughtfulness in accordance with his actual needs. To feel sure that this will, in fact, be the case will greatly lessen the sorrow, and help both my husband and myself settle better into this new phase in life.

Alv Orheim (EWGPWD) and Berit Orheim, Norway.



# 4. The physical environment of the residential care facility

## 4.1 Design and layout of the facility

Overall, residential care facilities need to comply with the legal requirements for buildings and hygiene, safety and fire regulations. In addition to these, several countries have specific requirements related to the design and layout of residential care facilities (please see table 7 for details).

Furthermore, in Belgium (Flanders), Croatia, the Czech Republic, Finland, Italy, Lithuania, Portugal, Romania, Spain and the UK (Northern Ireland, Scotland and Wales)

requirements exist related to the location of the premises which should facilitate that residents enjoy a social life in the community and receive visits, examples of this include:

- Location which is appropriate or close to urban areas, or easily accessible,
- Existence of public transport,
- Existence of car parking spaces for residents, visitors and staff.

Table 7: Requirements for the physical environment

<b>The building should be of sound construction and kept in good state of repair. The furniture and decoration should be appropriate.</b>	Belgium (Flanders), Croatia, Ireland, Malta, Spain, UK (Northern Ireland, Scotland and Wales).
<b>The physical environment should be as homely and comfortable as possible.</b>	Belgium (Flanders), Finland, Ireland, Lithuania, Malta, UK (Scotland).
<b>The premises/furniture/equipment have to be suited to needs of all residents (including residents with specific needs) and the design and layout suitable for its stated purpose.</b>	Croatia, Cyprus, Finland, Hungary, Ireland, Italy, Malta, Netherlands, Romania, Spain, UK.
<b>The design and layout should help to promote the wellbeing of the residents.</b>	Czech Republic, Finland, Ireland, UK (Scotland).
<b>The design and layout should help to ensure that residents live in safe surroundings.</b>	Czech Republic, Finland, Ireland, Luxembourg, Malta, Poland, Romania, UK (England and Scotland).
<b>All areas in the premises meet the privacy and dignity of each resident.</b>	Belgium (Flanders), Finland, Ireland, Spain, Slovenia, UK (England and Scotland).
<b>The building should be accessible.</b>	Belgium (Flanders), Czech Republic, Finland, Malta, Poland, Slovenia, Switzerland.
<b>It should be clearly signed and arranged to minimise confusion and promote independence of residents with cognitive impairment/dementia (e.g. find their way around easily).</b>	Croatia, Germany (Baden-Württemberg <sup>23</sup> ), Ireland, Luxembourg, Malta, UK England, UK Scotland (in guidance).

<sup>23</sup> Standards for the federal state of Baden-Württemberg in Germany.

## 4.2 Lighting, heating and ventilation

In addition to the relevant environmental health and safety requirements, in several countries it is stated that the lighting and temperature of the premises should be adequate and suitable for the needs of residents. Many countries specifically recognise the relevance of natural lighting and have requirements to maximise the amount of natural light in residential care facilities and to ensure that the areas used by residents are naturally ventilated. In addition, in some countries, it is stated that the lighting should help people to carry out daily tasks, such as reading or other activities (please see table 8 for details).

In Belgium (Flanders), Lithuania and Slovenia, it is specified that bedrooms should have curtains or other mechanisms to provide occupants with the means to control the amount

of daylight that enters their room. Likewise, the National Standards in Scotland state that the person should be able to control the lighting, heating and ventilation of his/her room, and the heating in the case of Ireland. In Belgium (Flanders and Wallonia), Ireland, Malta and the UK (Northern Ireland and Wales), the height of the windowsill should afford an unobstructed view when the residents are seated or when in bed. In Greece, in private facilities, bedrooms and other communal areas on the ground floor should have direct access to outdoors.

In addition, in some countries, particularly those with high temperatures in the summer (e.g. Cyprus, Turkey), residential care facilities are required to have air conditioning systems.

Table 8: Lighting, heating and temperature<sup>24</sup>.

<b>Lighting/ temperature suitable for the needs of residents.</b>	Cyprus, Finland, Germany (temperature), Ireland, Lithuania, Luxembourg, Portugal, Spain, Slovakia, Slovenia, Turkey, UK Wales.
<b>Natural lighting, domestic in character</b>	<p>Croatia, Czech Republic, Ireland, Lithuania, Luxembourg, Malta, Romania, Spain, Turkey, UK (Northern Ireland and Wales).</p> <ul style="list-style-type: none"> <li>• Belgium (Flanders): the window surface area must be at least 1/6 of the net floor surface area<sup>25</sup>. Resident rooms, lounges or dining rooms with a net floor area of more than 30m<sup>2</sup> must have a window surface area of at least 1/7 of the net surface floor area.</li> <li>• Lithuania: daylight factor<sup>26</sup> in bedrooms 0.5%.</li> <li>• England: minimum average daylight factor of 1% in bedrooms<sup>27</sup>.</li> <li>• Poland: window-to-floor area ratio<sup>28</sup> in bedrooms 1:8.</li> </ul>
<b>Good quality artificial lighting</b>	<p>Belgium (Wallonia), Greece, Lithuania, Malta, Switzerland, UK (Northern Ireland and Wales).</p> <ul style="list-style-type: none"> <li>• Belgium (Wallonia): the illuminating surface shall be at least equal to one sixth of the surface area of each living room or room of the residents, excluding any entrance.</li> <li>• Lithuania: common areas for leisure/entertainment 150 lux; educational areas and kitchen 300 lux; stairs, corridors and hygiene areas 100 lux.</li> <li>• Malta: in bedrooms 150 lux.</li> <li>• Switzerland (canton of Zurich): 300–500 lux, dazzle free.</li> <li>• Northern Ireland: 100–200 lux in toilets and 0–400 lux in bedrooms, dimmable lighting.</li> <li>• Wales: in bedrooms 150 lux.</li> </ul>

<sup>24</sup> In Scotland, many of these requirements are assessed and considered at the point of a care home applying to be registered, and taken into account in making a decision about the application.

<sup>25</sup> This is the actual occupied area not including unoccupied accessory areas such as corridors, stairways, toilet rooms, mechanical rooms and closets.

<sup>26</sup> The daylight factor is a unit of measurement that is used to quantify the amount of daylight in a room.

<sup>27</sup> British Standard on daylighting (Lewis, 2015).

<sup>28</sup> A window-to-floor ratio provides a rough rule of thumb for determining optimum areas of window in relation to the floor area of a room.

**Room temperature/ventilation**

- Belgium: minimum temperature of 22°C in the rooms. In case of a heat wave, at least one of the common spaces must be air-conditioned.
- Croatia: temperature of 20–22°C in bedroom areas, in corridors and other spaces 18°C. In case of high outdoor temperatures, the temperature in the rooms should be 5°C lower than outside.
- Czech Republic: The minimum temperature in the bedroom areas is, for warm weather, 24°C (-2°C) and in cold weather 22°C (-2°C).
- Greece: in public hospices: heating in all the rooms and air conditioning in the bedrooms. In private facilities: central heating (or other equivalent) system that ensures a standard 22°C throughout winter. Air conditioning should be installed in communal spaces and in bedrooms.
- Ireland: minimum temperature of 18°C (65°F) in bedroom areas and 21°C (70°F) in day areas. Rooms used by residents are individually and naturally ventilated with windows conforming to recognised standards
- Spain: temperature of at least 20°C.
- Poland: ventilation must ensure air exchange (WT and PN-83 B-034430 norm).

**Lighting that facilitates activities (reading etc.)**

Germany, Ireland, Malta, Portugal, UK Northern Ireland and Wales

**Resident able to control amount of lighting/temperature (blinds, curtains, etc.)**

Czech Republic, Ireland, Lithuania, Slovenia, Turkey, UK (Scotland)

**Accessible e.g. easy-to-use switches**

Germany

### 4.3 Adaptation and equipment to maximise residents' independence, call systems and use of closed circuit television (CCTV)

In Finland, Norway, Portugal and Switzerland (canton of Zurich), whereas, no specific requirements regarding the accessibility of residential care facilities exist, these facilities need to follow the requirements included in state regulation regarding accessibility of buildings and public spaces. In the case of Norway, universal design.

In the majority of the countries, requirements exist stating that residential care facilities should be accessible and promote the mobility and independence of residents, and in many cases, is mentioned that, suitable adaptations such as provision of ramps, grab rails, lifts, hoists, or other aids should be made. The National Standards in Ireland, specifically refer to the needs of people with dementia in this respect:

“residents, including those with (...) dementia or other cognitive impairment, have access to relevant communal areas, through the provision of, where required: ramps and passenger lifts, stair and chair lifts, grab rails, hoists and other aids, appropriate signage and colour, schemes to assist safe mobility”.

Examples of other specific requirements include:

- In Belgium (Flanders), steps, stairs and other obstacles must be avoided in all rooms accessible to the residents. Handrails and handles should be available to facilitate that residents can move around the building. Corridors accessible to residents must be at least 1.80m wide.
- In Belgium (Wallonia), corridors and stairways should be wide enough and have grab rails on both sides. The first and last step must have a strip of a bright colour that contrasts with the floor.
- In Finland, from 2018 onwards, new and renovated buildings will need to follow the new accessibility act. According to the new act, the passage to the exterior door must be easily visible, with even surface, not slippery and at least 1.20m wide, with a maximum 5% inclination. The minimum door width should be 0.80m. Thresholds, if unavoidable, should be 0.20m maximum. Corridors should be easily visible, even and not slippery. If a corridor is narrower than 1.50m, every 15metres there should be a minimum 1.50m-wide area for people to change direction. This also applies to the corridor and kitchen. The design of the building should enable the use of aids (such as wheelchairs) and personal assistance. In Finland, it is quite common for residential facilities to have saunas. Whilst there are no legal requirements about the existence of saunas in residential care facilities, if a residential care facility has a sauna, all the areas of the sauna have to be suitable for people with reduced mobility.
- In Greece, the height of handrails on corridors and staircases should be 0.80–0.90m. The width of the doorways should be wide enough for a wheelchair. Communal spaces should have glass doors which should be adequately signed in order to prevent accidents. Bathrooms should have outward opening or sliding doors.
- In Luxembourg, corridors wider than 1.20m should have grab rails on both sides of the corridor, those narrower than 1.20m should have grab rails on one side. Buildings of new construction are required to have corridors of at least 1.80m width. Doorways are minimum 0.90m wide and 2m high. Floors should not be slippery or smooth and should be adapted to the specific needs of residents who use walking aids or a wheelchair.
- In Slovenia, corridors should be at least 2m wide and have rails on both sides. Glass surfaces should be visibly marked and secured with fences. Floors should not be slippery. Stairways should be at least 1.20m wide, secured with grab rails on both sides.
- In Turkey, floors should not be slippery. Rugs should be fixed to the floor. The furniture should be comfortable and safe.
- In the UK (Northern Ireland), doorways in areas accessed by residents should have a clear opening width of at least 0.8m, in homes where residents need assistance when walking or use wheelchairs wider doorways are recommended. Floor coverings, wall finishes and soft furnishings should be suitable for the purpose of each room. Finishes that produce glare, dazzle and optical illusions should be avoided and where residents use wheelchairs, floor coverings should have non-directional pull. Changes in the texture of floor coverings or other indicators should be considered to identify key areas in the home, for example doorways or the top or bottom of stairs. The minimum corridor width in areas accessed by residents is 1.20m unobstructed between handrails, but in homes where residents need assistance when walking or use wheelchairs, a minimum width of between 1.50m and 1.80m is recommended.
- In the UK (Wales), doorways into communal areas, service users' rooms, bathing and toilet facilities

and other spaces to which service users requiring wheelchairs and assisted walking have access, should have a clear opening width of 0.80m.

- In the UK (Scotland), all inside doors should have a clear opening width of 0.84m, off wide corridor (of at least 1.2m). Slip-resistant flooring should be used in bathrooms, kitchens or where surface contamination cannot be effectively controlled. Where floor levels change, they should be clearly identified and hand rails should be considered. It should be noted that highly reflective materials may be a barrier for people with dementia.

Several countries have requirements for a passenger lift if the home has more than one floor (Belgium-Flanders, Finland, Germany, Greece, Italy, Ireland, Luxembourg, Slovenia, Turkey, Spain, UK). In Turkey and Scotland, it is required that the person should be able to operate the lift. In Malta, in the National Standards it is stated that independence of residents should be maximised, and in the UK there are references to the use of assistive technology to promote independence of residents.

In relation to call systems, in Belgium, Czech Republic, Germany, Ireland, Italy, Luxembourg, Malta, Switzerland (canton of Zurich) and the UK, call systems which are accessible to residents should be installed in all bedrooms and in toilets and bathrooms. In Ireland, residents should be instructed on how to use the call-bell. The National Standards in Ireland, Malta, England and Wales make reference to the use of CCTV cameras. In England, if any form of surveillance is used for any purpose, the provider must ensure that this is done in the best interests of people using the service and should be operated in line with current guidance. In Ireland, if CCTV systems are used to protect the safety and security of residents, they should not intrude on privacy and there is a policy on the use of CCTV which is informed by relevant legislation. In Malta, the use of cameras including CCTV is in principle restricted to entrance areas, passage ways, lifts and stairs for security purposes. However, for safety or communication reasons, management in agreement with residents or their representatives may introduce a camera in their rooms as long as this does not compromise the privacy of other residents. The more restrictive requirements are found in Wales, where according to the National Standards, CCTV cameras can only be installed in external doors (not inside the care home).

## 4.4 Bedrooms, communal and outdoor spaces

Among the countries that provided information for this topic, the most common minimum floor space (excluding en-suite facilities) seems to be 12m<sup>2</sup> for single, and 16 m<sup>2</sup> for double, bedrooms. The minimum size for residents' private room is larger than this in Belgium (Flanders), Finland, Luxembourg, Slovenia and Switzerland (canton of Zurich). In many countries, larger rooms are required for residents with disabilities or using a wheelchair. In Northern Ireland, for example, in such case, the size of single rooms should be 20m<sup>2</sup>.

In terms of occupancy, several countries allow for up to four residents to be accommodated in the same room. However, there is a shift in many countries and new requirements state that bedrooms should accommodate a maximum of two residents. Interestingly, in Finland, Norway and Northern Ireland, it is expected that all (or almost all) bedrooms in the facility should be single. Likewise, in Belgium (Flanders), Ireland<sup>29</sup> and Wales, an important proportion of rooms (90, 80 and 85% respectively) should be single rooms. Table 9 shows requirements per country in relation to the size of the bedrooms, maximum occupancy per bedroom, and provisions for the proportion of single rooms in residential care facilities. In some countries (see for example UK Northern Ireland), different requirements apply to the minimum floor

space and maximum occupancy of the room, depending on the date when the facility was registered (i.e. after or before the date when the National Standards or legislation were approved). The figures provided in Table 9 apply to new facilities (or facilities registered after the legislation or National Standards were in place), information about the year from which it applies and requirements for facilities registered prior to this date are provided in the footnotes.

Residential care facilities also need to provide adequate indoor communal spaces separately from the residents' private accommodation. In several cases, the legislation or National Standards make reference, in particular, to: sitting, recreational and dining spaces. In a few countries, there is a requirement for these spaces (e.g. recreational and dining) to be separate. In Finland, residential care facilities which accommodate more than 10 residents should have two separate communal spaces. In terms of the size of the communal areas differences across Europe exist (please see table 10 for details). Cyprus, Germany, Portugal, Slovenia and Spain require a minimum floor space of around 2 m<sup>2</sup> (or slightly less) per resident in communal spaces. On the other hand, Luxembourg seems to be one of the countries requiring the largest minimum space in communal spaces (5 m<sup>2</sup> per resident). In Hungary, Ireland, Luxembourg, Malta, Poland,

<sup>29</sup> Applies to all new buildings and extensions.

Turkey and the UK the communal spaces should include a space that could be used to meet visitors in private. In Luxembourg, a kitchenette and living area (“un espace de séjour”) should be accessible to residents and their families. In addition, several countries (e.g. Hungary, Ireland, Lithuania, Malta, Poland, Portugal, Slovenia, Turkey and Wales) require the existence of spaces to meet the spiritual/religious needs of residents.

Whereas the requirements for indoor spaces seems to be quite well covered in the majority of the countries, outdoor

spaces are less often addressed. Belgium (Flanders), Croatia, Cyprus, Finland, Greece, Ireland, Lithuania, Luxembourg, Malta, Romania, Switzerland (canton of Zurich), Turkey and the UK (Northern Ireland and Wales) have requirements for the existence of outdoor spaces which should be accessible to all residents (including residents with disabilities). In Greece, the outdoor space should be five times (in m<sup>2</sup>) the number of beds (e.g. for 50 beds the open space should be 250m<sup>2</sup>). In Northern Ireland, according to the National Standards, in “care homes registered to accommodate people with dementia there is a secure perimeter”.

Table 9: Requirements for residents’ private rooms

Country	Size single bedrooms <sup>30</sup>	Size other bedrooms <sup>31</sup>	Max. residents per room	Proportion of single bedrooms
Belgium (Wallonia)	12m <sup>2</sup>	9m <sup>2</sup> per resident	2 <sup>32</sup>	At least 50% single rooms
Belgium (Flanders)	16m <sup>2</sup>	Double: 30m <sup>2</sup>	2	Max. 10% of residents are in double rooms.
Croatia <sup>33</sup>	7m <sup>2</sup> per resident	7m <sup>2</sup> per resident	2	Max. 20 residents per unit. At least 2 bedrooms should be single
Cyprus	4m <sup>2</sup> per resident <sup>34</sup> , distance between beds at least 1m	4m <sup>2</sup> per resident <sup>34</sup> , distance between beds at least 1m		
Czech Republic	12m <sup>2</sup>	Double: 20m <sup>2</sup> 25m <sup>2</sup> (wheel chair users)	2	
Finland	25m <sup>2</sup> <sup>35</sup>			All single rooms unless residents want to share
Germany	12m <sup>2</sup>	Double: 18m <sup>2</sup> Triple or quadruple: 6m <sup>2</sup> per resident.	4	
Greece (public hospices)			2 (sometimes 3)	
Greece (private facilities)	12m <sup>2</sup>	Double: 18m <sup>2</sup> Triple: 24m <sup>2</sup> Quadruple: 30m <sup>2</sup>	4	
Hungary	6m <sup>2</sup> per resident	6m <sup>2</sup> per resident	4	
Ireland	12.5m <sup>2</sup> <sup>36</sup>		4	80% residents in single room

<sup>30</sup> Minimum floor space excluding en-suite facilities.

<sup>31</sup> Minimum floor space excluding en-suite facilities.

<sup>32</sup> From January 2015.

<sup>33</sup> Requirements that should be met to provide services to people with mild to moderate dementia (Rule book and its amendments on the minimum conditions for providing social services NN 66/2015).

<sup>34</sup> This does not include the space for cupboard and en-suite facilities.

<sup>35</sup> According to guidelines published in 2015.

<sup>36</sup> This requirement applies to all new builds and extensions.

Country	Size single bedrooms <sup>30</sup>	Size other bedrooms <sup>31</sup>	Max. residents per room	Proportion of single bedrooms
Italy			2	
Lithuania	5m <sup>2</sup> per resident	5m <sup>2</sup> per resident	2 <sup>37</sup>	
Luxembourg	16m <sup>2</sup> <sup>38</sup>	Double: 28m <sup>2</sup> <sup>39</sup>	2	
Malta	12m <sup>2</sup> <sup>40</sup>	8m <sup>2</sup> per resident	2	
Poland	9m <sup>2</sup>	6m <sup>2</sup> per resident	3 4 (bedridden)	
Portugal	10m <sup>2</sup>	Double: 16m <sup>2</sup> Triple: 20,50m <sup>2</sup>	3	Min. 20% single rooms Max. 20% triple rooms
Romania	6m <sup>2</sup>	6m <sup>2</sup>	3	
Slovenia	17,5m <sup>2</sup>	Double: 21,5m <sup>2</sup>		
Spain (Madrid)	5,50m <sup>2</sup> per resident 7,50m <sup>2</sup> (wheelchair users)	5,50m <sup>2</sup> per resident 7,50m <sup>2</sup> (wheelchair users)	6	
Switzerland (canton of Zurich)	14m <sup>2</sup>	Double: 20m <sup>2</sup> Triple: 27m <sup>2</sup> Quadruple: 36m <sup>2</sup>	4	
Turkey	9m <sup>2</sup>	Double: 16m <sup>2</sup> Triple: 22m <sup>2</sup> Quadruple: 26m <sup>2</sup>	4	
UK (Northern Ireland) <sup>41</sup> (residential & nursing homes)	12m <sup>2</sup> and 20m <sup>2</sup> (if registered for people with disabilities)		1	100% single rooms <sup>42</sup>
UK (Wales)	12m <sup>2</sup> <sup>43</sup> 13,5m <sup>2</sup> (wheelchair users)	Double: 16m <sup>2</sup>		85% single rooms
UK (Scotland)	12,5m <sup>2</sup> <sup>44</sup>	Double: 16m <sup>2</sup>	2	

<sup>37</sup> Applies from 2013; facilities prior to 2013, 4 residents.

<sup>38</sup> Applies to facilities from 2010, prior to 2010, 9m<sup>2</sup>.

<sup>39</sup> Applies from 2010, prior to 2010, 15m<sup>2</sup>.

<sup>40</sup> Pre-existing care homes have 10 years (from the date of implementation of these Standards) to comply with requirements for single and double rooms.

<sup>41</sup> Environmental requirements are different for existing buildings (buildings that already operate and are registered as nursing homes prior to 2008) and new buildings (i.e. buildings registered since 2008 as nursing homes and new extensions to any existing registered home). The requirements in the table apply to new buildings. Facilities prior to 2008: 11.5m.

<sup>42</sup> Two adjoining bedrooms with a connecting door or movable partition for residents who want to share a room. Facilities registered prior to 2008: 80% single rooms.

<sup>43</sup> This applies to care homes registered since 2002 and new extensions to existing homes. Facilities prior to 2002: 9.3 m<sup>2</sup>. This standard does not apply to existing homes with three residents or fewer.

<sup>44</sup> This applies to care homes applying to, and being registered after, 1st April 2002. For homes in existence and registered before that date the requirement is 10.25m<sup>2</sup>.

Table 10: minimum floor space for communal indoor spaces

Country	Communal space (excluding corridors and circulation areas)	Dining area
Belgium (Flanders)	Communal lounges and dining areas at least 4m <sup>2</sup> per resident	
Croatia	2m <sup>2</sup> per resident	
Cyprus	2m <sup>2</sup> per resident (separate from dining area)	2m <sup>2</sup> per resident
Czech Republic	A room of minimum size 18m <sup>2</sup> which could be a dining room with adequate seating arrangement	
Germany	A room of minimum size 20m <sup>2</sup> if more than 20 residents in the facility. In general, 0.75–1m <sup>2</sup> per resident. Accessible to all residents including those bedridden	
Greece (private facilities)	1m <sup>2</sup> per resident in dining room, living room and room for occupational therapy	
Hungary	A room of minimum size 20m <sup>2</sup> for social activities and dining area	
Ireland	Recreation and dining space provides a minimum of 4m <sup>2</sup> for each resident	
Luxembourg	5m <sup>2</sup> per resident	
Malta	Indoor communal space (indoor sitting, recreational and dining space) 4m <sup>2</sup> for each resident	
Portugal	Living room/activities 2m <sup>2</sup> per resident, minimum floor area 15m <sup>2</sup> It should accommodate at least 80% of the residents at any one time	
Slovenia	Living room/activities 1.5m <sup>2</sup> space per seat Number of seats at least half of the residents	1.5m <sup>2</sup> per resident and accessible to wheelchairs
Spain (Madrid)	1.80m <sup>2</sup> per resident, minimum floor area 12m <sup>2</sup>	1m <sup>2</sup> per resident – minimum floor area 10m <sup>2</sup>
Switzerland (canton of Zurich)	4m <sup>2</sup> per resident, larger communal rooms for people with dementia	
UK (Northern Ireland) (residential care and nursing homes)	4m <sup>2</sup> for each resident. This allows for dining space of at least 1.5m <sup>2</sup> per person and sitting space of 2.5m <sup>2</sup> per person. Dining room to cater at any one time all residents <sup>45</sup>	
UK (Wales)	Recreational and dining space amounting to 4.1m <sup>2</sup> for each resident (5.1m <sup>2</sup> for wheelchair users). Dining room to cater for all residents	
UK (Scotland)	3.9m <sup>2</sup> for each resident	

<sup>45</sup> Applies to new buildings (i.e. buildings registered since 2008 as nursing homes and new extensions to any existing registered home). Prior to 2008: 3.7m<sup>2</sup> for each resident (excluding corridors and circulation areas). This allows for dining space of approximately 1.4m<sup>2</sup>/person and sitting space of approximately 2.3m<sup>2</sup>/person.



## 4.5 Personal account



I have never lived in a care home, but my daughter Nelida and I had the opportunity to learn about some of the features of some care homes in Madeira, which made us think: what could be improved?

In Madeira, we don't have specialist care homes for people with dementia. Still, many care homes are trying to improve the care provided to residents who have dementia and all other residents. Some care homes are converted buildings (e.g. from an existing house). This means, that sometimes, there are barriers for residents with mobility needs, e.g. stairs, slopes in outdoors spaces, unsuitable floors. Many care homes

have made a great effort to modernize, for example, with lifts. Overall, new, purpose-built care homes have remarkably improved their psychical environment. Despite this though, in many cases, up to four residents have to share a room. To me, this is difficult to accept. I enjoy getting along with other people, but the bedroom is where we are able to maintain our privacy. Also, in many care homes converted from existing buildings, private rooms are very small and sometimes do not have a private bathroom. Our "borders" are easily invaded. Other aspects, such as the temperature and lighting, have been greatly improved due to the readiness to integrate automation systems or air conditioning systems in care homes. Common areas also have been improved: they are now more comfortable, stimulating, pleasurable and more intimate. For example, there are less people per common room and there are different rooms for different activities (e.g. exercising, arts, reading). This suggests that more attention has been paid to the individuality and occupation of each resident. In my opinion, the strength of Madeira's care homes is outdoors spaces. Gardens and landscape have been always an important aspect of houses in Madeira. I imagine that for people who live in care homes, outdoor spaces are an important space to be with others, to participate in activities or to spend some quality time. I have the impression that many positive changes were achieved last year. This has been partly due to social pressure, but also, as the people on the boards of these facilities, seem to be more aware of the importance of promoting a better quality of life for all the residents.

**Idalina Aguiar (EWGPWD) and Nélida Aguiar, Portugal.**

## 5. Workforce

### 5.1 The registered manager

All countries require the existence of a manager, coordinator or director of the residential care facility. In the majority of the cases, specific requirements exist in relation to the qualification, experience and other relevant aspects of this person (please see table 11 for further details). Several countries require that the manager of the facility holds a higher education qualification. In the majority of the cases, this includes a number of health or social related disciplines such as social work, nursing or allied health professions. Ireland, Malta, Spain and Switzerland (canton of Zurich) do

not provide details for the qualification of the manager. Differences also exist in terms of the required experience. Less than half of the countries have a requirement for experience, and the amount of work experience required varies from 2 years in the UK (Wales) to 5 years in Croatia and Slovenia. Belgium, Finland, Ireland, Malta, Slovenia, Spain and the UK emphasise the need of knowledge, qualification, experience or training related to management. In Spain and the UK (Northern Ireland and Scotland), the manager needs to be registered in an official register.

Table 11: Requirements for the manager of the residential care facility

Country	Qualifications	Years of work experience (minimum)	Other aspects
<b>Belgium (W)</b>	Higher education		Official course recognised by the Ministry of at least 300 hours
<b>Belgium (F)</b>	Suitable certificate, degree or similar educational qualification.	OR Three years of experience in a similar position	
<b>Croatia</b>	Degree in social work, social policy, law, psychology, sociology, social pedagogy, educational rehabilitation, speech therapy, pedagogy, medical, humanities or other social sciences.	At least five years of relevant work experience, of which at least three years should be in the field of social welfare or other social activities related to the academic degree.	
<b>Cyprus</b>	Degree in Social Work, or Social Welfare Institution Management, or Sociology, or Psychology, or Psychiatry, or Occupational Therapy, or Gerontology, or Medicine, or other relevant degree		
<b>Finland</b>	Suitable higher education degree (e.g. social work, nursing)		Knowledge of the industry Sufficient managerial skills
<b>Germany</b>	Nursing specialist		
<b>Ireland</b>	Appropriate qualifications	Sufficient practice and management experience	
<b>Lithuania</b>	Higher education		
<b>Luxembourg</b>	Degree in medicine, law, business, psychology, pedagogy, sociology, occupational or speech therapy, nursing, physiotherapy, social work, rehabilitation, nutrition, education – or – a bachelor's degree in Social and Educational Sciences. An exemption can be made if the director has a work experience of at least 10 years	Three years of professional experience in the field of social work, education, medicine, care, administration, management or the gerontological framework	The manager has to be able to speak at least two of the three official languages in Luxembourg  Competent in management and health related sciences. Familiar with the conditions/diseases associated with old age
<b>Malta</b>			

Country	Qualifications	Years of work experience (minimum)	Other aspects
Norway	The Health and Care Services Act 1990 (last amended 2017) addresses the qualifications, license and certificates for all staff.		
Poland	Degree in social work or in education	Experience is required	Additional training is required
Portugal	Higher education in social sciences and behaviour, health or social services	Experience (preferred)	
Romania	Graduate with a diploma: higher education in psychology, social work or sociology OR Graduate with a Bachelor's degree: higher education in legal, medical, economic or administrative sciences	Two years' work experience in the field of social services Five years' work experience in the field of social services	Additional training in specific field is an advantage.
Slovenia	Degree in social work OR Degree in psychology, pedagogy, law, administration, sociology, occupational therapy, theology or other education in sociology, health or medicine	Five years' work experience Five years' work experience in the field of social work	Training in management of social welfare institution
Spain			Registered with the registry of directors of social services Official course recognised by the Ministry of Social Services of at least 240h
Switzerland			Competent and trustworthy person The manager has to work full-time in the facility and should be registered with the Public Care Office of the Ministry of Family and Social Policies
Turkey	Degree in medicine, psychology, social work, management of health services or nursing		

Country	Qualifications	Years of work experience (minimum)	Other aspects
<p><b>UK (Northern Ireland)</b></p>	<p>Registered social worker or first level registered nurse or registered allied health professions</p> <p>OR</p> <p>A Level 5 Diploma in Leadership for Health and Social Care Services (registered)</p>	<p>Four years' work experience in health and social care setting. At least two of them, in operational management capacity</p> <p>Five years' work experience in health and social care setting. At least two of them, in operational management capacity</p>	<p>Registered with the Regulation and Quality Improvement Authority</p> <p>Knowledge and understanding of the legal responsibilities and of health and social care services available in the area for the service user groups served by the residential care home</p>
<p><b>UK (Wales)</b></p>	<p>National Vocation Qualification (NVQ) level 4 in care, social work qualifying award, NVQ level 4 award in the management of care or a similar qualification – or – first level registered nurse and NVQ level 4 award in the management of care or a similar qualification</p> <p>Managers require to have both a practice and management qualification.</p> <p><b>Practice qualifications:</b></p> <ul style="list-style-type: none"> <li>● Scottish Vocational Qualification (SVQ) Social Services and Healthcare at Scottish Credit and Qualifications Framework (SCQF) Level 9.</li> <li>● BA (Hons) Social Work (or equivalent).</li> <li>● A qualification meeting the registration requirements by the Health and Care Professions Council, General Teaching Council (Scotland), Nursing and Midwifery Council or the General Medical Council.</li> <li>● Degree/Diploma in Community Education.</li> </ul> <p><b>Management Qualification:</b></p> <ul style="list-style-type: none"> <li>● SVQ 4 Care Services Leadership and Management at SCQF Level 10, or any award in management that is certificated at or above SCQF Level 8 (minimum of 60 credits) showing evidence the award has been mapped against the National Occupational Standards (NOS); Leadership and Management for Care Services.</li> </ul> <p>Certain past practice and management qualifications are also accepted.</p>	<p>Two years' experience in a senior management capacity in the managing of a care setting within the past five year</p>	
<p><b>UK (Scotland)</b></p>	<p>Managers require to have both a practice and management qualification.</p> <p><b>Practice qualifications:</b></p> <ul style="list-style-type: none"> <li>● Scottish Vocational Qualification (SVQ) Social Services and Healthcare at Scottish Credit and Qualifications Framework (SCQF) Level 9.</li> <li>● BA (Hons) Social Work (or equivalent).</li> <li>● A qualification meeting the registration requirements by the Health and Care Professions Council, General Teaching Council (Scotland), Nursing and Midwifery Council or the General Medical Council.</li> <li>● Degree/Diploma in Community Education.</li> </ul> <p><b>Management Qualification:</b></p> <ul style="list-style-type: none"> <li>● SVQ 4 Care Services Leadership and Management at SCQF Level 10, or any award in management that is certificated at or above SCQF Level 8 (minimum of 60 credits) showing evidence the award has been mapped against the National Occupational Standards (NOS); Leadership and Management for Care Services.</li> </ul> <p>Certain past practice and management qualifications are also accepted.</p>		<p>Must be registered with the Scottish Social Services Council (SSSC). Over the five-year registration period managers must complete 25 days or 150 hours of Post Registration training and learning to maintain and develop effective knowledge, skills and values to deliver good practice. Managers must also be notified to the Care Inspectorate.</p>

## 5.2 Staff that should be present in the residential care facility

In Finland, Ireland, Italy, Malta and the UK (England, Northern Ireland and Wales) it is stated, that there should be at all times, sufficient numbers of staff with the necessary experience, skills and competences, to meet the needs of all residents.

In other countries, requirements exist for the presence in the residential care facility of the following professionals:

- Medical doctor: Belgium (Flanders), Croatia<sup>46</sup>, France, Greece (in private facilities and a psychiatrist in case

of hospices), Hungary<sup>47</sup>, Latvia, Netherlands<sup>48</sup>, Norway and Turkey.

- Nurse: Belgium (Flanders), Croatia, France, Germany, Greece (hospices and private facilities), Latvia, Luxembourg, Netherlands<sup>49</sup>, Norway, Poland, Slovakia, Switzerland and Turkey.
- Social worker and other allied health professionals (AHP): Belgium (Wallonia and Flanders), Croatia, Czech Republic, France, Greece (hospices and private facilities), Hungary, Latvia, Lithuania, Poland, Slovakia, Slovenia and Turkey.

## 5.3 Care assistant-to-resident ratio

This requirement refers to the minimum amount of care assistants that must be employed per residential care facility. In some countries, the ratio of care assistants to residents is not specified (e.g. Cyprus, Czech Republic, France, Ireland, Italy, Latvia, Norway and the UK). In some countries (e.g. Ireland, UK – England), each facility is required to provide sufficient numbers of suitably trained and capable staff to meet the needs of their residents. It is argued that each resident has different needs and that needs change over time. This is what should dictate staff ratios and each residential care facility should respond to this.

However, in some other countries references to ratios are made. For example:

- Belgium (Flanders): five care assistants to 30 residents.
- Croatia: five care assistants to 20 residents (this ratio is for units providing care to people with dementia).
- Hungary: 24 care assistants to 100 residents.

In some cases, ratios are not defined specifically for care assistants but refer to all staff providing direct care to residents (e.g. including nurses, AHP etc.). Examples of this approach are found in:

- Belgium (Wallonia): one member of staff to five residents.
- Finland: 0.5 care staff to one resident.
- Slovakia: one member of staff to two residents.

- Poland: 0.4 staff members to one resident, and 0.5 in the case of residents with (physical) disabilities.

Finally, another approach is found in some countries where the required ratio is calculated taking into account the level of dependency of residents, for example:

- Cyprus: for independent residents, one care assistant to 10 residents; for dependent residents, one care assistant to five residents.
- Germany: for residents who require care level 1 the ratio is of one care assistant to 13.40 residents; for care level 2, one to 4.60; care level 3, one to 2.80; care level 4, one to 1.99 and care level 5, one to 1.77.
- Greece (private facilities): during the day, for independent residents one nurse and one care assistant to 25 residents; one nurse and one care assistant to 15 dependent residents. Over 25 residents, one more care assistant should be provided per 11 residents.
- Lithuania: three to five care assistants to 10 residents with severe disability and 0.8 to three care assistants to 10 residents with mild to moderate disability.
- Luxembourg: in integrated centres for older people: one care assistant to 20, 10, 5 or 2.5 residents, respectively from residents who are more independent to those who have more care needs. In nursing homes, only the last two ratios (i.e. 1 to 5, 1 to 2.5 residents) apply.

<sup>46</sup> Units providing care to people with dementia must have a visiting psychiatrist (8 hours/month for every 50 residents or 4 hours/month for every 25 residents).

<sup>47</sup> A minimum of 4 hours presence per 100 residents.

<sup>48</sup> On-call physician who can reach the facility within 30 minutes.

<sup>49</sup> On-call nurse who can reach the facility within 30 minutes.

- Malta: the ratios of care staff are determined according to the assessed needs of residents and in accordance with the Barthel 20 index.
  - Portugal: one care assistant to eight residents; one care assistant to five highly dependent residents.
  - Romania: the ratio of staff (this includes care assistants but also other professionals providing care) to residents in facilities providing care to older people is calculated according to the needs of residents and in accordance with the minimum quality standards.
- For independent residents, who can carry out activities of daily living, the ratio is one to 10. For dependent residents the ratio is one to two and for people with disabilities, one to one.
- Slovenia: ratio of care staff (this includes care assistants but also other professionals providing care such as AHP) 0.25 for independent residents and 0.35 for dependent residents.
  - Turkey: one care assistant to 15 residents, in special units for older people one to 10.

Table 12: Ratio of staff to one resident according to dependency of the residents<sup>50</sup>

Country	Less dependent	More dependent
Cyprus	0.10	0.20
Germany	0.07 to 0.21 (level 1 to 2)	0.35 to 0.56 (level 3 to 5)
Greece (private facilities)	0.08 <sup>51</sup>	0.13 <sup>51</sup>
Lithuania	0.08 to 0.30	0.30 to 0.50
Luxembourg	0.20	0.40
Portugal	0.12	0.20
Romania	0.1	0.5 to 1 <sup>52</sup>
Slovenia	0.25 <sup>53</sup>	0.35 <sup>53</sup>
Turkey	0.06	0.10

Table 12 shows relevant differences in terms of the ratio of care assistants to residents in the different countries. Germany, Lithuania, Luxembourg and Poland (also Finland and Slovakia but in these cases all care staff are included) seem to require the highest ratios of care assistants to residents. However, due to the complexity and diversity of long-term care systems in Europe, any conclusions should be taken

with great caution as these figures may be due to differences in the type of residential care facility, type of care and services provided and residents who are most likely to live in these facilities. Also, these figures need to be considered along with the composition of the team providing care, ratios for other health and social professionals present in the facility and required training and skills.

## 5.4 Nurse-to-resident ratio

In relation to the presence of nurses and nursing specialists, the following requirements exist:

- Belgium (Flanders): five fully qualified nurses for every 30 residents. A nurse should be present at all times.
- Croatia: four nurses to 20 residents (in units providing care to people with dementia).
- Germany: If there are more than four dependent residents, every second member of the staff should be a nursing specialist<sup>54</sup>. There should be, at least, one nursing specialist during the night.
- Ireland: at all times care should be supervised by a registered nurse on duty. The number of registered nurses required is determined by the assessment tool. At any point in time, the number and skill mix of staff on duty is determined and provided according to a transparently applied, nationally validated, assessment tool, to plan for and meet the needs of the residents. This is subject to regular review.
- Lithuania: one nurse to 10–30 residents.
- Luxembourg: at least one member of the staff should be a registered nurse. In facilities with 50–100

<sup>50</sup> Own calculations, based on provided data.

<sup>51</sup> This figure includes care assistant and nurse.

<sup>52</sup> This ratio includes all staff providing care.

<sup>53</sup> This ratio includes all staff providing care.

<sup>54</sup> In Germany, a nursing specialist is a nurse or a geriatric nurse with at least two years of professional experience.

residents a second nurse should be present from 6am to 10pm. In facilities with more than 100 residents, a second nurse should be present at all times.

- Malta: at least one qualified registered nurse on duty during every shift.
- Netherlands: a qualified nurse on call who can reach the facility within 30 minutes.
- Portugal: one nurse to 40 residents, one nurse to 20 residents who are highly dependent.
- Switzerland (canton of Zurich): at least 50% of the staff providing care must be a nursing specialist.
- Turkey: in any residential care facility there should be at least one nurse (or “health officer”). One nurse to every 30 residents.
- UK Northern Ireland (Care Standards for Nursing Homes): at least 35 per cent of the staff should be registered nurses and 65 per cent care assistants.

## 5.5 Qualification and training

In some countries, like Cyprus and Ireland, it is stated that all staff, including care assistants or care workers, should have the competencies to manage and deliver services to all residents. In other countries, specific requirements in regards to the minimum qualifications that care assistant should hold exist, for example:

- Croatia: 500 hours of basic education over a 6-month period for care assistants (this training is not dementia specific).
- Czech Republic: basic education and a 150 hours expert course.
- Germany: completed training.
- Greece (private facilities): license to practice if required and health certificate<sup>55</sup>.
- Ireland: all nursing staff are, where possible, facilitated to undertake a relevant post-registration qualification in the nursing and care of older people. All newly recruited care staff and those in post less than one year should commence training to FETAC (Further Education and Training Awards Council) Level 5 or equivalent within 2 years of taking up employment. Long-standing care staff should have their competency and skills assessed to determine their need for further training and suitable arrangements should be put in place to meet their identified training needs.
- Malta: at least training at MQC (Malta Qualifications Framework) level 3 and a recognised “care of the elderly” certificate.
- Poland: secondary education and 2-year vocational training.
- Slovakia: accredited course of 220 hours.
- Spain: professional qualification on health and social care for dependent people in welfare institutions (Decree 1368/2007).

- Turkey: qualified as technicians for the care of older people or training in the care of older people certified by the Ministry of Education.
- UK (England): care certificate.

Also, in some cases, it is specified the minimum percentage of care staff members who should have completed a particular qualification:

- Hungary: at least 80% of the care staff has a relevant qualification.
- Romania: specialised personnel represent 60% of the total staff.
- UK (Wales): at least 50% of the care staff hold NVQ (National Vocational Qualification) level 2
- UK (Scotland): at least 50% of the care staff hold SVQ (Scottish Vocational Qualification) level 2.

In relation to the training, in the majority of the cases it is required that staff receive training which often can be in-house or provided externally. In some cases, there is a minimum number of hours of training that staff need to complete. For example, in Belgium (Flanders), full-time members of staff<sup>56</sup> should complete 20 hours of training over a period of two years. In the Czech Republic, staff should receive a total of 24 hours, and in Portugal 35 hours of training per year. In Malta, staff are entitled to three paid days of training and in the UK (Wales) to five paid days per year. Belgium (Flanders), Germany, and the UK (England and Scotland) offer training in dementia care, however this training is not mandatory. According to the National Standards for Nursing Homes, in the UK (Northern Ireland) staff induction should include training on communication and engagement with people with dementia.

<sup>55</sup> According to the new requirements for hospices (currently under consultation), medical personnel will need to have work experience in the field of dementia, psychogeriatric and behavioural neurology.

<sup>56</sup> This does not apply to domestic staff.



## 5.6 Personal account



**(Helga):** I was diagnosed with Lewy body dementia (LBD) at the age of 54. From my perspective, residential care facilities should have a team consisting of people who are experts by training (i.e. professionals). I don't think volunteers should be responsible for providing this type of care. Certainly I would not like this for myself. Also, it is very important that staff providing care to me is fluent in my mother tongue. The number of staff should be according to the stage of dementia and symptoms. At night, and considering that one of the symptoms of LBD is hallucinations, one-to-one care would be essential. The staff should be sufficiently qualified especially geriatric and psychiatric nurses. My dream is to have a supporter who matches the characteristics of my personality: the belief in God, love for arts, love for animals and a quite educated personality. These are some of the things that I would appreciate if I had to move to a residential care facility:

- A garden or orchard with different flowers.
- Animals outside (sheep, hens) and inside (cats, dogs, birds).
- I would be happy to watch a film and talk about it.
- I would like do some painting or art work.

**(Juliane):** I have been supporting Helga for a while now. I also have personal experience of working in care homes in Germany. From my perspective, it is important that all staff in the care home work together as a team (including housekeepers, nurses, psychologists, activity supporters etc.). All professionals, no matter the country they are coming from, should have the same professional training. As well, it is extremely important to have a profound knowledge of dementia and of the cultural background of the resident. In my experience, trained volunteers can also collaborate with the staff members and help with tasks that staff can't carry out because of lack of time. In my own experience, in many care homes, the staff-to-resident ratio should be improved in the evening and at night.

Helga Rohra (EWGPWD) and Juliane Katrin Visser, Germany.

## 6. Provision of care and rights

### 6.1 Admission

In the majority of the countries, at the time of admission, prospective residents (and/or their representatives) should be informed in writing about the key aspects of the service provision. This information has to be given before or on the day of admission. In Belgium (Wallonia), the Czech Republic, Ireland, France and Slovenia, prospective residents should also be informed about their rights and obligations. In Ireland, according to the National Standards, information on rights should be provided in an accessible format and residents should be supported in understanding their rights. In addition, often the resident is required to sign a contract (or agreement) which should describe, among other aspects, the services that will be provided and often, their cost. The National Standards for nursing homes in Northern Ireland refer specifically to the importance of this pre-admission stage for people with dementia:

“It is vital that at the pre-admission stage prospective residents, their relatives and representatives have all the information they need to make an informed choice about moving into the home. This is particularly important for those residents whose capacity to make informed choices might be limited due to learning disability, mental health issues or cognitive impairment such as dementia”.

In the Czech Republic, Ireland, Malta and the UK (Northern Ireland, Wales and Scotland) it is stated that the information has to be written in a language and format suited to the prospective resident. In Malta, the information has to be available in English and Maltese. In Turkey, information about the residential care facility should be available in an accessible format.

The National Standards in Malta, Ireland and the UK (Northern Ireland and Wales) specifically state that admissions into a residential care facility should be planned. In Ireland and

Northern Ireland, the residents' needs should be assessed prior to admission to a residential care facility to ensure that their needs can be met by the facility. In Northern Ireland, the residents' medical history (e.g. medication and treatments), referral forms and any necessary aids and equipment should be in place prior to admission.

In Bulgaria, Croatia, the Czech Republic, Ireland, Lithuania, Malta, Romania, Slovenia, Turkey and the UK (Northern Ireland, Wales and Scotland), it is stated, that there should be opportunities for the prospective resident (and his/her next of kin, representative or friends) to visit the residential care facility, spend some time in it and meet the staff as well as other residents before making a decision about moving in. In some countries (e.g. Netherlands), visiting the care facility prior to admission is encouraged but it is not stated in the regulation.

Specific provisions exist in Ireland and in the UK (Northern Ireland and Wales) regarding the support that a resident should receive from staff members around the time of admission. In Ireland, residents should be consulted with, supported and involved in the planning for their transition into the residential care facility. The prospective resident should be offered the opportunity to meet with a member of staff prior to admission, to discuss what the transition into the residential service will mean and the application for admission. In Wales, prospective residents are given the opportunity for staff to meet them in their own home and also can benefit from a place on a “trial basis”. In Northern Ireland, the manager or a senior member of staff should visit the resident prior to admission and a named member of staff should be identified to provide support for the resident for the first few days and a key worker from the staff team subsequently. In Hungary, before admission, some health care professionals (e.g. GP, social workers, etc.) have to assess if the prospective resident is entitled to admission.

Table 13: Requirements in relation to the admission of residents

<b>Residents being informed in writing about internal regulations (information about the residential care facility, services provided, charges etc.) and signing a contract/agreement.</b>	Belgium (Wallonia and Flanders), Bulgaria, Croatia, Czech Republic, Hungary, Finland, France, Netherlands, Germany, Ireland, Lithuania, Luxembourg, Malta, Portugal, Romania, Slovenia, Slovakia, Turkey, UK (Northern Ireland, Wales and Scotland).
<b>Residents being informed in writing about their rights and obligations.</b>	Belgium (Wallonia), Czech Republic, Ireland, France, Slovenia.
<b>Prospective residents being able to visit the facility before admission.</b>	Bulgaria, Croatia, Czech Republic, Ireland, Lithuania, Luxembourg, Malta, Romania, Slovenia, Turkey and the UK (Northern Ireland, Wales and Scotland).
<b>Specific support from staff around the time of admission.</b>	Croatia, Ireland, Luxembourg, Poland, Slovenia, UK (Northern Ireland and Wales).

A common provision related to consent at the time of admission, is the need for the resident to sign a contract or admission agreement that sets out the terms and conditions of accommodation and residence. The relevant national legislation on decision making, legal capacity<sup>57</sup> and involuntary internment should also be taken into account for residents who may lack capacity to consent or may need support to consent at the time of admission or at any other time. Often, this legislation was developed for internment in hospital settings or is related to people with mental health problems. Some countries, however, have provisions which apply specifically to residential care settings. These provisions for moving into or out of the residential care facility, follow in some cases a relatively flexible approach which allow a relative or the appointed guardian to make these decisions (e.g. Croatia, Norway, Slovakia, Slovenia, Turkey), whereas in other countries, these decisions have to be approved by Court (e.g. Czech Republic, Netherlands). In countries where this legislation has shifted to assisted or supported decision-making (e.g. Ireland, UK), the resident should be supported for as long as possible in making these decisions. Some examples are provided below:

- In Norway, according to the Regulations for nursing homes and special dementia units (article 4), if a resident with dementia (or if for some any other reason the person cannot safeguard his/her own interests) wants to move out of the residential care facility, or go to a different care home, this has been decided in consultation with their relatives.
- In Croatia, Slovakia, Slovenia and Turkey, if the person has an appointed legal guardian, the legal guardian can make this decision and sign the contract/agreement on behalf of the person.
- In the Czech Republic, if the resident has an appointed legal guardian, additional approval from the Court (or guardianship council) is required for admission. If a resident living in a residential care facility has a serious disagreement with the service provided to him/her but is no longer able to terminate the contract him/herself, the service provider should inform the Court of this disagreement within 24 hours. The Court has then to decide within 45 days whether the person should or should not stay in the residential care facility. Similarly, in the Netherlands, residents admitted under BOPZ law (The Psychiatric Hospitals (Compulsory Admissions) Act – Wet bijzondere opnemingen in psychiatrische ziekenhuizen, BOPZ), cannot leave the facility without approval from the Court.
- In Ireland, each resident, where appropriate, should be supported to make informed decisions and have access to an advocate. Residents with a cognitive impairment should receive the support they require to uphold their right to exercise their legal capacity. Effective arrangements that protect the will and preferences of each resident who lacks capacity to give informed consent are in place. Each resident's consent to treatment and care is obtained in accordance with legislation and current evidence-based guidelines. Where residents express a wish to leave care and return home, they are involved in planning and discussing the best way to prepare for their move on.
- In the UK, in keeping with the different mental capacity legislation that exists across the nations, a person should be presumed to have mental capacity to consent or refuse care or treatment unless proven

<sup>57</sup> For further information on this topic, please see Dementia in Europe Yearbook 2010 and 2016.

otherwise. Residents should be involved in decision making in line with relevant guidance on consent, treatment and care. In the Standards for nursing homes in Northern Ireland, the resident (or their representative) and the Registered Person should sign the agreement prior to, or within five days of, admission. Where the resident or their representative

is unable or chooses not to sign, this is recorded. Neither the Registered Person nor any staff member acting as an appointee or agent on behalf of a resident may sign the written agreement on the resident's behalf. The agreement should be made available in a format and language suitable for the resident.

## 6.2 Assessment of needs, care plan and provided care

Overall, all countries have provisions related to the need to document some personal, social and health related information about the resident and develop an individual care plan. In some countries, the required information and the care plan tend to focus more on medical and nursing issues, whereas in other countries this seems to take a more holistic approach (please see table 14 for

details). Differences can also be observed in relation to the expected involvement of the resident and his/her family in drawing up and reviewing the care plan. In Romania and Northern Ireland (National Standards for nursing homes), there are references to staff training in or having the necessary skills to develop care plans for the residents.

Table 14: Assessments of needs and care plans

Country	Content	Who is involved?	Revisions
<b>Belgium (F)</b>	<p>The individual care and guidance plan for each resident should include at least the following information:</p> <ul style="list-style-type: none"> <li>• Personal details,</li> <li>• Attending physician,</li> <li>• Person(s) to be notified in case of an emergency,</li> <li>• Personal characteristics, life history,</li> <li>• Individual needs or wishes,</li> <li>• Agreement on the care offered,</li> <li>• Coordination of care services,</li> <li>• Agreements on leisure and social activities.</li> </ul> <p>The care plan should support the greatest level of personal autonomy and self-responsibility.</p>	The care and guidance plan should be approved by the resident (or family member/carer).	
<b>Belgium (W)</b>	<p>Each resident should have an individualised record of care. This should include the indications for the medical, paramedical and nursing care and physiotherapy. It should contain details of how this care will be implemented and any observations or remarks from the staff who implemented it. It should also include the date of medical visits, medication prescribed and dosage, care required, the examinations/tests that were required and diet.</p>		
<b>Bulgaria</b>	<p>Each resident should have an individualised plan of care which includes the medical care, nursing care and care provided by allied health professionals. The care should also include social work and therapy (i.e. speech therapy, work therapy). The plan should contain details of how the care will be implemented and by whom.</p>	The resident and his/her family	The care plan is reviewed regularly according to the needs of the resident.
<b>Croatia</b>	<p>The individual needs of each resident should be assessed in particular, the nursing and medical care needs, treatment and evaluation. The biography of each resident with key life facts provided by family of the person with dementia should be available to the staff.</p>	The professionals (nurses, social workers) involved in developing the care plan should evaluate it on regular basis and modify the individual care plan if it is necessary in collaboration with GP and with approval of resident and family members.	The care plan should be revised regularly by the professionals (nurses, social workers) who were involved in developing it.
<b>Cyprus</b>	<p>A file with the resident's personal data and history should be kept. Each resident should receive a medical evaluation and a care plan should be developed.</p>		

Country	Content	Who is involved?	Revisions
<b>Czech Republic</b>	The individual needs of each resident should be assessed, in particular the nursing and medical care needs, treatment and evaluation. Regarding social care, the “goals” of care must be set in a care plan and evaluated.	Professionals involved in developing a care plan should evaluate it annually and modify it if necessary.	Annually or when any changes in the resident’s health status occurs.
<b>Finland</b>	The service plan must be based on the assessment of the older person’s functional capacity and the social and health care services that are needed to support the person’s wellbeing, health, functional capacity and independent living and to ensure a good care of the person.	The older person (and if necessary, his/her family members, other people close to him/her, or the legal guardian) must discuss the plan. The person’s views must be recorded in the plan.	When important changes occur in the older person’s functional capacity that affect the person’s service needs.
<b>Germany</b>	The following information has to be documented for each resident (article13 LTCI) <ul style="list-style-type: none"> <li>• care history including relevant biographical information,</li> <li>• care plan,</li> <li>• care report,</li> <li>• proof of implementation.</li> </ul> Public hospices and private facilities should have a personal file for every resident which should include an assessment of the resident’s needs. In private facilities, a personalised therapeutic program should be developed and reviewed every 6 months, there should be a weekly report of every activity. In hospices, changes are monitored on ongoing basis and taken in account.	Staff of the institution, residents themselves, family caregiver or legal guardian.	Ongoing process.
<b>Greece</b>			Every six months.
<b>Hungary</b>	The individual care plan should contain: <ul style="list-style-type: none"> <li>• assessment of the resident’s physical and mental health,</li> <li>• necessary tasks to improve or maintain the resident’s health status and their timing,</li> <li>• other elements of support/care.</li> </ul> An individual assessment is carried out for all residents initially and the care plan is developed and continually assessed. Individual care plans are based on holistic ongoing assessments which identify personal, health, social and recreational goals, where appropriate. The cognitive ability of residents is assessed and they receive the necessary care and support to maintain a good quality of life.	The professionals involved in developing the care plan should evaluate it annually and modify the individual care plan if necessary.	The professionals involved in developing the care plan should evaluate it annually and modify the individual care plan if needed.
<b>Ireland</b>		Residents’ participation in the care planning process is central to supporting them to identify their goals, needs and preferences and what supports need to be put in place by the service to ensure that their needs are met.	Residents can expect that their care plan will change as their circumstances and/or need for support changes.

Country	Content	Who is involved?	Revisions
Italy	<p>An individual care plan should be drawn up for all residents. The individual plan should indicate the objectives to be achieved, the content and modalities of the intervention and how it will be evaluated.</p>		
Latvia	<p>An individual social care or social rehabilitation plan in accordance with the functional condition of the resident should be developed. The plan shall include the following:</p> <ul style="list-style-type: none"> <li>● a definition of the problem to be solved;</li> <li>● the purpose of the social rehabilitation or social care;</li> <li>● the tasks of the social rehabilitation or social care; and</li> <li>● the evaluation of the social rehabilitation or social care.</li> </ul>		
Lithuania	<p>An individual social care plan is provided to residents, it should contain detailed information about the person's contacts and family, information from his/her doctor about his/her health status, information about his/her social needs, the measures to be taken, provided services, expected results and follow-up actions and a brief description of the implementation process and of any changes made to the plan.</p>	<p>If possible, the resident and his/her legal representatives, family members/relatives should be involved in the development, implementation and monitoring of the plan.</p>	<p>The plan should be reviewed not less than once a year or when there is a change in the residents' situation.</p>
Malta	<p>A resident's plan of care generated from a comprehensive assessment shall be drawn up with the involvement of the resident and close relatives and/or representative. This plan shall provide the basis for the care to be delivered. The individual plan of care shall set out in detail the action that needs to be taken by care staff to ensure that all aspects of the health, personal, spiritual and social care needs it shall be based on the outcome of the initial and ongoing assessments, including results from the Barthel 20 index.</p>	<p>Involvement of the resident and close relatives and/or representative. It shall be recorded in a style accessible to the resident, and agreed and signed by the resident and/or representative if applicable.</p>	<p>To reflect changing needs, the individual plan of care shall be reviewed and updated by nurse in charge or his/her delegate at least once every three months, or after any significant change in the resident's general medical, psychological, behavioural, or social condition. The advice of other health professionals shall be sought as the case dictates. An annual routine multidisciplinary review is advocated.</p>
Netherlands	<p>A care and living plan is written shortly after admission in the care facility. It contains: the living situation, mental well-being and autonomy, physical well-being and health.</p>		<p>The plan is reviewed and adapted regularly as required.</p>

Country	Content	Who is involved?	Revisions
Norway	The municipality has to prepare an individual plan for patients and users in need of long-term and coordinated services according to the Health and Care Services Act. The Ministry may, in regulations, provide further information on the patient and user groups to which this applies and make demands on the contents of the plan.	Individual support plans should be developed between resident, the carers/family and staff.	Any necessary changes are made after discussion with the resident and his/her family.
Poland	Residential care facilities should set up therapeutic care teams, consisting mainly of the staff providing direct care to the residents. They are responsible for drawing up and implementing the individual support plans. An individual support plan should be ready in 6 months from the day of admission.	Individual support plans have to be developed and implemented in cooperation with the resident (if such cooperation is feasible according to resident's health and/willingness to participate in this task).	
Portugal	An individual care plan for each resident should be developed according to the project of life and the potential of each resident. For this, an assessment of their needs has to be carried out.	The resident and the family must be involved in.	As the individual plan must always be updated, it shall change as the person circumstances and/or need for support change. There is no deadline foreseen in the legislation but the internal regulation may establish deadlines to review the individual plan.
Romania	The care and support provided to residents must be based on the evaluation of the individual needs and personal situation of each beneficiary. The resident should be assessed in terms of biopsychosocial status, health status and degree of autonomy preserved, communication capacity, family and social relationships, education level, socio-economic situation, special treatment needs and recovery/rehabilitation needs, educational, cultural and spiritual needs, possible risks, possible addictions as well as vocational assessment.	The residential care facility must have specialised personnel able to draw up the care and intervention plan. A multidisciplinary team consisting of at least 3 specialists in the field of medicine, social work and psychology should draw up the plan. The resident or his/her legal representative should receive a copy of the individual plan, presented in an accessible form (easy to read, Braille, audio format, etc.)	The residential care facility must monitor the resident's situation and the implementation of the plan. The plan has to be updated within 3 days of completion of a re-assessment of needs,



Country	Content	Who is involved?	Revisions
Slovakia	Residential care facilities should have an individual assessment and care plan for each resident.	The social worker, resident and relatives.	The plan is reviewed when the situation of the resident changes.
Slovenia	The services and care provided should be according to the resident's needs and wishes.	The resident, his/her legal representative and staff should be involved in developing the plan.	Revised every six months.
Sweden	The canton of Zurich does not have detailed requirements concerning this. The Health Department examines in each case if the care plans are sufficient for the concrete needs of the residents (e.g. the needs for people with dementia have to be respected). In other cantons specific requirements exist (e.g. Berne). There are forms that have been filled at the admission stage, covering very detailed information including personal, mental and physical health and social information, functioning in activities of daily living, etc. The Care Technician Evaluation Form includes:		
Turkey	<ul style="list-style-type: none"> <li>• Personal information,</li> <li>• List of medicines prescribed,</li> <li>• Health history,</li> <li>• General evaluation of functioning/level of independence,</li> <li>• Recommendations of the rehabilitation team,</li> <li>• Determination of care needs,</li> <li>• Care Plan,</li> <li>• Habits and hobbies,</li> <li>• Social activities/programme planned.</li> </ul>	The Care Plan is drawn up according to the assessment at admission, especially taking into account the Initial Care Technician Evaluation Form.	The plan is reviewed based on the annual check-up and treatment plan which is written and signed by the doctor, if necessary, other revisions can be made on the Nurse Observation Form.
UK (England)	<p>The things which a registered person must do, include:</p> <ul style="list-style-type: none"> <li>• carrying out, collaboratively with the relevant person, an assessment of the needs and preferences for care and treatment of the service user;</li> <li>• designing care or treatment with a view to achieving service users' preferences and ensuring their needs are met;</li> <li>• enabling and supporting relevant persons to understand the care or treatment choices available to the service user and to discuss, with a competent health care professional or other competent person, the balance of risks and benefits involved in any particular course of treatment (...)</li> </ul>	Each person using a service, and/or the person who is lawfully acting on their behalf, must be involved in an assessment of their needs and preferences as much or as little as they wish to be. Providers should give them relevant information and support when they need it to make sure they understand the choices available to them.	Assessments should be reviewed regularly and whenever needed throughout the person's care and treatment. This includes when they transfer between services, use respite care or are re-admitted or discharged. Reviews should make sure that people's goals or plans are being met and are still relevant.

Country	Content	Who is involved?	Revisions
<p><b>UK (Northern Ireland)</b> <b>Care homes</b></p>	<p>An individual comprehensive care plan is drawn up as the assessment of the resident's needs is carried out, and includes details of:</p> <ul style="list-style-type: none"> <li>• Any personal outcomes sought by the resident,</li> <li>• The daily care, support, opportunities and services provided by the home and others,</li> <li>• How specific needs and preferences are to be met if the resident is from a specific minority group,</li> <li>• How information about the resident's lifestyle is used to inform practice,</li> <li>• The resident's agreed daily routine and weekly programme,</li> <li>• The management of any identified risks,</li> <li>• Strategies or programmes to manage specified behaviours,</li> <li>• Directions for the use of any equipment used to assist the delivery of care.</li> </ul>	<p>Residents are encouraged and enabled to be involved in the assessment process but when a resident is unable or chooses not to be involved, this is recorded. The resident's representative, where appropriate, and relevant professionals and disciplines are also involved.</p> <p>A copy of the care plan is made available to the resident in a language and format suitable for them.</p>	<p>The initial assessment details obtained at the time of referral are revised as soon as possible and at the latest within one month of the resident's admission. The care plan is kept up-to-date and reflects the resident's current needs. Where changes are made to the care plan, the resident, or their representative where appropriate, the member of staff making the changes and the manager sign the revised care plan. When a resident or their representative is unable to sign or chooses not to sign, this is recorded.</p>
<p><b>UK (Northern Ireland)</b> <b>Nursing homes</b></p>	<p>Prior to admission an identified nurse employed by the home visits the prospective resident and carries out and records an assessment of nursing care needs. This assessment includes information received from other care providers including family members as appropriate. Each resident's health, personal and social care needs are set out in an individual care plan which provides the basis of the care to be delivered and is re-evaluated in response to the resident's changing needs. An initial plan of care based on the pre-admission assessment and referral information is in place within 24 hours of admission. A detailed plan of care for each resident is generated from a comprehensive, holistic assessment and drawn up with each resident.</p>	<p>All residents have a named nurse who has responsibility for discussing, planning and agreeing the nursing interventions. This is done in partnership with the resident and their relatives and includes their values and preferences in terms of physical safety and promoting independence and how emotional, social and psychological needs will be met alongside the physical and other healthcare needs. The care plan is written in a suitable format and so as to be accessible to and understood by the resident and their relatives. Staff are trained in developing care plans.</p>	<p>Re-assessment is an ongoing process that is carried out daily and at identified, agreed time intervals as recorded in care plans.</p>

Country	Content	Who is involved?	Revisions
UK (Wales)	<p>Each resident's health, personal and social care needs, are set out in an individual plan of care. The plan sets out in detail the action which needs to be taken by care staff to ensure that all aspects of the health, personal and social care needs of the service user are met. The plan meets relevant clinical guidelines produced by the relevant professional bodies concerned with the care of older people, and includes a risk assessment, with particular attention to prevention of falls</p> <p>The personal plan should include:</p> <ul style="list-style-type: none"> <li>• what the person prefers to be called,</li> <li>• personal preferences as to food and drink, and any special dietary needs,</li> <li>• social, cultural and spiritual preferences;</li> <li>• leisure interests,</li> <li>• any special furniture, equipment and adaptations that the person may need,</li> <li>• who should be involved in reviews of the person's care,</li> <li>• any special communication needs the person may have,</li> <li>• what communication arrangements need to be put in place if the person's first language is not English,</li> <li>• individual health needs and how these should be met (where appropriate they take account of the person's ethnic and cultural background),</li> <li>• when, and in what circumstances, friends, relatives and carers will be contacted,</li> <li>• the person's arrangements for taking any medication, including any need to inform professionals,</li> <li>• an independent person to contact if the person wants to make a complaint or raise a concern,</li> <li>• any measures of restraint which staff may have to use for the person's own safety or for the safety of others.</li> </ul>	<p>The plan is drawn up with the participation of the service user, recorded in a style accessible to the service user, agreed and signed by the service user whenever capable and/or representative (if any).</p>	<p>The service user's plan is reviewed by care staff in the home at least once a month, updated to reflect changing needs and current objectives for health and personal care and actioned.</p>
UK (Scotland)		<p>Staff should develop with the resident a personal plan which provides details of his/her needs and preferences and sets out how they will be met, in a way that is acceptable for the resident. The person should receive a copy of his/her personal plan.</p>	<p>The personal plan should be reviewed with the resident every six months, or sooner if the resident wants or if his/her needs have changed.</p>

The personal and medical care that should be provided in residential care facilities is overall well described in the relevant legislation or National Standards, in particular in relation to nutrition and hydration needs. The type and amount of food and drinks provided should be nutritionally balanced and suited to the residents' needs. In the majority of the cases, it is stated that residents should receive information about the daily menus or that the menus should be displayed. In some cases, such as Belgium (Wallonia) and Northern Ireland, the menu should offer residents a choice of meal at each mealtime. In Wales and Scotland, it is specified that food (including liquidised meals) should be presented in a way that is appealing and attractive. Some countries have specific details of the times when meals should be provided (e.g. Belgium Wallonia, Poland, UK Wales). The National Standards in Ireland and in the UK make reference to the religious or cultural dietary needs of residents, and in Scotland, it is stated that meals should reflect the resident's food preferences. In Scotland, it is also stated that residents can have snacks and hot and cold drinks whenever they like and that they can decide where (e.g. in their own room or in the dining room) and when to eat. The latter is also the case in Ireland.

Likewise, the social care that should be provided in the residential care facility is overall well described, and in general in all countries, there are references to opportunities to participate in social events, entertainment and activities provided by the residential care facility and to maintain links with family and friends. The legislation or National Standards in Belgium (Flanders), the Czech Republic, Germany, Greece (private facilities), Finland, Italy, Latvia, Poland, Portugal and Slovakia make reference to the provision of rehabilitation services in residential care settings. In the UK (Scotland), the resident can continue to receive any health-care service (e.g. physiotherapy) that he/she was receiving at home and should have opportunities to participate in

physical activities in or outside of the facility. Whilst the majority of the legislation and National Standards state that the residential care facilities should promote and maintain the contact of residents with family, friends, volunteers and the community at large (e.g. visits and/or participation of these people in activities and in daily life), the legislation in Belgium (Flanders) specifically requires the involvement of family members, carers and volunteers in the management of the facility.

On the other hand, only a handful of countries have provisions in relation to the transition of residents to hospital and on the management of behaviours that challenge. In Belgium (Flanders), Finland, Netherlands and the UK (England and Northern Ireland nursing homes) provisions exist for the prevention of unnecessary hospitalisations and for ensuring that if the transfer is necessary, this occurs in a coordinated manner. In Northern Ireland, when residents with confusion or dementia are transferred to hospital, documentation such as 'This is Me' must accompany the patient. The appropriate transfer forms and documentation should also be with the resident on their return to the residential care facility.

In Germany, behavioural problems are mentioned in the LTCI but these are not linked to dementia. In Malta, an administrative policy and procedure regarding the use of sedatives and antipsychotic medication for the management of behavioural and psychological manifestation of mental health problems should be in place. These policies and procedures have to be available to residents and their legally appointed substitute decision maker. In the Netherlands, the Quality Frame states that staff should be able to recognise challenging behaviours and seek appropriate help. The most detailed descriptions are found in the National Standards in Ireland and Northern Ireland (nursing homes). Please see box 7 for further details.

## Box 7: Management of behaviour that challenges

### Ireland

The residential care setting's procedures for managing and responding to residents' behavioural and psychological symptoms and signs of dementia, promote positive outcomes for the resident. They are based on staff knowing and understanding the resident's usual conduct, behavioural and psychological symptoms and signs of dementia and means of communication, and having an awareness of and ability to adapt the environment in response to behavioural and psychological symptoms and signs of dementia.

Each resident with a cognitive impairment who exhibits symptoms that cause them significant distress, or who develops behavioural and psychological symptoms and signs of dementia, is assessed at an early opportunity to establish aggravating factors or underlying causes. They are continuously assessed thereafter if the distressing symptoms, or the behavioural and psychological symptoms and signs of dementia persist. Early interventions that may prevent an escalation of such behaviour or distress are used and recorded in their individual care plan and evaluated as to their effectiveness.

Where a resident's behavioural and psychological symptoms and signs of dementia places them or others in imminent danger, short-term, proportionate and non-dangerous restraint measures may be taken by staff without prior formal assessment. Precipitating factors and behavioural and psychological symptoms and signs of dementia are clearly recorded in a restraint register, along with any actions taken.

### Northern Ireland (nursing homes)

A specific documented behaviour support plan for the management of behaviour that challenges is drawn up and agreed with residents, their relatives and relevant professionals and are regularly reviewed for effectiveness. The plan identifies activities that can have a positive and preventative effect to minimise episodes of distress.

Residents with behaviours that challenge and their relatives have the support they need to ensure they can take an active part in these reviews. Proactive and preventative strategies are always considered and evidenced within documentation as the first option. Restrictive interventions are evidence-based, proportionate and the least restrictive option required.

All staff receive regular training (and ongoing updates) that is appropriate to the level and type of behavioural challenges within the home. Training is delivered by a suitably competent professional or trainer. Induction covers initial information on behaviour that challenges.

## 6.3 Decision making, participation and involvement

The legislation or National Standards, in several countries, give a particular emphasis to the residents' right to autonomy and independence, highlighting that residents should be enabled and supported in making decisions about their daily lives and in exercising control over their lives (e.g. Belgium Flanders, Czech Republic, Finland, Germany, Ireland, Latvia, Lithuania, Malta, Netherlands, Slovenia, and the UK). In addition, in some countries, it is stated that residents should be encouraged and supported to participate in the daily life of the facility and supported in expressing their views and opinions about the care and services that they receive (e.g. Belgium, Finland, France, Germany, Hungary, Ireland, Turkey, UK).

Some examples of how this is addressed include:

- Finland: care must be provided so that residents can feel that they are living a safe, meaningful and dignified life, and that can participate in meaningful activities promoting and maintaining their wellbeing, health and functional capacity.
- Ireland: residents are actively involved in determining the services they receive and are empowered to exercise their human and individual rights including the right to be treated equally in the allocation of services and supports, the right to refuse a service or some element of a service and the right to exit a particular service or be transferred to another service.

Residents make their own choices, participate in the running of services and contribute to the life of the community, in accordance with their wishes.

- Malta: the licensee shall operate the home so as to maximize residents' capacity to exercise personal autonomy and choice. Residents and/or their representatives shall be given access to information on how to obtain the necessary legal advice regarding the assessment of mental capacity, the appointment of a representative, and the preparation of a will.
- Netherlands: residents have the opportunity to maintain as much self-control over their lives as possible. Staff weigh the safety risks against the quality of life with the resident and his/her family.
- Slovenia: staff should respect the person's autonomy and individuality. The individual should, for as long as possible, make his/her own decisions about his/her life and support he/she receives.
- UK (England): providers should support the autonomy, independence and involvement in the community of the service user.
- UK (Wales): the registered person conducts the home so as to maximise service users' capacity to exercise personal autonomy and choice.
- UK (Scotland): standard 17 "You make choices and decisions about day-to-day aspects of your life and about how you spend your time" and standard 11 "You are encouraged to express your views on any aspects of the care home at any time".

The National Standards in the UK (Northern Ireland, Wales and Scotland) also make reference to the residents' civic rights as for example the right to vote and participate in all aspects of political processes, and that these should be respected, upheld and facilitated where necessary. In Hungary, residents can appeal to independent legal representatives who regularly visit them and who help to protect the residents' rights.

In some countries (e.g. Belgium, France, Germany<sup>58</sup>, Hungary and Lithuania) residential care facilities should set up a residents' committee composed of residents and relatives, which provides suggestions or advice regarding the services and care provided. In Belgium (Flanders), the residential care facility should always ensure that at least half of the people attending the meeting are residents. In Lithuania, residential care facilities have a Board consisting of residents, legal guardians, family members or close relatives, staff representatives, representatives of other institutions, non-governmental organizations and representatives of the community where the facility is located. The composition of the board is periodically reviewed and updated.

There are also quite comprehensive descriptions across the relevant laws and National Standards about the right of the resident to make a complaint and the existence of clear procedure for this. In Ireland, Turkey and the UK, residents should be supported in accessing independent advocacy services.

## 6.4 Personal account



My name is Petri and I am from Finland. I have frontotemporal dementia (FTD). Getting the diagnosis was very hard. Finnish doctors and nurses don't know much about FTD. I had never heard about FTD before. I also didn't know that you can have dementia if you are young. When I was in the rehabilitation programme, the psychologist noticed my skills in public speaking. Since I got dementia, I speak a lot and I am uninhibited and brave. I see those things as gifts, which this disease has given to me. The disease can give also good things, not only bad ones. The psychologist told me that I could become an "expert (educator) by experience" and that many people could benefit from my experiences. Those words gave me more power and self-confidence. With training from The Alzheimer Society of Finland I have become an expert (educator) by experience. Since, and particularly due to social media, many people have asked me to give lectures. The latest invitation was from in my own hometown to talk to nurses and doctors about what is like to live with FTD. Since I got FTD I am very sensitive to odours. I also have migraines. I want to talk about this to them. All the feedback that I got so far has been very positive and rewarding. When I see the audience laughing and crying at times, I know I have succeed. I hope this works helps to provide better care to people with dementia and FTD.

**Petri Lampinen (EWGPWD), Finland.**

<sup>58</sup> This is stipulated in guidelines which are not compulsory.

## 7. End-of-life care

### 7.1 General overview

No provisions regarding palliative care at the end of life for older people living in residential care facilities were found in Bulgaria, Cyprus, Hungary, Italy, Latvia, Poland, Portugal, Slovakia and Turkey<sup>59</sup>.

In Finland, Germany, Netherlands, Sweden and the UK (England) guidelines about care at the end of life exist, but the recommendations in these documents are not binding in nature. In Finland, the care guidelines specifically recommend the avoidance of unnecessary transfers to hospital in the final stages of dementia. In 2017, the Government of Croatia has approved the National Program for the development of Palliative Care in the Republic of Croatia (2017–2020). This plan addresses issues related to palliative care in primary care and in care homes for the older people. In the plan, people with dementia are recognized as a vulnerable group with special needs.

Specific reference to the provision of end-of-life care in residential care facilities can be found in the legislation or National Standards in Belgium (Flanders and Wallonia), France, Ireland, Lithuania, Luxembourg, Malta, Romania, Switzerland<sup>60</sup> and the UK (Northern Ireland, Wales, Scotland).

- In addition to the provision of care, comfort and pain relief, in Ireland, Lithuania, Malta and the UK

(Northern Ireland and Wales) there is a reference to the need to respect the values and preferences of the resident when providing care at the end of life and treat the person with dignity and respect. In Ireland every effort should be made to ensure that the resident's choice as to the place of death, including the option of a single room or returning home, is identified and respected as far as practicable.

- In Finland, France, Ireland, Lithuania, Malta, Netherlands, Romania, Switzerland and the UK, the requirements state that the religious and spiritual needs and practices of the resident should be met.
- In France and Luxembourg, residential care facilities should develop a project or plan including their approach to end-of-life care. In France, this plan needs to be developed jointly by the director of the centre and the medical doctor and it should also include the planned collaboration with specialist palliative care teams in the area.
- In Belgium (Flanders) the medical doctor and the head nurse should promote a culture of palliative care and raise awareness among staff. In Belgium (Wallonia), a federal law guarantees the provision of end-of-life care to all patients. However, further details about how the care is implemented are provided in regional legislation.

### 7.2 Involvement of the resident and family

The legislation or National Standards<sup>61</sup> in Belgium (Flanders), Finland, Ireland, Lithuania, Malta, Netherlands and the UK (Northern Ireland and Wales), state that residents should have the opportunity to receive adequate information and their wishes and preferences concerning end-of-life care should be discussed in advance and respected. In Ireland, for example, in line with the residents' wishes, their family and friends are facilitated to be with them when they are very ill or dying and overnight facilities are available for their use.

In Belgium (Flanders), Ireland, the Netherlands and the UK (Northern Ireland and Wales) the preferences and arrangements should be recorded in the care plan of the resident. There are specific references to involving family members in these discussions and in decision making if appropriate (if that is what the resident wants) in the majority of the cases. In Romania, the residential care facility should inform relatives, either in writing or by telephone, about the person being at the end of life, and of the passing of the resident within 24 hours of his/her death. In Ireland, upon the death of the resident, time and privacy are allowed and support is provided for their family, friends and carers.

<sup>59</sup> In some cases, a legal framework for palliative care exists but not in the context of residential care facilities. For example, in Portugal, the existing legal framework applies to palliative care provided in primary care, hospital settings and integrated continuous care units. In other cases, policies may exist but for people with other conditions e.g. cancer.

<sup>60</sup> At cantonal level.

<sup>61</sup> Guidelines in the case of Finland and the Netherlands.

## 7.3 Last moments of life

In a few countries, details related to the last moments of life of the resident are provided. Largely, these requirements refer to the possibility of the residents to spend the last moments of life in their room and to be accompanied (if they wish so) by their loved ones, which in most cases include family and friends, and in the UK (Northern Ireland and Wales) there is also a specific reference to other residents and staff members. Northern Ireland has additional requirements for the last moments of life, including the need to identify a key worker for residents who are approaching the end of life and specific arrangements to ensure that any resident is not left alone while dying.

Examples of existing requirements include:

- Lithuania: All necessary care should be provided in the resident's private bedroom, if the resident is sharing the room with other residents, the privacy and dignity of the other residents should be respected.
- Malta: Relatives and friends of a resident who is dying shall be allowed to stay with him/her for as long as they wish, unless the resident makes it clear that he/she does not want them to, or unless their presence is disturbing the dying resident or other residents unduly.
- Switzerland (canton of Zurich): The residential care facility should facilitate that family members and other relatives can accompany the resident and say farewell to the resident with dignity. Residents have the right to be accompanied by their own pastor.
- UK (Northern Ireland – nursing homes): When the resident is believed to be imminently dying, their family and friends (including other residents) are enabled, as far as possible, and in accordance with the person's wishes, to spend as much time with them as they wish. This includes overnight stays if feasible. In addition:
  - A key worker is identified for residents approaching the end of life.
  - There is a private space available where relatives can talk privately.
  - In the event that relatives are unable to be present, the home makes arrangements to ensure someone is deployed to sit with the resident so that they are not left alone while dying.
  - Systems are in place for timely access to any specialist equipment or drugs which may be necessary to deliver end-of-life care including weekends and out of hours.
  - Relevant support and information is provided to relatives during the last days of life and after death.
- UK (Wales): residents are able to spend their final days in their own rooms, surrounded by their personal belongings, unless there are compelling medical reasons which prevent this. Relatives and friends of a resident who is dying are able to stay with her/him, unless the resident makes it clear that he/she does not want them to, for as long as they wish. Staff and residents who wish to offer comfort to a person who is dying are enabled and supported to do so.
- UK (Scotland): staff are sensitive and supportive during the difficult times when someone dies. There should be somewhere for the people important to the resident to stay during the resident's last few days and hours, if that is what they wish (both the resident and the people who are important to him/her). The staff should make sure that the bereaved relatives, friends and carers can spend as much time with the person after his/her death as they need to.



## 7.4 Staff training in end-of-life care

Six countries provided examples of requirements for staff training about end-of-life care.

- Training for doctor and nurses (Belgium – Flanders, Finland, UK – Northern Ireland):
  - In Finland, nurses and doctors in the residential care facility should have sufficient knowledge of end-of-life care. Also, in the UK (Northern Ireland) there is a reference to nurses in nursing homes having up-to-date knowledge and skills in providing symptom control and comfort. In Belgium (Flanders) the medical doctors and head nurse should provide advice and training on palliative care to staff members (e.g. nurses and allied health professionals).
- Training for staff (Ireland, Germany, Luxembourg, UK – Northern Ireland and Wales):
  - In Ireland and the UK (Northern Ireland and Wales), staff should be appropriately trained to provide effective end-of-life care. In the UK (Northern Ireland) there should be accessible educational material on palliative care for staff, residents and their relatives.
  - In Germany, end-of-life care is one of the thematic areas for training for staff working in residential care facilities.
  - In Luxembourg, at least 40% of the staff should have training in palliative care of a minimum duration of 40 hours.

## 7.5 Personal account



**(Chris):** The palliative care for a person who is living with dementia and their families, should start far earlier in the diagnosis, to improve their lives and wellbeing, to help control any pain and other problematic symptoms, and to provide psychological, social and spiritual support to allow the best quality of life. This should then continue and overlap with end-of-life plans to allow and assist with the best death possible. Everyone should be assisted to live well and, die well, in a safe and comfortable place of their choice.

**(Jayne):** The word palliative is derived from the Latin 'Palliare', which means cloak, a wrapping around of care for all aspects of the journey, whatever that journey may be. There have been studies into upskilling staff in residential settings in the UK to have the confidence to follow the process of end of life to its conclusion, with the support of the whole system – GPs being called for pain relief, if necessary; of not automatically calling the paramedics; if paramedics are called, decisions made not to remove the dying to hospital in their final hours; staff being 'permitted' (encouraged) to say their goodbyes, and other residents too. And afterwards, an acknowledgement of their life, leaving the setting through the front door, not squirrelled away furtively, secretly. This has resulted in a truly holistic approach, with everyone being involved, staff, residents, relatives; that the natural process of someone dying doesn't need to be something that creates anxiety, and fear; that people can 'go gentle into that goodnight', if we who are not dying allow them to.

Everyone is then allowed that natural grieving for the passing of a member of their community, within that community. Unfortunately, the knock on effect of keeping people in their residential setting through their dying inevitably means that the dying rates of that residence increase, which sends a red flag to the UK care inspectorates, and investigations are started into that residence, which detrimentally affects their ratings.

There is still a long way to go.

Chris Roberts (EWGPWD) and Jayne Goodrick, UK.

## 8. Abuse and use of restraint

### 8.1 General overview

In several countries the topic of abuse is not specifically addressed in the context of residential care. Often, in these cases, provisions exist in the penal code, Constitution or other national plans that can apply. This is the case for example of the Czech Republic, Greece, Italy, Poland and Portugal. In the Netherlands and in Germany, abuse is also addressed in different documents (guidelines and Charter of Rights of people in need of long-term care respectively), but these recommendations are not binding. According to the legislation for health and social services in Finland, France, Lithuania, Slovenia and Turkey, any health care professional

who is aware of any form of abuse (or suspects it) or of unfair treatment should immediately report it to the authorities. This also includes the staff working in residential care facilities. Also, there should be clear recording of any accident that happens in the facility. In Lithuania and Turkey, the legislation also provides details of how the finances of the residents should be handled.

Requirements addressing the topic of abuse specifically in residential care facilities exist in Belgium (Flanders), Ireland, Malta, Romania and the UK.

### 8.2 Types of abuse, identification and reporting

The following types of abuse are highlighted in the legislation or National Standards:

- Belgium (Flanders): there is a particular focus on sexual and financial abuse.
- Ireland: (following the Council of Europe's definition) all types of abuse, including physical abuse, sexual abuse and exploitation, psychological threats and harm, interventions which violate the integrity of the person, financial abuse, neglect, abandonment and deprivation (whether physical or emotional) and institutional violence with regard to the place, the level of hygiene, the space, the rigidity of the system, the programme, the visits, the holidays.
- Malta: physical, verbal, financial, psychological or sexual abuse, neglect, discriminatory abuse or self-harm, inhuman or degrading treatment, whether through deliberate intent, negligence or ignorance.
- Romania: any type of abusive, negligent or degrading treatment of a resident. Residents should be protected against abuse, neglect, discrimination, degrading or inhuman treatment.
- UK (England): any behaviour towards a service user that is an offence under the Sexual Offences Act 2003(a); ill-treatment (whether of a physical or psychological nature) of a service user; theft, misuse or misappropriation of money or property belonging to a service user; neglect of a service user.
- UK (Northern Ireland): all forms of abuse, neglect, exploitation, and serious harm – including online.
- UK (Wales): physical, financial or material, psychological or sexual abuse, neglect, discriminatory abuse or self-harm, inhuman or degrading treatment, through deliberate intent, negligence or ignorance.

- UK (Scotland): the Adult Support and Protection (Scotland) Act makes provisions to protect adults at who may be at risk of "harm". Harm is any type of harm and includes financial, physical, psychological, sexual, neglect, as well as self-harm or neglect.

In all the above mentioned countries the requirements include that the residential care facility shall ensure that all residents are safeguarded from abuse and, in the majority of cases, neglect or ill-treatment are also mentioned. Overall, in the majority of the cases, financial abuse is well addressed in the National Standards or legislation. As an example, in the UK (Northern Ireland and Wales) the National Standards go into great detail about the procedures and practices for ensuring that residents retain their independence in dealing with their own money and finances, they receive support if needed for handling it and eventually, about how staff could become involved with a resident's finances. In Belgium (Flanders), residential care facilities are required to develop a "frame of reference" for inappropriate sexual behaviour toward residents.

In Ireland, Malta and the UK, robust policies and procedures should be in place to support the residents' right to protection from any type of abuse. Likewise, in the three countries, residents should be supported and enabled to safely report any concerns and/or allegations of abuse to staff or in the case of Malta and the UK, to the Regulator or relevant Authority. All suspected, alleged or actual incidents of abuse or of improper treatment should be fully investigated and acted on promptly.

Interestingly in Ireland, it is stated, that residents should be assisted and supported to identify and recognise abusive

and neglectful behaviour and to develop the knowledge, self-awareness, understanding and skills needed for their own self-care and protection. Likewise in the UK (Northern Ireland), residents and their relatives should be informed and know how to make a complaint or allegation of abuse, neglect or exploitation. In Romania, residential care facilities must encourage and support residents to identify any form of abuse, neglect, or degrading treatment that they are subjected to by staff in the facility, family members or any other person they are in contact with. Abuse should be reported in writing and addressed to the director of the facility (or management).

There are references in the National Standards in Ireland to abuse in the case of residents with dementia or cognitive impairment, and it is stated that staff should be aware of the difficulties that residents with a cognitive impairment

may have in communicating an allegation of abuse and/or neglect. The service should have arrangements in place to address any communication difficulties to facilitate residents to report such concerns.

The National Standards or legislation make reference to training on abuse in Ireland, Romania and the UK (Northern Ireland and Wales). In particular in Northern Ireland (both in the National Standards for residential care and the ones for nursing homes), within their probationary period of employment, staff should complete training on and be able to demonstrate knowledge of protection from abuse, indicators of abuse and responding to suspected, alleged or actual abuse. A refresher training on the protection of vulnerable adults should be provided for staff at least every three years.

### 8.3 Restraint

The ways in which freedom is restricted may be broadly defined as measures or means of restraint. Examples include physical and psychological restraint as well as the use of mechanical, chemical, environmental, electronic and other means or devices. Coercive measures could also be considered as a means of restraint as they restrict a person's freedom to choose not to do something (Alzheimer Europe, 2012). Inappropriate or unlawful use of restraint is considered as a form of abuse.

Several countries did not to find any legislation for restraint in the context of residential care (Belgium Wallonia, Bulgaria, Cyprus, Croatia, Italy, Latvia, Luxembourg, Poland, Portugal and Slovakia).

Table 16 provides information on legislation/National Standards of relevance to this topic. The legislation on restraint in Lithuania, the Netherlands and Norway is currently under review. In Finland, the Ministry of Social Affairs and Health established a working group in 2010 to work on this topic. An Act (the "Autonomy Act") was published in 2014 which should have come into force at the end of 2014. However, this proposed Act lapsed at the end of the term of the previous government. The preparation of the Autonomy Act is expected to continue in 2017 (Hoppania et al., 2017).

Table 16:

Country	Regulation/National Standard
Belgium (Flanders)	<ul style="list-style-type: none"> <li>• Nursing and care home standard B.10 e</li> <li>• Quality legislation 2003</li> </ul>
Czech Republic	<ul style="list-style-type: none"> <li>• Social Service Act No. 108/2006 Coll art 89</li> </ul>
Finland	<ul style="list-style-type: none"> <li>• The Autonomy Act – not yet into force</li> </ul>
France	<ul style="list-style-type: none"> <li>• Code of Social Action and Family (amended by Law No.2015–1776 2015)</li> </ul>
Germany	<ul style="list-style-type: none"> <li>• § 1906 Civil Law Code</li> </ul>
Ireland	<ul style="list-style-type: none"> <li>• National Standards for Residential Care Settings for Older People in Ireland 2016</li> </ul>
Latvia	<ul style="list-style-type: none"> <li>• Regulation No. 291 of the Cabinet of Ministers on “Requirements for social service providers”</li> </ul>
Lithuania	<ul style="list-style-type: none"> <li>• New Law on Mental Health Care is being drafted</li> <li>• Social Care Act</li> </ul>
Malta	<ul style="list-style-type: none"> <li>• National Minimum Standards</li> </ul>
Netherlands	<ul style="list-style-type: none"> <li>• The new Care and Coercion Bill is currently under preparation.</li> </ul>
Norway	<ul style="list-style-type: none"> <li>• A special committee, appointed by the Government, has been established to review existing regulations (§4A in the Health and Social Care Act) concerning restraint. The Norwegian Health Association is represented on the committee.</li> </ul>
Slovakia	<ul style="list-style-type: none"> <li>• Act No. 578/2004 Coll. on healthcare providers, healthcare professionals and professional organisations, and amending certain acts</li> </ul>
Slovenia	<ul style="list-style-type: none"> <li>• Mental Health Act</li> </ul>
Sweden	<ul style="list-style-type: none"> <li>• The Social Service Act and the Health and Medical Service Act contains no specific provisions about restraint as regards to people with dementia. This means that such measures are not permissible. In emergency cases, however, the necessity law can be cited.</li> </ul>
Switzerland	<ul style="list-style-type: none"> <li>• Law on Protection of Adults</li> </ul>
Turkey	<ul style="list-style-type: none"> <li>• Quality Standards</li> </ul>
UK (England)	<ul style="list-style-type: none"> <li>• Health and Social Care Act 2008 (Regulated Activities) Regulations 2014</li> <li>• Mental Capacity Act 2005</li> </ul>
UK (Northern Ireland)	<ul style="list-style-type: none"> <li>• Minimum Standards for Residential Facilities and Care Standards for Nursing Homes</li> </ul>
UK (Scotland)	<ul style="list-style-type: none"> <li>• The Human Rights Act, 1998 makes it unlawful for any UK public body to act in a way which is incompatible with the European Convention on Human Rights.</li> <li>• Mental Health Legislation Adults with Incapacity (Scotland) Act 2000; Adult Support and Protection (Scotland) Act 2007; Mental Health (Care and Treatment) (Scotland) Act 2003.</li> <li>• Promoting Excellence: A framework for health and social care staff working with people with dementia and their carers.</li> <li>• Rights, Risks and Limits to Freedom (Mental Welfare Commission for Scotland Good Practice Guidance).</li> </ul>

In the majority of the cases (see for example Belgium – Flanders, Czech Republic, France, Ireland, Malta, Switzerland and the UK) residential care facilities are required to have a written procedure or clear policy that should guide the use of restraint. In Belgium and the Czech Republic, the types of restraint mentioned are physical restraint and isolation of the resident. In Latvia, there should be information about the procedures to follow if a resident needs to be isolated (if necessary, with supervision and only for a period of time no longer than 24 hours). In Malta, the references are to physical and chemical restraint. In Sweden, the Social Service Act and the Health and Medical Service Act have no provisions on the use of restraint in dementia. Current legislation regulating the use of physical restraints in geriatric care does not allow staff to strap a resident to a bed with a belt or a similar device or to lock residents in their rooms (Pellfolk et al., 2012).

Also, in all the cases, the requirements include that restraint should only be used in exceptional situations (in Belgium-Flanders, Czech Republic and Lithuania, if there is danger to the physical integrity or health of the resident or other residents, and in Switzerland also in case of important disruption to the daily life of the residential care facility), for the least amount of time possible and in the least restrictive form possible. Any decision with regard to restraint should be appropriately assessed, recorded in the resident's care plan with a summary of the nature and duration of the measure and its motivation. A medical doctor should be involved in decisions related to the use of restraint in Belgium (Flanders), France, Finland, Ireland, the Netherlands, Slovenia. In Ireland, Malta and the UK, there are references in the National Standards to staff training in restraint.

## Box 8: Use of restraint in residential care facilities

### UK – England and Wales

In England and Wales, older people living in a residential care facility (a care home) should be treated with respect for their dignity and human rights and “must be assumed to have capacity unless it is established that they do not”. Therefore, unless older people do not have capacity, restraint may only take place with their consent or in emergency to prevent harm. The Mental Capacity Act (England and Wales) allows restraint and restrictions to be used, if they are in a person's best interests. Extra safeguards are needed if the restraint used will deprive a person of their liberty. These are called the Deprivation of Liberty Safeguards. Care homes must request a standard authorisation to the local authority. If a standard authorisation is given, one key safeguard is that the person has someone appointed with legal powers to represent them. Restraint must be proportionate to the harm that is being sought to prevent and the least restrictive measure should be used.

## 8.4 Personal account



In my mid-fifties I started to experience memory problems and finally I was diagnosed with Early Onset Alzheimer's in 2012 at the age of 62. There is no way I can describe the shock of receiving this diagnosis and, as I tried to come to terms with it, there was more bad news as I learned that there are no formal supports available for people with dementia under the age of 65. Having spent my adult life working in the disability sector and campaigning for human rights, I could not accept this and I knew I had to fight for my rights and for the rights of all people living with dementia. This led me to become involved in the Irish Dementia Working Group and later the European Working Group of People with Dementia. As advocates we are a voice for every person with dementia, including the thousands

of people in nursing homes and hospital beds who may not be able to speak out for themselves. People living with dementia have the same human rights as everyone else, including the right to liberty and the right to privacy. Many of us want to remain living in our own homes, but if a time comes when we require long-term care, we and our families need to know that these rights will be met.

When a person with dementia moves into a care home, they may feel incredibly confused and experience further stress. We must ensure that people are not subject to the overuse of chemical and physical restraint in these situations and call on all European countries to introduce legislation ensuring that restraint is only used as a measure of last resort. How these laws are implemented is key and restraint should only be used by staff with appropriate training in dementia and human rights. It is also vital that restraint is not used in response to behaviours such as wandering and this is something I feel very strongly about. Having an inquisitive nature I can easily imagine a time when I would feel the need to wander and explore and I want to know that I would be treated with dignity and respect in that situation.

We must also ensure that a robust system of checks and balances is in place whenever restraint is used and a person with dementia is deprived of his or her liberty. Article 14 of the United Nations Convention of the Rights of People with Disabilities provides protection for persons with disabilities in relation to deprivation of liberty, but disappointingly, my home country of Ireland is the only European country that has not yet ratified this convention.

Having working in the disability sector for many years, and from personal experience visiting loved ones in nursing homes, I have seen first-hand situations where people living in long-term care were not afforded their dignity and where their rights were not respected. I hope this is changing and in time that we will see a decrease in the use of restraint and a society in which people with dementia are truly valued and given the care and respect they deserve.

**Helen Rochford-Brennan (EWGPWD), Ireland.**

## 9. Conclusions

The quality of care provided in residential care facilities in Europe is a complex and challenging topic. There are differences in the way long-term care is organised and provided across Europe due to cultural, economic and political factors. This makes meaningful comparison difficult. In this report, we focused on existing care standards and regulatory requirements that residential care facilities need to meet when providing care. The report does not address other relevant aspects such as the access to or the cost of this type of care.

A high percentage of the population in residential care settings has dementia, not all of whom have a diagnosis. Even though many of the existing standards and requirements for older people in residential care are relevant to people with dementia, only a few address their specific needs. This oversight is important as people with dementia have different and often more complex needs and therefore require a different approach or provisions.

People with dementia in these settings should have the same rights and opportunities as other residents to have a good quality of life. People in more advanced stages of dementia may be less able to defend their interests and rights and to communicate their preferences. Clear, accessible, legally binding standards and appropriate training for staff to address this issue are not yet widespread in Europe. In this way, staff, residents and supporters could be aware and well-informed about their rights and what they should be able to expect from care.

The size of the private and common spaces, access to outdoor spaces, privacy and the right to choose (e.g. whether or not to share a room or what or where you want to eat) are all essential to the wellbeing of residents. Some standards

recognise this and provide clear rules, whereas in other countries these factors are often not addressed and it may be possible for residents to share their room with up to 4 other people.

The quality of the care provided is not dependent solely on the number of staff but also on having the right skill mix and on the qualifications, training and experience of the staff. Several countries have strict ratios for personnel or qualifications, whereas others allow for more flexibility. Only a handful of countries had specific legal requirements related to dementia training for professionals on the issues addressed in this report. Dementia training on challenging behaviours or supported decision making would be helpful for the staff providing care and could also have a great impact on the lives of residents.

The use of restraint and end-of-life care for people living in residential care settings are some of the most concerning gaps identified in the report, especially as a lot of people with dementia spend their last days of life and die in these settings. The use of restraint also represents significant ethical and legal challenges and is a topic of particular relevance to people with dementia who may be vulnerable and unable to understand and express their wishes. Restraint should seldom if ever be used on people with dementia, and if used monitored and for the shortest period of time.

Whilst many national dementia strategies have been developed in recent years in Europe, in some countries dementia is not recognised as a public health priority. We hope this comparative report will be useful in advancing the understanding of this topic and improving the standards of care and the quality of life of people with dementia in residential care.

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## 12. Appendix

The questionnaire used to collect the information for this report was drafted on the basis of discussions during a meeting with 23 representatives of AE member organisations (i.e. national Alzheimer associations) from 19 different European countries on 1 March 2017. A number of concerns were raised in this meeting which were taken into account and guided the approach and development of the questionnaire:

- Firstly, it was decided that a description of the different types of residential care facilities in each country was beyond the scope of the report. This type of information has been already covered in other reports. For example, information about long-term care facilities in Europe including availability of beds, type of long-term care facilities, organisational status and funding can be found in the report produced by the PACE project “Palliative care systems and current practices in long-term care facilities in Europe” (Froggatt et al., 2017). For the purpose of this report, the following definition was agreed “a collective institutional setting where care is provided for older people who live there, 24 hours a day, seven days a week, for an undefined period of time. The care provided includes on-site provision of personal assistance with activities of daily living. Nursing and medical care may be provided on-site or by nursing and medical professionals working from an organisation external to the setting”. (Froggatt et al., 2017, p.3). This definition includes nursing and (residential) care homes. Independent and assisted housing, sheltered housing, respite care and day care centres are not addressed in the report.
- Secondly, it was anticipated that most countries would not have a legislative framework for residential care facilities providing care specifically to people with dementia. Therefore, it was decided to ask about the framework that is applicable to the residential care facilities which provide care to people with dementia in the country. This is most often, residential care facilities for older people and in addition, in some cases, facilities for people with disabilities, mental health problems or people with dependency needs.
- Finally, some countries have a single document (often called National or Minimum Standards) where all or

most of these issues are addressed. However, several countries do not have such a document and the information is spread across several other documents and laws. This was taken into account in the design of the questionnaire.

The questionnaire was developed by AE staff with support from five representatives from AE member organisations who provided feedback and suggestions on the draft questionnaire. The initial plan of work was presented to the European Working Group of People with Dementia (EWGPWD). The final questionnaire was then sent to all AE members in April 2017 for completion. In countries where AE has no members (i.e. Latvia and Lithuania), or in cases where AE members could not provide the information, other national experts were identified by AE and invited to participate. In addition, relevant literature, national standards and laws, which were available online in English, were also reviewed.

The information for each country was completed by the national Alzheimer association and/or other relevant expert(s) and was sent back to AE. The list of national experts who contributed to the each national report is available at the end of this report. Most countries provided information which applies to the whole country. However, a slightly different approach was taken in some countries:

- In Belgium, separate reports were provided for Wallonia and Flanders. Likewise, in the United Kingdom (UK) separate reports were provided for England, Northern Ireland, Wales and Scotland. This approach was taken as, in both countries, the relevant laws and policies are quite distinct in the different parts of the country. For these two countries, it is specified in the report whether the information refers

to the whole country (when there is reference just to the country, i.e. the UK or Belgium) or parts of the country (e.g. in this case there is reference to the country and the parts to which the statement applies e.g. UK – England and Wales).

- In the case of Austria, Italy, Germany, Spain and Switzerland, whereas some provisions may exist at national level, the legislation related to residential care is developed at regional level and each of the regions has specific requirements/standards (e.g. Länder in the case of Austria and Germany, Comunidades Autónomas in Spain and Cantons in Switzerland). As it would have been impossible to cover the existing regulation for all regions, where appropriate, some of these countries provided information on the regulatory requirements in one of these regions (e.g. State of Baden-Württemberg, Comunidad Autónoma de Madrid and Canton of Zurich respectively). These were chosen as they are among the largest and most populated regions in these countries.

Once all the national information was compiled, the comparative report was written following an iterative process. A first draft of the comparative report was drafted by AE based on the analysis of the information on the 33 questionnaires that were returned to AE. The first draft of the report was then circulated among all participating countries, which provided feedback and amendments where necessary. All suggestions and comments were addressed and incorporated in the comparative report. The final text was then sent to all participating countries for approval. In addition, members of the EWGPWD were invited to share their experiences with and views on each of the topics addressed in the report by providing a short written testimonial (“personal accounts”).

