

Dementia in Europe Yearbook 2022

Employment and related social protection
for people with dementia and their carers





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1. Preface



It gives me great pleasure to introduce the Dementia in Europe Yearbook 2022, which this year focuses on employment and social protection for people with dementia and their carers across Europe.

Employment and social protection are some of the most complex challenges that people with dementia, their families and carers face. For people of working age who receive a diagnosis of dementia, it is likely that many will face a significant loss in earnings as a result of their condition, as the symptoms may gradually prevent them from remaining in employment. Similarly, working age informal carers may find themselves having to reduce their hours or leave the workforce altogether, as they take on greater responsibilities such as managing household tasks, as well as providing care and support to the person with dementia.

This is even before consideration is given to the additional costs associated with a diagnosis of dementia, including those in relation to services, support, medicines and products, the reimbursement of which varies considerably across Europe, as we have set out in our previous European Dementia Monitor reports.

Therefore, even when individuals have retired, the additional financial impact of dementia will be profoundly felt.

It is therefore incumbent upon governments to ensure that the policies and legislative framework on employment and social protection ensure that people living with a diagnosis of dementia, as well as their families and carers, receive adequate financial support, in a way that upholds their rights, as set out in Charter of Fundamental Rights (CFR), the European Pillar of Social Rights (EPSR) and the United Nations Declaration on the Rights of Persons with Disabilities (UNCRPD).

Yet, the picture emerging from countries across Europe suggests that this is not happening and that the approaches of governments are not adequately upholding these rights. From the survey responses of our members, a number of key themes emerged.

The first is the limited number of dedicated policies

or initiatives included within national dementia strategies to support people with dementia or cognitive difficulties, and their carers, to continue in employment. Additionally, policies do not take into account the specific symptoms associated with dementia and the progressive nature of the condition. Another key issue emerging is the complexity and variable levels of support provided to both people with dementia and/or carers in the form of social protection.

We heard a number of countries suggesting that the process for benefits was overly bureaucratic and complex, with the level of financial support often regarded as insufficient to adequately meet the needs of people with dementia or their carers.

Most importantly, we collected and present testimonies and examples of people with lived experience throughout the Yearbook which should be read carefully by anyone seeking to bring improvements to the lives of people with dementia, their families and carers. Whilst there are examples of good practice where people have been well supported to continue working or move into retirement, these contributions illustrate that too often people with dementia experience little in the way of support from employers, with abrupt cessation of their employment. This is often stressful, emotionally as well as financially, as the routine, identity and purpose of the individual are fundamentally altered.

Alzheimer Europe is grateful to our members for highlighting resources and good practice examples, both of their own work and that of governments and other organisations, which we have incorporated in a dedicated section. It is our hope that these will help in the development and spread of better policies and practice across Europe.

However, it is evident that the good practice examples themselves cannot, by themselves, deliver the profound systemic changes which are needed to support people with dementia and their carers. As such, Alzheimer Europe concludes this Yearbook with recommendations

aimed at different stakeholders, including national governments and the EU.

Finally, I wish to thank our members for their contributions, without whom, this publication would not be possible. I would also like to acknowledge the work of our Policy Officer, Owen Miller, for his work in compiling the information in the Yearbook and writing the report.

Jean Georges
Executive Director
Alzheimer Europe



2. Introduction

2.1 Background to this report

Previous editions of the Alzheimer Europe Yearbook included examinations of “social support” in 2007 and 2008, looking at the full range of supports available to people, including financial support, supports and services.

For the purposes of this Yearbook, the focus will be narrower, exclusively examining policies as they relate to employment (relevant for people with dementia and their carers), whilst focusing on a specific aspect of social protection, i.e. those specifically given based on a person’s disability and/or inability to work – sometimes referred to as earnings-replacement benefits.

This is important, as these policies will have the greatest impact upon the financial circumstances of a person living with dementia and their carer, which in turn, directly affect their quality of life, as well as their ability to face the additional challenges a diagnosis of dementia brings, including the significant financial burden.

The policy context of this work is complex, especially as a result of differences in employment law and social security systems, which are highly variable between countries. In addition, legislative protection, particularly in relation to employment, have both national and European legislative aspects which must be considered.

In tandem, the rights-based approach to disabilities has grown significantly in the past decade, particularly since the development and entry into force of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2008, which has guided and shaped a broad range of national and European policies and legislation, such as the European Commission’s Disability Rights Strategies.

The EU itself is party to the UNCRPD (from 2011), with all Member States having individually ratified the Convention (from 2018).

The UNCRPD states that “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” As such, the protections of the UNCRPD are clearly relevant for people with dementia.

In addition, the declaration of the Charter of Fundamental Rights (CFR) in 2000, along with the proclamation of the European Pillar of Social Rights (EPSR) in 2017, has further solidified comprehensive and overlapping obligations for the protection and support of citizens, both for the EU and its Member States.

As such, this report identifies some of the key points of the respective conventions and charters relating to employment and social protection, before identifying where these themes are applied (or absent) in the policies and systems across countries in Europe.

To ensure that the Yearbook covers a significant breadth of the policies, legislation and provisions across Europe, the report is split into the following sections:

- Section three: Current policy context for employment and social protection
- Section four: National policies and strategies
- Section five: National legal protection relating to employment
- Section six: National social protection
- Section seven: Experiences of people with dementia and carers
- Section eight: Good practice examples
- Section nine: Conclusions and recommendations
- Section ten: Acknowledgements.

In section seven, we have included contributions from people with dementia and carers, from different countries across Europe, including some members and supporters of the European Working Group of People with Dementia (EWGPWD). Specifically, we asked for experiences of work following a diagnosis of dementia

or experience of accessing social protection, in both instances asking what was done well and what they would like to see changed in these processes.

These contributions provide a useful insight into the lived experience, identifying some of the key areas which must be addressed to ensure that people with dementia, their families and carers are adequately supported following a diagnosis of the condition and throughout the duration of the illness.

2.2 Terminology

The use of the term “social support” in the previous Yearbooks incorporated a broad range of services, welfare benefits and other measures designed to ensure the highest possible quality of life. This included health, social care and psychosocial support and services.

In using the term “social protection”, we reflect the terminology used both at an EU and international level. This term still implies the broad range of support and services for the wellbeing of individuals, as outlined above.

However, for the purposes of this report, our interest and our focus are more narrowly applied to those aspects of social protection related to employment and welfare benefits which supplement or replace income as a result of a person’s diagnosis or their caregiving role.

We appreciate that health, social care and social protection at country level are organised in considerably different ways, with eligibility and accessibility overlapping to a greater degree in some countries than in others. As such, in an effort to try and keep the focus on those matters most closely related to employment and rights, we have not included an individual’s entitlement to health or social care services, though we of course are fully aware of how crucial these services are in maintaining the health and wellbeing of people living with dementia, their families and carers, following a diagnosis.

2.3 Methodology

In March 2022, at a public affairs meeting attended by Alzheimer Europe’s national member organisations, Alzheimer Europe presented the policy context, whilst also setting out its proposed approach for the 2022 Yearbook, its structure and a proposed timeline, inviting comments and input from members.

Following this meeting, a small group of members were invited in April 2022 to help contribute to the development of a questionnaire which would be sent to members, with this group helping to shape the approach and questions within the survey.

In April 2022, Alzheimer Europe distributed the survey to its member organisations, with deadline set for receipt by June 2022. In total, Alzheimer Europe received 21 responses (including two from the UK). Table 1 shows the countries who responded to the survey.

Alzheimer Europe analysed the findings from the completed surveys, identifying overarching trends and themes, as well as examples and resources which may be of interest to other organisations working in the field of dementia. Members were given an opportunity to review a draft text of the report late in 2022.

2.4 Caveats to this report

The findings in section four through six reflect the information received through the survey responses, which were completed by our national member organisations. The good practice examples and resources included within this report in section eight are those which have been suggested by our members. The process for the development and distribution of the survey is outlined in the previous subsection.

The landscape of national and EU policy, strategies and legislation related to social protection and employment is incredibly complex and, as already noted, at a national level these are implemented and applied in different ways, with the interaction and overlap between different facets of social protection varying considerably.

It is not possible to fully map out this complexity for each country and it is not the intention of this report to do so. Rather, the Yearbook seeks to draw out the commonalities of the approaches of different systems, as well as the extent to which the rights of people with dementia and their carers are reflected in these systems. Furthermore, the report identified examples of good practice and useful resources which can promote the rights of people with dementia and their carers, whilst also identifying gaps and barriers which must be addressed.

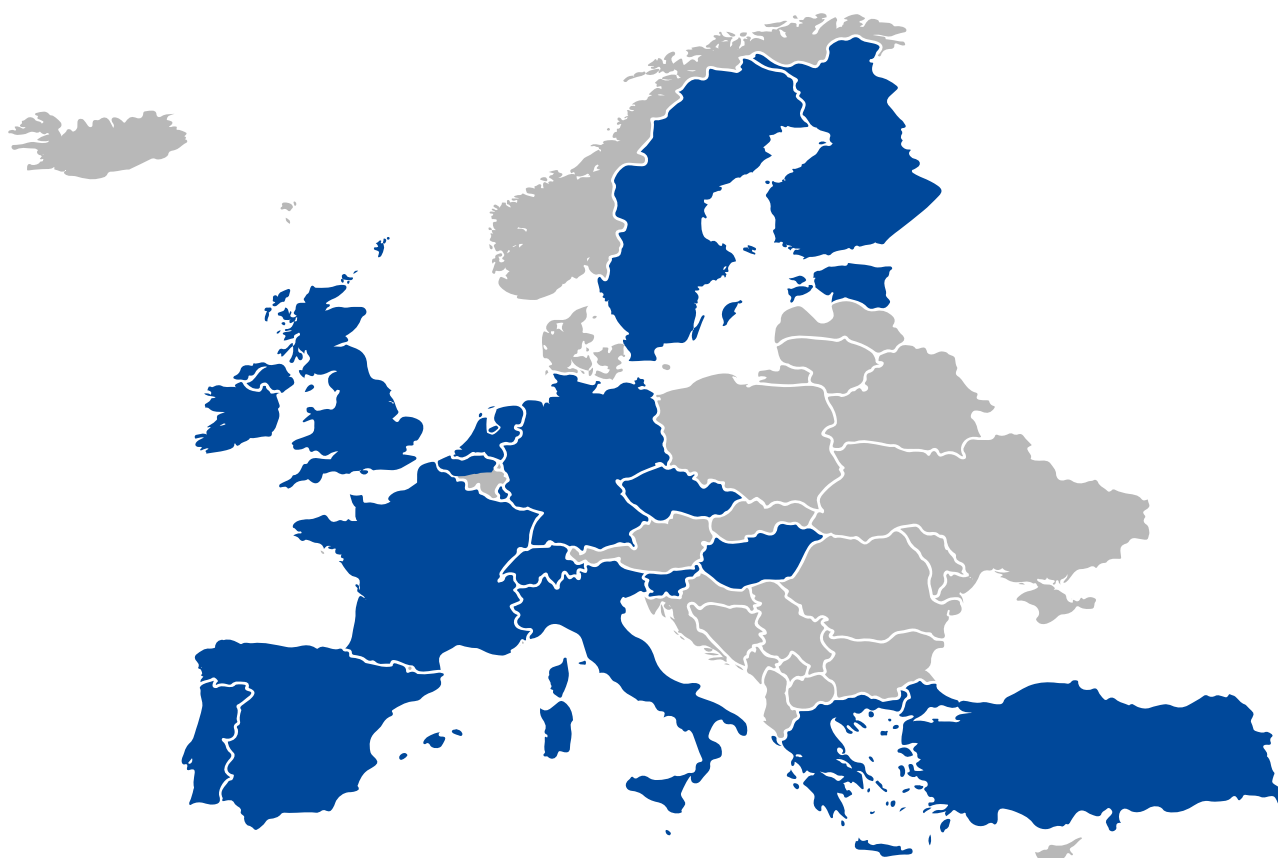
Whilst the UNCRPD applies to all of the countries included in this report (as signatories of the

Convention), there are non-EU countries for whom the Charter of Fundamental Rights and the European Pillar of Social Rights do not apply. However, the Yearbook will still use these as part of the analysis, given the importance and the relevance of the rights that they articulate.

Finally, it is important to note that the existence of policies or legislation in a country, for example within a dementia strategy or other policy document, does not guarantee that the specific measures are being implemented or universally applied across that country.

Countries who responded to the survey

| | | |
|--------------------|-------------|--|
| Belgium (Flanders) | Hungary | Slovenia |
| Czech Republic | Ireland | Spain |
| Estonia | Italy | Sweden |
| Finland | Luxembourg | Switzerland |
| France | Malta | Turkey |
| Germany | Netherlands | United Kingdom (England, Northern Ireland and Wales) |
| Greece | Portugal | United Kingdom (Scotland) |



3. Current policy context for employment and social protection

In this section, Alzheimer Europe provides an overview of the key points in relation to the current policy context at a European and international level. In particular, the section sets out key policy developments, including those relating to disabilities, employment and social protection, which have been developed and have come into effect in the past two decades.

3.1 United Nations Convention on the Rights of Persons with Disabilities (UNCPRD)

3.1.1. Relevant articles of the Convention

The United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) was adopted on 13 December 2006, opened for signatures on 30 March 2007 and entered into force on 3 May 2008.

For the EU, the Convention entered into force on 22 January 2011, with Ireland becoming the final Member State to ratify the UNCPRD in 2018. Each signatory is subject to reporting to the UN Committee on the Rights of Persons with Disabilities on a five-year cycle, with the most recent cycle of the review of the EU taking place early in 2022.

The Convention is intended to be a human rights instrument with an explicit, social development dimension, affirming that persons with disabilities must enjoy all human rights and fundamental freedoms. It clarifies and qualifies how all categories of rights apply to persons with disabilities and identifies how adaptations should be made for persons with disabilities to effectively exercise their rights.

The UNCPRD contains 50 articles in total. Alzheimer Europe has identified 17 for which this subject matter has direct or indirect relevance in relation to employment and social protection, with those in bold (eight), deemed to be have the greatest relevance to the subject:

- Article 3 – General principles
- Article 4 – General obligations

- **Article 5 – Equality and non-discrimination**
- Article 6 – Women with disabilities
- **Article 8 – Awareness-raising**
- **Article 9 – Accessibility**
- **Article 12 – Equal recognition before the law**
- Article 17 – Protecting the integrity of the person
- **Article 19 – Living independently and being included in the community**
- Article 20 – Personal mobility
- Article 21 – Freedom of expression and opinion, and access to information
- Article 25 – Health
- **Article 26 – Habilitation and rehabilitation**
- **Article 27 – Work and employment**
- **Article 28 – Adequate standard of living and social protection**
- Article 29 – Participation in political and public life
- Article 30 – Participation in cultural life, recreation, leisure and sport

There is also an Additional Protocol to which 22 EU Member States are signatories. However, as the Protocol deals primarily with governance and operation of the CRPD, rather than the rights of persons with disabilities, the articles of the Protocol have not been included here.

3.1.2. General Comment 8 - United Nations Convention on the Rights of Persons with Disabilities (UNCPRD)

On 9 September 2022, the UN Committee on the Rights of Persons with Disabilities released its new General Comment 8 on the right to work and employment, clarifying the Committee's interpretation of Article 27 of the UNCPRD. Specifically, the comment provides clarity on:

- Open labour market and sheltered employment
- Discrimination at work or during recruitment
- Reasonable accommodation
- Working conditions and pay.

Sheltered employment

The General Comment clarifies that “sheltered employment” goes against the Convention, explicitly stating that the phrasing of Article 27 “clearly indicate[s] that segregated employment settings are inconsistent with the right.”

In addition, the General Comment specifies that sheltered employment may take many forms, including segregation of persons with disabilities, the organisation of certain tasks by people with disabilities, the emphasis on medical rehabilitation etc. One exception is allowed for, in settings where businesses are managed and led by persons with disabilities (or jointly owned or have democratic accountability) – these are not considered sheltered employment if they provide just and favourable conditions of work on an equal basis with others.

Discrimination at work or during recruitment

The Committee clarifies that there are four main types of discrimination that can occur in employment and recruitment, sometimes simultaneously. These are:

- Direct discrimination
- Indirect discrimination
- Denial of reasonable accommodation
- Harassment.

It further notes that protection from discrimination also includes association, for example, where family members or a person who is connected with a person with disability are discriminated against at work.

Reasonable accommodation

The General Comment provides additional clarity in relation to the concept of reasonable accommodation, highlighting the need for changes to be negotiated with the individual, as well as noting that the duty begins at the point where a request is made or the need becomes apparent. Furthermore, the individual’s preferred solution should be considered the best

unless it imposes undue burden (defined as being unduly costly, difficult, extensive, substantial, or disruptive to achieve) on the employers.

Working conditions and pay

The General Comment states that workers with disabilities have the right to receive equal remuneration as workers without disabilities when they perform the same or similar jobs, or jobs with equivalent value. In relation to working conditions, it is elucidated that the working conditions and terms of employment (e.g. retirement benefits, sick leave, holiday entitlement etc.) should be in line with those of other workers.

3.2 The Charter on Fundamental Rights

The Charter of Fundamental Rights of the European Union outlines the key personal freedoms and rights enjoyed by citizens of the EU into a single legally-binding document. The Charter was declared in 2000, and came into force in December 2009 along with the Treaty of Lisbon.

The purpose of the Charter is to promote human rights within the EU. Many of the rights that are contained in the Charter were previously set out in the EU Treaties, the European Convention on Human Rights and various case law of the Court of Justice of the European Union. These contain 54 articles, spread across seven titles, including:

- Dignity
- Freedoms
- Equality
- Solidarity
- Citizen’s rights
- Justice
- General provisions governing the interpretation and application of the Charter.

As with the section on the UNCPRD, the following articles taken from the Charter are those we consider as having the greatest relevance for people living with dementia and their carers, in the context of employment and social protection. Those highlighted in bold are considered as having the most significant impact.

Dignity

1. Human dignity – everyone has the right to be treated with dignity.

Freedom

6. Right to liberty and security.

15. Freedom to choose an occupation and right to engage in work – for non-EU citizens who have the right to work in the EU, they should have the same working conditions as EU citizens.

Equality

20. Equality before the law.

21. Non-discrimination – forbids discrimination on grounds of sex, race, colour, ethnic or social origin, genetic features, language, religion or other belief, political opinion, membership of a national minority, property, birth, disability, age or sexual orientation.

23. Equality between men and women – this does not prevent positive measures to give advantages to the under-represented gender (in a workplace for example).

25. The rights of the elderly – to live a life of dignity and to participate in social and cultural life.

26. Integration of persons with disabilities.

Solidarity

27. Workers' right to information and consultation within the undertaking – workers (or their representatives) must be consulted in situations that are covered by EU law (for example, transfer of undertakings).

28. Right of collective bargaining and action – both employers and workers have the right to negotiate collective agreements, and to take collective decisions to protect their interests (for example, to take strike action).

29. Right of access to placement services – free placement services should be available to assist people to look for work.

30. Protection in the event of unjustified dismissal.

31. Fair and just working conditions – this includes the right to safe working conditions, a maximum working week, rest periods and to annual leave.

33. Family and professional life – this includes the protection of pregnant workers and parents on maternity or parental leave.

34. Social security and social assistance.

35. Health care - under the conditions established by national law.

Citizens' rights

45. Freedom of movement and of residence.

Justice

47. Right to an effective remedy and to a fair trial – this includes a right to legal aid where you are deemed to lack sufficient resources.

3.3 European Pillar on Social Rights

The European Pillar of Social Rights (EPSR) was proclaimed in 2017 by the EU to act as a compass for a strong social Europe. The EPSR sets out 20 principles in three main areas:

- Equal opportunities and access to the labour market
- Fair working conditions
- Social protection and inclusion.

Unlike the UNCRPD or the Charter of Fundamental Rights, the European Pillar of Social Rights is not a legally binding document, rather a strategic outline of the principles which should underpin and guide the policies and legislation developed by the European Union.

All 20 principles relate to some extent to the lives of people with dementia, their families and carers, persons with disabilities, as well as to the subject of employment and social protection.

As with the previous subsections, those held to be the most relevant, are included in bold.

Equal opportunities and access to the labour market

1. Education, training and life-long learning
2. Gender equality

3. Equal opportunities**4. Active support to employment****Fair working conditions****5. Secure and adaptable employment****6. Wages****7. Information about employment conditions and protection in case of dismissals****8. Social dialogue and involvement of workers****9. Work-life balance****10. Healthy, safe and well-adapted work environment and data protection****Social protection and inclusion****12. Social protection****13. Unemployment benefits****14. Minimum income****15. Old age income and pensions****16. Health care****17. Inclusion of people with disabilities****18. Long-term care****19. Housing and assistance for the homeless****20. Access to essential services**

3.4 European Union measures giving effect to the policies relating to disabilities, employment and social protection

The previous subsections have outlined the broad scope of the key rights-based frameworks which are in place and have particular relevance for this subject.

In this section, we aim to provide an overview of some key European legislation and strategic documents which aim to give effect to these rights.

3.4.1 European legislation

Non-discrimination in employment

Adopted in 2000, the Employment Equality Directive (2000/78/EC) prohibits discrimination and harassment on the ground of disability (amongst others) as regards employment. The Directive recognises that

the failure to provide 'reasonable accommodation' in the workplace could constitute discrimination.

A Commission Report reviewing the Directive (as well as the Racial Equality Directive) (COM(2021)139) has identified a number of areas to improve the functioning and implementation of the Directive, including:

- The need for closer monitoring by Member States of the implementation of the Directives, in particular in relation to protection against victimisation and the application of effective, proportionate and dissuasive sanctions.
- Continuing efforts at national and EU level to:
 - Raise awareness among the public at large and among those particularly at risk of discrimination, in particular about their rights and existing support mechanisms
 - Support projects; the Commission will continue to promote equality and support victims through EU funding channels, including through the 'citizens, equality, rights and values' (CERV) programme and the Justice programme
 - Offer regular information and training for policymakers, judges and lawyers on non-discrimination law, including key issues such as indirect discrimination, harassment, the burden of proof, sanctions, and algorithmic discrimination
- Encouraging data collection at national level, with a focus on statistics, complaints, judgments, sanctions and breakdowns by equality factors (including those considered potentially sensitive, such as ethnic or racial origin), to ensure data comparability over time and between regions/countries.

Workplace adaptations

The Employment Equality Directive requires making reasonable accommodation, including workplace adaptations, in favour of persons with disabilities. Concerning the minimum safety and health requirements for the workplace, the issue of specific measures that need to be taken to meet the needs of workers with a disability (e.g. adapting doors, passageways, staircases, washbasins, lavatories and workstations) is addressed in the 1989 Directive on Health and Safety at Work (89/654/EEC) and was

reiterated in the European Pillar of Social Rights (Principle 17).

Financial incentives

In order to create more equal opportunities for disadvantaged groups, including people with disabilities, a 2014 Commission Implementing Regulation (651/2014) declares certain categories of aid, such as those used to support the employment or training of people with disabilities, compatible with the internal market. Such aid (financial support to companies) is therefore allowed to a certain degree. In 2009, the Commission published a communication establishing criteria for analysing the compatibility of State aid with EU law for the training and employment of disadvantaged and disabled workers. In particular, aid for employing disabled workers is allowed if the Member State can demonstrate that granting such aid pursues an objective of common interest and can show the necessity and proportionality of such aid.

Accessibility

The 2019 Accessibility of Goods and Services Directive (Directive (EU) 2019/882) aims at improving the functioning of the internal market for accessible products and services, by removing barriers created by different rules in Member States.

Whilst the provisions on built environment are not binding, Member States are encouraged to align requirements as much as possible. Persons with disabilities should benefit from fewer obstacles when accessing transport, education or the labour market.

Social protection

The 2019 Directive on access to social protection for workers and the self-employed (2019/C 387/01) recommends that Member States provide access to adequate social protection to all workers and self-employed persons, as well as establishing minimum standards in the field of social protection of workers and the self-employed. In particular, the Directive sets out that Member States social protection systems should reflect the principles of formal coverage, effective coverage, adequacy and transparency.

Whilst the exact implementation and details of social protection remain purely within the competence of the

Member States, there is a Social Protection Committee (SPC), an advisory policy committee to the Ministers in the Employment and Social Affairs Council (EPSCO). This operates in the framework of the Open Method of Coordination (OMC), a “soft governance” mechanism which aims to spread best practice and achieve convergence towards EU goals, in policy areas which fall under the partial or full competence of Member States. In this instance, it seeks to promote social cohesion and equality through adequate, accessible and financially sustainable social protection systems, pensions, and healthcare and long-term care.

The SPC's tasks include:

- Monitoring the social situation and the development of social protection policies in the Member States and in the EU
- Promoting discussion and coordination of policy approaches among national governments and the Commission
- Preparing reports, formulating opinions or undertaking other work within its fields of competence, at the request of either the Council, the Commission or on its own initiative
- Preparing Council discussions on social protection and on the country-specific recommendations in the context of the European Semester.

Work Life Balance

The Work-life Balance Directive (EU) 2019/1158 introduces a set of legislative actions designed to modernise the existing EU legal and policy frameworks, with the aims of:

- Better supporting a work-life balance for parents and carers,
- Encouraging a more equal sharing of parental leave between men and women, and
- Addressing women's underrepresentation in the labour market.

The Directive entered into force on 1 August 2019. Member States had three years to adopt the laws, regulations and administrative provisions necessary to comply with the Directive, which should have been transposed nationally by August 2022.

The specific measures relevant for people with dementia, their families and carers include:

- The introduction of carers' leave whereby workers providing personal care or support to a relative will be entitled to five days of leave per year.
- Extending the right to request flexible working arrangements to carers and working parents of children up to eight years old.

Employment Guidelines

The Council Decision (2018/1215) on Employment Guidelines was adopted in July 2018, adopting common priorities and targets for the national employment policies (building on four initial guidelines for economic policies, agreed by the Council in a previous Recommendation (2015/1184)).

The additional recommendations aim to align the text guidelines along with those of the the European Pillar of Social Rights, whilst framing the scope and direction of Member States' policy coordination, as a basis for Country Specific Recommendations within the European Semester Process. The four additional employment guidelines are structured as follows:

- Guideline 5: Boosting demand for labour
- **Guideline 6: Enhanced labour supply and improving access to employment, skills and competences**
- Guideline 7: Enhancing the functioning of labour markets and the effectiveness of social dialogue
- **Guideline 8: Promoting equal opportunities for all, fostering social inclusion and combatting poverty**

Guidelines 6 and 8 are bolded above, as they include specific references to the additional needs of persons with disabilities and the labour market, whilst also highlighting the specific needs for social protection to offer adequate levels of income.

Public employment services

As with social protection, many of the powers relating to public employment services belong to the Member States. However, the EU Network of Public Employment Services (PES) was established in 2014 through a joint Decision of the Council and Parliament (573/2014/EU), provides a platform for cooperation and exchange of good practices, including on disability. The role and

the mandate of the group updated and extended to 2027, by Decision (2020/1782).

The network comprises all EU Member States, as well as Norway, Iceland and the European Commission, aiming to:

- Compare PES performance through benchmarking
- Identify evidence-based good practices and foster mutual learning (individual PES practices can be found in the PES Repository and outputs from the network activities can be found in the PES Knowledge Centre)
- Promote the modernisation and strengthening of PES service delivery
- Prepare inputs to the European Employment Strategy and the corresponding national labour market policies.

3.4.2 European strategic drivers

European Strategy on the Rights of Persons with Disabilities 2021-2030

Published on 2 March 2021, the European Commission's "Union of Equality: European Strategy on the Rights of Persons with Disabilities 2021-2030" (ESRPD) builds on the previous European Disability Strategy 2010-2020, seeking to improve the lives of people living with disabilities across a range of policy areas by ensuring their rights are upheld. In particular, the strategy references the Charter of Fundamental Rights (CFR), the European Pillar of Social Rights (EPSR) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

The Strategy contains commitments from the European Commission and recommendations for Member States, reflecting the division in competencies on policy matters affecting people with disabilities. The commitments and recommendations are spread across eight areas:

- Accessibility – an enabler of rights, autonomy and equality
- Enjoying EU rights
- Decent quality of life and living independently
- Equal access and non-discrimination
- Promoting the rights of persons with disabilities globally

- Efficiently delivering the strategy
- Leading by example
- Awareness, governance and measuring progress.

The ESRPD contains dozens of commitments and recommendations, including a number relating to its implementation and the UNCRPD e.g. a monitoring framework and data collection.

The actions most directly relevant for employment and social protection have been identified and included below.

Under section 4.3 “fostering access to quality and sustainable jobs”, the Commission highlighted the “flagship initiative”, intended for 2022, in which the Commission will present measures to improve labour market outcomes of persons with disabilities, which seek cooperation with the European Network of Public Employment Services, social partners and organisations of persons with disabilities to support Member States in the implementation of the relevant Employment Guidelines through the European Semester.

The Commission also committed to publishing, in 2021, an implementation report on the EU Employment Equality Directive (referenced in section 3.4.1) and, if appropriate, follow up with a legal proposal in particular to strengthen the role of equality bodies.

In the same subsection, the Commission also called on Member States to:

- Establish, by 2024, targets for increasing the employment rate of persons with disabilities and reducing employment rate gaps between persons with and without disabilities to help achieve the 2030 headline targets in the EPSR Action Plan (examined below)
- Strengthen the capacities of employment services for persons with disabilities and enhance work with social partners and organisations of persons with disabilities
- Facilitate self-employment and entrepreneurship, including for persons with intellectual and psychosocial disabilities, through providing support on legal and business matters.

Under section 4.4 “consolidating social protection systems” the Commission committed to:

- Launching, in 2022, a study on social protection and services for persons with disabilities to examine good practices on disability benefits, old-age income, health insurance, cash and non-cash benefits as well as on extra-costs due to disability
- Providing guidance to support Member States in further reforms of social protection focusing on persons with disabilities and disability assessment frameworks, including upon requests through the Technical Support Instrument.

In addition, the Commission called on Member States to define measures to further tackle gaps in social protection for persons with disabilities to reduce inequalities, including by compensating extra costs related to disability and eligibility for disability benefits.

Under section 5.2 “Equal access to social protection, healthcare, education and goods and services include housing”, the Commission urges Member States to enable the Commission’s horizontal equal treatment directive (Proposal COM/2008/0426) on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation.

This would offer similar protections as are available in relation to employment, extending into other areas, including social protection.

Under section 6, “Promoting the rights of persons with disabilities globally”, the Commission committed that the High Representative for Foreign Affairs and Security Policy / Vice-President of the Commission (HRVP) would organise regular structured dialogues during the annual UNCRPD Conference of State Parties, as well as in other settings, to enhance cooperation, with a specific focus on accessibility and employment.

It is welcome to see the Commission include its own internal commitments, including a “flagship initiative” on adopting a renewed HR strategy that will include actions to promote diversity and inclusion of persons with disabilities, as well as working to ensure the

continuous removal and prevention of barriers by all services for staff and public with disabilities and strengthening internal reporting mechanisms by the management of all Commission services on diversity, including reasonable accommodation for staff with disabilities.

Under Section 9, “Awareness, governance and measuring progress”, the Commission committed, by 2023, to developing new disability indicators with a clear roadmap for implementation, including in relation to persons with disabilities in employment, education, social protection, poverty and social exclusion, living conditions, health, use of new communication technologies, supporting the indicators for the EU Social Scoreboard, the European Semester etc.

On 20 September 2022, the European Commission announced a Disability Employment Package, one of the flagship initiatives announced in the Strategy for the Rights of Persons with Disabilities 2021-2030. The Package envisages six areas for action:

1. Strengthening the capacities of employment and integration services
2. Promoting hiring perspectives through affirmative action and combating stereotypes
3. Ensuring reasonable accommodation at work
4. Preventing disabilities associated with chronic diseases
5. Securing vocational rehabilitation schemes in case of sickness or accidents
6. Exploring quality jobs in sheltered employment and pathways to the open labour market.

The first deliverable was completed in September 2022 with the publication of a practitioner toolkit for Public Employment Services (PES), with the other areas expected to be completed in 2023.

Action Plan for the European Pillar of Social Rights

The European Commission launched its proposal for an Action Plan for the EPSR in March 2021. Following this, in May 2021, the European Commission, Member States, social partners and civil society committed to three headline targets to be achieved by 2030:

1. At least 78% of people aged 20 to 64 should be in employment
2. At least 60% of all adults should participate in training every year
3. The number of people at risk of poverty or social exclusion should be reduced by at least 15 million, including at least 5 million children.

The report notes that the new targets will be supported by a revision of the Social Scoreboard, enabling the Commission to monitor progress towards the implementation of the Social Pillar principles as part of the well-established policy coordination framework in the context of the European Semester.

New metrics with relevance to employment and social protection included:

- Disability employment gap
- Benefit recipients’ rate [share of individuals aged 18–59 receiving any social benefits (other than old-age) among the population at-risk-of-poverty] Total social expenditure by function (% of GDP): Social protection, healthcare, education, long-term care
- Coverage of unemployment benefits among short-term unemployed.

As with the Disability Strategy, the report also includes a number of commitments for its own actions, or encourages Member States to take actions.

This includes the commitment from the Commission to publish a report on the Employment Equality Directive. The Commission encourages:

- Member States to advance and conclude the negotiations in Council on the Commission proposal for a horizontal Equal Treatment Directive
- Member States to transpose the Work-life balance Directive by August 2022
- Companies to put in place mechanisms to combat discriminatory practices in recruitment, selection and promotion, and promote diversity in the workplace.

In relation to social protection, the Commission committed to:

- Launching a High-Level Expert Group to study the future of the welfare state, its financing and interconnections with the changing world of work and to present a report by end 2022
- Starting a pilot in 2021 to explore by 2023 launching a digital solution to facilitate the interaction between mobile citizens and national authorities, and improve the portability of social security rights across borders (European Social Security Pass - ESSPASS), building on the initiative for a trusted and secure European e-ID (expanding the existing Electronic Exchange of Social Security Information system).

In addition, the Commission encouraged:

- Member States to further extend access to social protection, in line with the Council Recommendation on access to social protection, and to submit their plans by 15 May 2021 setting out their national measures
- The European Parliament and the Council to conclude negotiations on the revision of social security coordination rules.

European Semester

The European Semester process, established by the EU in 2010, is a cycle of economic, fiscal, labour and social policy coordination within the EU. It is part of the European Union's economic governance framework. Although the European Semester was initially mainly an economic exercise, it has evolved, integrating other relevant policy fields in the process.

Following the proclamation of the European Pillar of Social Rights (EPSR) in 2017, the European Semester also provides a framework for coordinating and monitoring member states' efforts in delivering on the principles and rights set out by the pillar.

As part of this, the European Commission's country reports monitor, among other things, actions taken by Member States to enhance the participation of people with disabilities in the labour market. Accordingly, on 5 June 2019, the Commission released its country-specific

recommendations (CSRs), with 18 Member States having a disability-specific recommendation within their reports.

In most cases, these comments related to increasing support for persons with disabilities to enter into the labour market and reducing the risk of poverty and/or social exclusion. The comments also covered issues such as educational facilities and, to a lesser extent, community-based services and independent living.

The 2021 cycle saw countries evaluated on their Recovery and Resilience Plans, following the exceptional circumstances of the pandemic, therefore the format was not comparable to previous years.

In 2022, recommendations focused on matters related to energy crisis, Green and Digital transitions, the war in Ukraine and recovery from COVID 19, with the Commission continuing to rely on the National Recovery and Resilience Plans to cover the main problems found in each country.

Member States have specific measures identified in relation to disability, however, there are fewer specific recommendations. In total, six CSRs made a specific reference to persons with disabilities, compared to the 20 made in 2020. The most recent countries to be issued with recommendations include: Belgium, Estonia, Hungary, Latvia, the Netherlands and Poland.

A range of policy issues are covered across the broader country analysis, as well as the CSRs, including:

- Employment of persons with disabilities
- Poverty and social inclusion of persons with disabilities
- Social services, de-institutionalisation and community-care
- Social protection for persons with disabilities
- Education, training and labour-related skills.

4. National policies and strategies

Alzheimer Europe wished to determine strategic and policy positions of countries in relation to employment support for people with dementia and their carers, examining specific dementia strategies or other policy documents (e.g. on employment, disabilities etc.). As such, we asked our members to outline what, if any, government policies were in place.

4.1 Dementia strategies

It should be noted that not every country has a dementia strategy and of those countries which do, the focus is often primarily on health and care services and support, in addition to areas such as awareness raising, dementia inclusive communities and research. Where social protection is referenced, it is usually in the broader definition of the term, enveloping health and social care services, as well as a broad range of welfare benefits, including earnings replacements benefits. As such, there are additional aspects of strategies which may have some overlapping relevance (e.g. respite or daycentres), which we have not included here.

In the main, the national dementia strategies are limited to the extent in which they address the subjects of employment or employment related benefits of either people with dementia or carers. Where countries do acknowledge them, the commitment to actions vary considerably.

For example, in the Czech Republic, there is a broad reference to the need for employers to be trained to recognise the needs of persons with dementia and their carers, whilst committing to no specific activities in this area.

It is notable that in France, the Neurodegenerative Diseases Roadmap contains references to employment retention for people with Multiple Sclerosis or Parkinson's disease, yet not for Alzheimer's or dementia, with no reference to carers (despite inclusion in the national Neurodegenerative diseases Plan 2014-2019).

In Germany, the national dementia strategy contained a number of dedicated actions in relation to provided support for people with dementia in the workplace, including:

- Measure 2.3.1 Expansion of information and continuing educational resources for relevant bodies/officers in companies – development of a handbook for companies providing information about dementia and outlining the needs of people with early onset dementia.
- Measure 2.3.2 Support of local support networks by integration offices – provision for people with dementia in the workplace through support in the form of trained contact persons, integration offices and other counselling and support services will be sensitised to the topic of dementia.

For carers, the German national dementia strategy also contains the following measures:

- Measure 2.6.1 Advancing of family care leave – On the basis of the first report of the independent advisory board on reconciling care and employment, the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (BMFSFJ) is initiating a broad social discussion and investigation of strengthening family care leave and nursing care leave
- Measure 2.6.2 Expansion and development of networks for 'care and employment' - The federal states and the local authority associations are working to establish and expand network structures to facilitate reconciliation of care and employment through companies, municipalities, family care-givers and stakeholders in long-term care and social health services at the local level, in particular to support the relatives of people with dementia.
- Measures 2.6.3 Support for care pilot programmes in companies – The federal states are supporting programmes to qualify employees in companies to become company care pilots with dementia-specific knowledge.
- Measures 2.6.4 Provision of information for companies and employees on the subject of 'care

and employment’ – By means of its ‘success factor family’ programme for companies, the BMFSFJ will work to ensure that employers provide their employees with better information on reconciling care and employment.

In Greece, the National Dementia Plan included a specific commitment (Axis 5: Legislation – Rights of people with dementia and their caregivers), which committed to overarching changes across a broad range of issues, including rights, social protection and other types of support.

In Ireland, the National Dementia Strategy identifies the specific Irish social protection and support available to persons with dementia and carers, as well as highlighting some of the challenges faced by persons living with younger people with dementia who are still in the labour market. However, there are no specific measures or commitments in the strategy in relation to employment.

Similarly, the Maltese strategy identifies the likelihood of persons with early-onset dementia potentially still being in the labour market, whilst also noting that carers often reduce or leave gainful employment, whilst identifying that for the latter, flexible working and telework may support carers to continue working. However, for people with dementia, the strategy does not address support relating to employment or social protection in this area. For carers the strategy (in 6.3.4, point “o”) identifies the needs to “Provide support to caregivers to continue working whilst providing care. The caregiver pension should also reflect the specific and significant financial needs of dementia care”.

In the Netherlands, it is noted that almost 20,000 people with dementia will have young onset dementia and that this population will often still be in work, noting the impact of lost income and the distinct support needs of this group. However, no specific measures in relation to employment are addressed within the strategy, either for people with dementia or carers.

In Spain, the national Alzheimer plan contains point 2.5.3 which identifies the need to design tools to

facilitate communication and understanding of the diagnosis and its implications for patients and families as well as to incorporate into these tools a general catalogue of available benefits and resources (services, benefits and aid from the different social protection systems: social services, health, housing, social security, employment, etc.) and the general protocol for accessing them. This would be prepared with the collaboration of the respective Ministries responsible for the various benefits and resources.

At the time of writing, Slovenia did not have a national dementia strategy in place, however, one was under development. In the draft, a chapter was dedicated to the protection of the rights of persons with dementia and their carers, namely to prepare the legislative framework that will enable to properly regard dementia as a disability and to fully protect the rights of patients and their carers, including for employment and social protection. As part of this, it included a reference to ISO 25551 – “Ageing societies - General requirements and guidelines for carer-inclusive organisations”.

4.2 Other strategies or policy documents

As dementia is a condition which more commonly occurs later in life, it is sometimes included under the umbrella of mental health and is recognised as a disability (under the UNCRPD). As such, Alzheimer Europe asked its members to highlight any strategies and policy initiatives in these other areas launched by governments, which may have relevance for people with dementia and their carers.

In the Czech Republic there is a strategic framework for employment policy until 2030, as well as a national plan for the promotion of equal opportunities for persons with disabilities until 2025, both of which have relevance for people with dementia and their carers.

Estonia is in the process of developing a new Welfare Development Plan for 2023-2030, which recognises that relatives of those in need often do not want or cannot stay out of the labour market. As such, it seeks to ensure a baseline of social guarantees for people with a caregiving role, to

improve their awareness and skills in both asking for help and providing care at home, and to find ways to better support their work and family life.

One of the intended activities is to improve the working environment and employment relations of employees, to maintain health in the work environment and to prevent health damage, including considering specific needs of workers (e.g. working with flexible arrangements etc.)

Finland's "National Programme on Ageing 2030 - For an age-competent Finland" has a specific aim "The functional capacity of older working-aged people has improved and careers have a longer duration, particularly in the services for older people", which has relevance for people with dementia and their carers, however, the practical emphasis is more on mental well-being and capacity, as well as musculoskeletal issues as a cause of early retirement.

France produced a specific "Acting for Carers Plan (2020-2022)" which included a number of specific measures related to the employment of informal carers, including the following measures:

- Measure No. 5 - Compensated leave for family carers for employees, the self-employed, civil servants and the unemployed, from October 2020.
- Measure No. 6 - Leave for close caregivers, which can now be taken immediately upon joining a company, without waiting a year as before, from January 2020.
- Measure No. 7 - Periods of leave to care for the family will no longer be counted in the calculation of unemployment benefits, to avoid a drop in benefits, from November 2019.
- Measure No. 8 - Automatically taking into account compensated family carer's leave for the purposes of retirement rights, without any formalities from October 2020. Beyond that, the ongoing consultation on the universal pension system includes this major issue of taking into account periods of assistance.
- Measure No. 10 - Facilitating the career paths of carers who have had to stop working for a long-time to support a relative, in particular with a new system of recognition of experience acquired as a family carer, in 2021.

The French Government has committed to a continuation of the follow-up of the "Acting for caregivers" strategy beyond 2022, with stakeholders (including France Alzheimer) expressing their wish to see it renamed "Acting with caregivers".

In Germany, the Federal Ministry of Family Affairs established an advisory board on the compatibility of care, which has drawn up proposals for amendments to the legislation which governs care time. The Ministry is expected to carry out further work on this area in 2022, in response to the proposals.

Malta adopted a National Strategic Policy for Active Ageing 2014-2020, which included a dedicated theme on "Active participation in the labour market". Active ageing policies seek to increase the number of older workers in the labour market, whilst enabling persons above statutory retirement age to remain in or re-enter employment, including the following recommendations:

- Continuous vocational education and training for older adults
- Improving healthy working conditions, age management techniques and employment services for older workers
- Taking a constructive stand against ageism and age discrimination
- Implementing employment-friendly tax/ benefit systems
- Encouraging mentoring schemes in occupational organisations
- Strengthening the available measures reconciling work and informal care.

Available financial incentives are aimed both at encouraging workers to remain in employment or encouraging employers to recruit older workers, including amending tax brackets of workers and allowing workers above retirement age (irrespective of their earned income) to receive their pension entitlements.

For carers, the policy notes the role of carers as a barrier to work, whilst also highlighting a previously successful scheme involving the payment of pension contributions by the government for women

re-entering employment. This policy, along with other initiatives such as the creation of support structures (e.g. childcare centres and pre-school care, and payments of pension contributions by the state if women re-enter employment), resulted in the doubling of female participation in employment in Malta from 2004 to 2019 to 55%.

In addition, Malta's Office for Disability Issues (within the Ministry for Inclusion and Social Wellbeing) launched a National Strategy on the Rights of Disabled Persons titled 'Freedom to Live'. One of its objectives, 'Work and Employment', is aimed to be achieved through a number of specific action points, including:

- Specific Disability Equality Training (DET) and information targeting all employers
- Pre-employment, employment, and job retention strategies
- Work-related supports and adjustments

- Promoting social enterprise incentives
- Improved career guidance services
- Media campaign to promote disabled persons in employment, creating awareness of services, and certify inclusive employers.

Portugal published a "National Strategy for the Inclusion of People with Disabilities 2021-2025", with the further strategic axis dedicated to work, employment and professional training.

In addition, the National Institute for Rehabilitation has a "Practical Guide on the Rights of Persons with Disabilities", which covers the rights and legal protection afforded to persons with disabilities in Portugal, including a dedicated section on employment (under section 2) and information on social protection (under section 3).



5. National legal protection relating to employment

Each country within Europe has its own legislation and regulations in relation to employment. Whilst there is some European legislation in this area (as referenced in 3.4.1), these are broad in scope and allow for significant variations in implementations. This section aims to provide a high-level overview of the situation in Europe, highlighting some of the notable commonalities and differences in the systems, including where there are differences between protections for people with dementia and carers.

5.1 People with dementia

In this subsection, we focus on employment protection for people with dementia, particularly those which offer protection against discrimination based on disability. Where countries have legislation law which overlaps or addresses multiple issues (e.g. social protection, right to leave etc), those aspects related to welfare benefits and payments will be addressed in section 6.

Findings

The legal employment protection afforded to persons with dementia varied between countries, with some falling under the labour code of the country, whilst others referenced legislation focused on disability, safety and/or rehabilitation in the workplace.

It was notable that in some countries, including Spain, Sweden and the United Kingdom (as a whole) the protections in relation to employment are covered by broader overarching discrimination legislation, which either specifically addresses persons with disabilities (Spain) or includes disability as a protected characteristic (Sweden and UK).

The provisions of the UK's Equality Act 2010, specifically refer to concepts of direct discrimination, indirect discrimination, harassment and victimisation. This broadly reflects the different types of discrimination identified in General Comment 8 on Article 27 of the UNCRPD.

Notably, the Spanish General Law on the Rights of People with Disabilities and their Social Inclusion commits to the elimination of all forms of discrimination (including those relating to employment), referencing different articles of the Spanish Constitution, as well as the UNCRPD.

Finland reported that persons with disabilities were protected under section 15 of the Non-Discrimination Act (1325/2014), specifically in the context of reasonable adjustments. However, crucially, it was noted that people with dementia are not always recognised as having a disability and that implementation in this regard often varied locally. Similarly, Germany reported that whilst the social insurance code in the country addresses rehabilitation and participation of persons with disabilities, dementia is often not recognised as a disability until the point where a person has severe dementia and is unable to work.

The Dutch system was notable for its approach in the assessment and protection of workers, which was the only one to define a protected period of time, as part of its Gatekeeper Improvement Act. Under the law, a company doctor and an employment expert examine what someone can still do. During these two years, the employee continues to receive (part of) his/her salary and keeps his/her job. The employer is not allowed to dismiss someone during these two years. After these two years of illness, a medical examination is carried out by the UWV, Uitvoeringsinstituut Werknemersverzekeringen (Employee Insurance Agency), who assesses the person's ability to work. In the case of dementia, the person will usually be referred under the WIA, Werk en Inkomen naar Arbeidsvermogen (Work and Income according to Labour Capacity Act), which was introduced in 2005. Thereafter, individuals will receive welfare benefits where they are assessed as fully or partially incapacitated for work.

It is also useful to note that the organisations in Belgium (Flanders), the Czech Republic and Estonia noted their respective country's policy and legislative provisions for providing support to businesses which employ persons with disabilities. Malta also

has a similar scheme in place to reintroduce people into the labour market, which includes both people with dementia and carers (we have included this as a good practice example in Section eight of the report). In Portugal, the Act of the Government no. 209/2009 contains a legal framework which provides both financial and technical support for professional rehabilitation centres and entities, as well as for workplace adaptations.

5.2 Carers of people with dementia

In this sub-section we focus on employment protection for carers. For some countries, there is an overlap between employment protection and social protection. In this section we will examine the right to leave and employment protection, whilst the following section will place a greater emphasis on the monetary aspects of the support.

Work Life Balance Directive

Alzheimer Europe was particularly interested to see the extent to which countries had transposed, or were in the process of transposing European Directive 2019/1158 (the Work-Life Balance Directive). Greece confirmed that its new Labour Law introduced in 2021, was a transposition of the provisions of the Work-Life Balance Directive, whilst Estonia explained that its Employment Contracts Act of 2022 was a transposition of some aspects of the Directive (however, its Employment Contract Act 2018 had already introduced some of the provisions). Luxembourg noted that the process was underway, with an Opinion on the Bill due from the Council of State in August 2022.

In Portugal, the Government has made a proposal to the parliament that is now to be considered by the Parliamentary Commission on Labour, Social Security and Inclusion on the law Proposta de Lei n.º 15/XV Procede à alteração de legislação laboral no âmbito da agenda de trabalho digno (To change the labour legislation in the framework of the work with dignity agenda).

No other countries explicitly mentioned the Directive – it is unclear if this reflects a lack of progress in transposition, a lack of awareness about the Directive and

its obligation, or whether countries already met the Directive through existing legislation.

Findings

The majority of countries report that there was some right to leave or employment protection for carers, which varied significantly, with some countries having eligibility criteria, often in the form of minimum required service (usually between 6 months and 1 year). It was noted that in the UK, the government had committed to making carer leave a day-one right but had not taken forward any initiatives.

Belgium (Flanders) was exceptional insofar as in addition to its leave for caring (by suspending the employment contract or reducing working hours by 20% or 50% for between 12 and 24 months, only in three-month blocks), people working in the private or social sectors were eligible for a supplementary interruption payment.

The Carers Leave Act 2001 in Ireland was also notable, especially for longer-term periods of leave. The Act provides for the entitlement of an employee to undertake long-term unpaid leave to provide full-time care and attention to a person who needs such care. However, it is unique insofar as there is a minimum statutory entitlement of 13 weeks (and a maximum of 104 weeks). Employers may (providing reasonable grounds are given) refuse an employee to take Carer's Leave for any period of less than 13 weeks. The Act protects a person from penalising a person on the grounds that they exercised their rights.

By comparison, the Work and Care Act in the Netherlands distinguishes between different types of leave, including emergency, short-term (paid at 70%) and long-term leave (unpaid), with the yearly entitlement calculated based on the hours worked (twice the weekly hours worked for short term leave, six times the weekly hours worked for long-term leave). Employers can only refuse where a compelling business reason exists. This was also true in Germany, where short term leave (up to 10 days) was paid at 90%, whilst longer-term leave of up to 6 months could be taken but was unpaid. As part of its laws, people also have the right to go down to 15 hours of work per week, though the hours dropped are not paid.

A key distinction in France is that the law stipulates that the maximum length of leave is determined by collective agreements (or 3 months where no collective agreement exists), which can be renewed, but cannot exceed one year across an employee's career.

Other points

Countries including Belgium (Flanders), Malta and Turkey noted that slightly preferential and additional forms of leave and flexibility were available to civil service employees in their respective countries.

Portugal was a notable exception for its law (Informal Carers Legal Framework), which specifically makes provision for the support of carers in their socio-professional life, with a view to returning to the labour market after a period of being a caregiver, through skills development, training and other support to encourage them to the labour market.

In the case of the UK, discrimination by association is also covered by the legislation. As such, a carer looking after a person with dementia, is protected from direct discrimination, including in relation to employment.

This is clarified in the "Employment: Statutory Code of Practice", produced by the Equality and Human Rights Commission, which provides examples of discrimination based on disability, as well as examples of discrimination by association, including one related to being a carer of a person with a disability.

In the UK (Scotland), the Carers (Scotland) Act 2016, in force since April 2018, aims to ensure that unpaid carers are recognised as needing support with their caring role and obliging local authorities to meet their needs. This requires local authorities to formally assess informal carers, working with them to determine the unpaid carer's personal outcomes and meet their eligible needs, as well as maintaining an information and advice service for unpaid carers to provide information and advice about certain topics, including unpaid carers' rights, income maximisation, advocacy etc.



6. National social protection – welfare benefits

In this section, we will provide an overview of the situation in relation to social protection available to people with dementia and their carers across Europe. This section aims to provide an overview of the welfare benefits.

Whilst not providing a detailed breakdown of each country, the overview will identify common strengths and weaknesses across social protection systems relevant for people with dementia, as well as any notable or unique features within countries, which we believe are useful to highlight.

In addition, each subsection contains an outline of the positive and negative aspects of benefits across Europe. These reflect the feedback provided by our members and are not mapped against specific benefits.

Finally, each section contains any additional initiatives or actions which we believe may be relevant, as well as future actions to which governments have committed in order to improve social protection in this area.

6.1 People with dementia

Social protection linked to earnings replacements vary significantly in scope across European countries, with different benefits available to individuals. Disability pensions and various forms of monetary allowance (as a form of earnings replacement) are the most common forms of support, however, others do exist, including those focused on providing financial assistance for health and social care services, as well as home adaptations or mobility aids.

The majority of earnings replacement benefits are subject to strict eligibility criteria, including:

- Age
- Severity of the illness
- Maximum level of income from other sources (per week/month), including household income in some cases
- Previous employment prior to retirement.

These differences, as well as the varying benefit rates, differences in cost of living etc. make direct

comparison difficult. Despite this, some key trends have been identified, as well as some defining factors of the different systems.

Findings

A number of countries (Czech Republic, Estonia, Finland, Germany, Ireland, Luxembourg, Malta, Netherlands, Portugal, Sweden, Switzerland and Turkey) have some form of invalidity/disability pension, to which persons under retirement age were entitled when they were no longer able to work (either completely or to some extent, usually with percentages of incapacity to work). In these cases, eligibility was usually contingent upon having previously paid sufficient contributions or a defined period of years of work– these prior earnings or contributions were frequently a consideration in the amount of support to which an individual is entitled. In the cases of Estonia and Sweden, the entitlement to this benefit was for a maximum of five years, whilst in Finland, it was reported that this benefit was usually easier for people aged over 60 (but still under retirement age) to access, even though this was not a formal requirement.

For other countries, allowances and regular payments, related to disability and/or unemployment were the most common forms of other types of social protection (not including support relating to health or social care) available to persons with dementia under the age of retirement.

As noted, the social protection for persons of working age a number of countries has different tiers or levels of support, depending on the perceived disability and/or the inability to work. As part of this, however, for the majority of countries, support from benefits was predicated on the working age person having stopped work completed. In Germany, the incapacity pension allowed for some work (3-6 hours per day) to be carried out, however, it was noted that people with dementia rarely benefited from this benefit. In Greece, patients with a 67% disability (certified by the

health committee) have the opportunity to take six additional days off per year, or working one hour less per working day.

The majority of benefits reported by members related to those of people of working age, however, some countries (Estonia, Finland, Greece, Ireland, Malta, Portugal, Slovenia, Switzerland, Turkey and the UK (all) reported that additional social protection benefits (not including retirement age pensions) are available to people with disabilities who have reached the age of retirement. These fall into three distinct categories: Benefits specifically for retired persons with a disability, benefits which continue into retirement and those which supplement low income. From our experience of working with members on this area, we are aware that it is likely that other support and services (e.g. through social care, etc.) will become available to people once they have reached the age of retirement, however, as they are beyond the scope of this report, they were either not reported or have been omitted.

Applications and assessments for social protection benefits almost universally involved some element of medical assessment, either by specified persons/panels of an organisation or medical certification. Additionally, countries reported the need for supplementary information, evidence and documentation to be submitted as part of the process, to demonstrate the impairment to daily function, the inability to work or to demonstrate the need for financial support (especially where means testing was applied). The UK (Scotland) noted that its social security system was attempting to make the process easier for applicants by making greater use of existing information (e.g. social care assessments), only holding in-person meetings where necessary.

Ireland, France and Turkey highlighted that benefits are means-tested based on the income of the whole household. Although not explicitly mentioned by other countries, it is possible that this will be the case where means testing exists. Related to this, the UK (all) was the only country to report benefits that have a defined rate based on whether they are paid to an individual or a couple. Review periods for the assessment varied across countries, with the most common review period being six months or a year.

Perhaps unsurprisingly, the focus of social protection is broad, usually relating to disability and/or capacity for work, rather than disease specific. However, some benefits did have provisions which specifically recognised dementia or allowed for specific accommodation. For example, in Greece, a person with dementia is only assessed one time, at the beginning of the application. In the UK (all), a person considered terminally ill can apply for the highest rate of disability benefits, without needing to satisfy usual elements – in UK England, Wales and Northern Ireland, a doctor must confirm that the person is likely to die within 12 months, whilst Scotland's is not based on length of time but rather the stage of illness, availability of curative treatment and the increased need for care and support – government guidance specifically acknowledges dementia and neurological conditions. However, the process still requires clinical assessment and is subject to the assessment by a clinician, therefore entitlement is not automatic. In Portugal, the specific part legislative provision of the invalidity pensions (Law of Parliament 90/2009) allows for slightly more favourable criteria for people living with dementia.

Positive aspects of available welfare benefits

Alzheimer Europe asked members to report on what they felt were aspects of social protection systems which worked well for people living with dementia. From the responses received, factors which were identified included:

- The economic support granted to persons with dementia or disabilities through these forms of social protection provided a minimum level of guaranteed income to the individual when they could no longer work
- The legal recognition the benefit afforded the person with dementia (i.e. in recognition of their need for support, their disability etc.)
- Automatic entitlement (i.e. not means tested) benefits reduced the complexity of access
- The regular review of benefits to assess the amount given, usually in the context of another economic marker (e.g. minimum wage or inflation)
- Where below pension age, the continued contributions to the person's pension ensured the person was not disadvantaged upon reaching

the statutory retirement age (though this was not universal).

Negative aspects of available welfare benefits

Conversely, Alzheimer Europe wished to identify what elements of social protection systems created difficulties for people living with dementia. It should be noted that the criticisms were more frequent than the positives and demonstrated significant shortcomings across countries. From the responses received, the following common factors were identified:

- The insufficient amount of the benefits was a recurring theme, with some countries noting that the level had not increased in recent years.
- The poor accessibility of benefits was frequently highlighted by respondents, in particular the complex, bureaucratic and restrictive eligibility criteria, including:
 - Long timescales for applications and processing of claims
 - Strict eligibility criteria, particularly the in relation to functional and medical assessment of the person – often only persons assessed as having the most severe levels of disability were eligible for support, whilst other systems had a different levels of support depending on assessed need
 - Time limited nature of certain benefits, such as unemployment or sickness benefit
 - For social insurance systems, the required minimum contributions before eligibility for support was a barrier
- In some countries, benefits are age dependent, meaning that people over the pension age are ineligible to receive them
- In some countries, entitlement to different benefits can overlap (e.g. for disability assistance, state pensions etc.) – in the case of Malta a person may not be in receipt of two different types of benefit concurrently and will receive the benefit with the higher amount.

Additional points

The system of benefits for persons with disabilities and older people is complex and interconnected, with health and social care often overlapping and interlinked to create a broader package of support

for an individual. These benefits are sometimes administered or provided by different organisations (sometime a mix of state, private and social sector), whilst responsibility is sometimes split across national, regional and local levels.

Some countries reported on some of these additional types of supports. For example, for housing support, housing adaptations and assistive technologies, Finland, Ireland, Italy, Luxembourg, Switzerland, UK (all) highlighted these as part of the social protection available to persons with disabilities. Italy was unique in offering tax discounts for people to purchase assistive technologies. In addition, Ireland, Switzerland, Turkey and the UK (all) reported having some level of eligibility for assistance with public transport, either for the person themselves, or the accompanying person.

Two countries mentioned training for individuals, in relation to unemployment support, Estonia and Finland. In the case of the latter, this consists of two different memory training programmes (for those aged over or under 68) specifically tailored for people with memory disorders.

As noted, the support available for those above or below retirement age varies, creating different entitlements depending on age. One clear example of a disadvantage created by this system was in France, who reported that whilst persons under 60 with dementia are considered as having a disability, adults aged over 60 are considered as adults with a loss of autonomy, a legal distinction, which creates inequality and disadvantages for people with dementia in relation to the social protection to which they are entitled.

6.2 Carers

As with the welfare benefits for persons with dementia, support for carers varied across European countries, with the majority of earnings replacement benefits being means-tested and/or subject to strict eligibility criteria, including:

- Age
- Number of hours of care provided

- Severity of the illness of the cared for person
- Conditional on the receipt of certain benefits by the cared for person
- Maximum hours of employment (per week/month)
- Maximum level of income from other sources (per week/month)
- Previous employment prior to caring.

These differences, as well as the varying benefit rates, differences in cost of living etc. make direct comparison difficult. Despite this, some key trends have been identified, as well as defining characteristics and relevant developments.

Findings

It was notable that in Belgium (Flanders), Estonia, Finland, Sweden and Switzerland, some support provided to carers is assessed and delivered at the local level, with the amounts of benefits mostly related to the level of care and support needed by the cared-for individual. However, this is also the case for the majority of centrally administered benefits.

A number of countries highlighted the time-limited nature of the earnings replacement benefits available to carers, including Czech Republic (90 days), Slovenia (7 days, with 14 days extension) and Sweden (100 days). Similarly, France covered up to 66 days of earnings replacement, despite the number of eligible days of leave for carers leave being considerably longer. In the Netherlands, short-term paid leave was limited to the equivalent of twice the number of hours worked in a week. However, as other countries specified that minimum levels of need or disability criteria must be met as part of the eligibility criteria, it is likely that some equivalent level of minimum time exists in other countries.

Estonia's unemployment benefit (for a registered unemployed person who has been employed or engaged in an activity equivalent to work for at least 180 days during the preceding 12 months), recognises care provided for a sick, disabled or incapacitated person, allowing the carer to claim an allowance that is paid on the basis of a daily rate for up to 270 days.

Continuing on the theme of eligibility, it was notable that some countries had restrictive criteria in place

regarding the relation or position of the carer to the cared-for person. For example, both Malta and Portugal reported that the benefits were restricted to those co-habiting, whilst Slovenia reported that only the spouse of a person was eligible for the support. Similarly, in Turkey, where a person with disabilities is cared for at home, the assessment for certain types of support done so based on means testing of the incomes of the members of the household.

The age criteria for benefits varied considerably between countries, however, a majority of benefits were aimed at people who are considered as being economically active, which usually related to being over 18 and under retirement age (which varied by country). However, other countries, including Finland, Germany, Italy, Luxembourg, Malta and Turkey did not report that the person must be under retirement age. The UK (all) provides additional pension credits where the retired person provides care (although this is subject to the level of state pension received).

Despite this, there were few references (with the exception of Germany, Luxembourg, the Netherlands, Switzerland and the UK) to the ongoing contributions of caregivers in receipt of these benefits, to social insurance/pension schemes etc. to ensure that the carer was not negatively affected by their role.

Another aspect of conditionality frequently reported by countries (Finland, Germany, Ireland, Malta, Portugal and Turkey) was that the carers could only receive support where the cared-for person had a minimum level of assessed disability, where they provided a minimum number of hours of care (Luxembourg) or the cared-for person was in receipt of a qualifying benefit (UK – all). France noted that the conditionality of the degree of dependency of the cared-for person was lifted by a ministerial decree in September 2022.

A slightly different approach was also taken in France, whilst not a direct earnings replacement, benefits related to tax credits/relief, where a person employs some form of homecare/home help service to assist with the care needs of the cared-for person. This was also true in Ireland, with an additional measure existing whereby jointly assessed spouses are eligible for a deduction where one person provides care for

the other. In Finland, it is also possible to claim a tax deduction related to household work, as well as nursing and caregiving that is done at home. In practice, if one hires a private nurse/caregiver, it's possible to have tax return and also if one hires a caregiver for one's parents.

Positive aspects of available benefits

Alzheimer Europe asked members to highlight some positive aspects associated with the benefits available to carers. These include:

- The formal recognition that assessment and receipt of the benefit gives to the carer, as well as the acknowledgement of the work they do
- Allowing continued support from the informal caregiver, potentially allowing them to remain in a familiar environment and with family members or carers
- Providing (limited) economic support for the relative who cares for the person, especially where the carer has had to reduce or give up work
- In some cases, access to one benefit may also qualify an individual for an additional amount in another benefit (e.g. through a pensions supplement).

Negative aspects of available benefits

Our members also expressed a number of shortcomings and problems with the benefits available to carers, including:

- Regional variations in the availability, level and eligibility of support for carers creates inequity (in those countries where support is provided locally)
- The amount of support provided was frequently considered to be inadequate, especially for carers of working age
- Where benefits are time limited, this was highlighted as particularly problematic
- The challenges faced by people with dementia, were also commonly cited as barriers experienced by carers, including poor accessibility of benefits, with assessments and eligibility criteria creating systems which are complex, bureaucratic and inaccessible to many, including:
 - Limitations on who can access the benefit (e.g. only spouses, co-habitants etc.)
 - Limitations on other income and working hours

per week, which limit the ability of carers to maintain employment.

- Carers are not assessed in their own right – e.g. consideration of the cared-for person's condition does not necessarily reflect the need of the carers for support
- In some countries, benefits are age dependent meaning people over the pension age are not ineligible to receive them
- In some countries, entitlement to different benefits can overlap – in the case of the UK for example, a carer may wish to claim carers allowance. However, if they are entitled to another “overlapping benefit” which has a greater than the weekly value of the carers allowance, they cannot then be paid carers allowance.

Future plans

In the responses to our survey, some countries highlighted some of the work which is ongoing or has been proposed to address some of the issues identified.

In Italy, a proposed new law, “Norms for the promotion of the dignity of the elderly and for the taking care of the non-self-sufficient” (“Norme per la promozione della dignità delle persone anziane e per la presa in carico delle persone non autosufficienti”). Measures to support cohabiting informal caregivers, include:

- Special protections in the field of social security and insurance and for the insertion and reintegration into the labour market
- Interventions for training and certification of acquired skills
- Psychological support interventions, thus avoiding that their welfare commitment may result in a detriment to their working life, to the completion of study and training paths as well as to the exercise of parental and educational responsibilities towards their children of minor age.

In the UK (Scotland), a new Scottish Carer's Assistance will replace Carers Allowance, as this benefit is being brought under the control of the Scottish Government (having previously been the responsibility of the UK Government), which is consulting on possible changes to the benefit.

The proposals include a number of improvements, including providing a better service for carers, linking it to others supports e.g. social care, employability, education and bereavement support.

Other proposed changes include:

- Removing education restrictions so carers can study full-time and receive Scottish Carer's Assistance
- Increasing the length of time that Scottish Carer's Assistance will be paid after the death of a cared for person, from eight to 12 weeks
- Increasing the length of time that Scottish Carer's Assistance will be paid when a cared for adult goes into hospital or residential care, from four to 12 weeks
- Increasing the amount carers can earn and still get Scottish Carer's Assistance
- Allowing carers to add together hours spent caring for more than one person to reach the 35 hours a week caring requirement for Scottish Carer's Assistance
- Providing an additional payment per week, where a carer cares for more than one person (who receives a disability benefit).

In Sweden, it was noted that as part of the manifesto of the governing party, there has been a commitment during the previous election to ensure “equal-rights to equal care” for all, across all of the 290 local authorities, to ensure consistency of supports and services.

Additional points

Countries provided other examples of some of the types of support provided to carers, however, as they are not directly linked to employment and are not related to earnings replacement benefits, we have not given them significant focus here.

Some countries highlighted carers' eligibility for respite care. We are also aware that these are offered in other countries, however, these are often only for a few hours and access is often poor. Furthermore, access to this is not specifically related to employment. Similarly, countries referred to daycare services. Again, these are not specifically linked to employment per se, and are more so services for the person with dementia themselves. Alzheimer Europe has covered the availability and affordability of these services as part of the Dementia Monitor 2020³.

A number of countries, including Finland and Luxembourg (state provided/funded) and Hungary and Spain (association provided), highlighted the training schemes offered to carers to allow them to better support the cared-for person with dementia. Again, we are aware that such schemes are offered in many countries, often by our members, however, these are more commonly focused on how to manage on a day-to-day basis in the role of an informal caregiver.



7. Experiences of people with dementia and carers

It is important to consider that whilst the legislation and policies examined in this Yearbook have the potential to improve the lives of people living with dementia and their carers (as well as persons with disabilities more broadly), the day-to-day reality experienced by people will often differ considerably, as implementation and practice varies across countries, employers and organisations.

As such, it is essential that the voices and experiences of people living with dementia, as well as those of carers, are also heard and understood. Alzheimer Europe sought the experiences of people living with dementia and carers, asking associations to provide examples, with some providing first hand accounts, others explaining examples where they have supported individuals. Alzheimer Europe also approached the European Working Group of People with Dementia (EWGPWD) and their supporters, asking for their lived experience of working whilst having dementia or of accessing social protection.

Whilst these stories span across a number of years, they illustrate gaps in legislation and policies across Europe which have resulted in people having poor experiences, either in the work place or when accessing social protection.

7.1 Belgium (Flanders) - Réal Larnou



Réal Larnou is a current member of the EWGPWD.

I have been working in a bank for more than 30 years, and in the last 10 years I was a relationship manager for the agricultural sector. On daily basis I was responsible for credit applications of farmers, which involved visiting these clients at their farm to work out a credit call.

About three years ago, while driving to one of my clients, I suddenly had a loss of orientation. This must have been the first sign that something was wrong. However, at that moment, I was not aware that this was my first confrontation with a symptom of Alzheimer's, not knowing what Alzheimer's disease really was.

About a year later, I made a mistake in a daily routine file. Never before had I made such a similar mistake. Although, neither the customer, nor my employer was disadvantaged, I experienced this as a breaking point in my career.

I felt I had no other option than to decide to stop working. I wanted to find out what was really wrong with me and made an appointment with my doctor. The struggle for a diagnosis lasted almost 6 months. On 1 July 2021, the diagnosis Alzheimer was confirmed.

On the one hand, the diagnosis was a relief, because I finally knew what was wrong. On the other hand, it was very confronting because I had always hoped to end my career in a positive way.

The diagnosis of Alzheimer's disease meant for me the immediate end of my current function – I was not allowed to continue my specific role as a part-time job. My specific role was very stressful, with high targets and a lot of administration.

Therefore, I was convinced that it was better to stop working instead of going on and no longer being satisfied with my job. However, my colleagues and employer were very understanding about my position.

7.2 Belgium (Flanders) Ikuko Van Laer



Ikuko Van Laer is the wife and caregiver of Geert Van Laer (member of the EWGPWD until October 2022).

It is a continuous challenge to access welfare benefits for me. First of all, it is absolutely not clear which kind of benefit we can get. Secondly, many documents are required to receive benefits and it is not clear which documents are actually required. In my case, I can get help from a social worker. Without her help, I can't manage this complicated task. There are some benefits we can receive automatically by recognition of Geert's disability. This is of course easier but is an exception in most cases.

At the time of Geert's diagnosis, my husband was not in the condition to do these types of things by himself anymore. The way he was talking made it seem that he was no different than before, despite the fact

that he could not even remember being diagnosed. He repeated paying for some things and forgot to pay for others. It was therefore absolutely necessary to take over the financial matter which he was doing before but it was very hard. Without giving income details, we aren't eligible for most of benefits. Even now, Geert is sensitive about money matters, so I do these takes only during his absence.

For benefits, every case should be treated differently, however, some level of support is surely needed. The person who receives a diagnosis of dementia likely faces difficulty in doing this kind of administrative job. For the person without a partner or a family support, it must surely be a serious problem.

If we were able to have a clear table of needed information about all possible benefits, it would be easier. But we are living in Belgium – it is a small country with many governments. We are living in Dutch speaking Flanders, so we can get benefits from the Belgian government (Federal Overheid dienst/ Service Public Federal), from Flanders (Het Vlaams Agentschap voor Personen met een Handicap [VAPH]) and from the city in which we live. The benefits from cities really vary – some cities give a lot and other cities give nothing. The income replacement for the person with incapacity is paid by the engaged health insurance. The social worker of our engaged organisation helps me for most other benefits also – this kind of guiding person is absolutely needed.

7.3 France - Valérie Rousseau

This example is a translation of a testimony featured in the "White Book" by France Alzheimer.

At 51, Valérie Rousseau works as a caregiver while accompanying her husband Christian, 56, a young patient living with Alzheimer's disease. If continuing her professional activity "does her good", the double responsibility she must assume on a daily basis brings a lot of tiredness.

"Christian is on hold for long illness since 2016, he was diagnosed two years earlier. I wanted to wait for the diagnosis to be definitive to evoke it around me

and in particular to my employer. My hours have not been adjusted but I no longer work in contact with patients, I am now assigned to a hospital laboratory."

For Valérie, continuing her professional activity is essential, this brings her a balance and allows her to "see something else". She recognizes nevertheless that the accumulation of these two missions remains difficult to manage. "You always have to be on the go, at work and then at home, it is very complicated..." If Valérie manages to invest in both work and at home, she can't help asking herself this question: "What would happen if I got sick myself?"

Even if the announcement of the disease was very difficult to accept for the couple, Valérie and Christian are doing everything they can to continue to lead a normal life. In addition to participating in the actions of France Alzheimer, they keep going to the movies or in restaurants. Nevertheless, the financial difficulties penalise them daily. "Christian does not reach more than half a pay today so I can't stop or take time for me. I could take some time off but it would not be

remunerated [It was before the compensation of the caregiver leave] so it is impossible, regrets Valérie. Same if you come from the hospital sector as it is my case, we remain alone when you are affected by Alzheimer's disease." Creating an official status of employed caregiver, as have recommended some elected officials, Valérie would be in favour of it but on one condition. "You must not lose financially."

7.4 Germany – Lieselotte Klotz



Lieselotte Klotz is a current member of the EWGPWD.

When I was diagnosed with Lewy body dementia in 2017, I was 57 years old. My first thought was: "It can't and mustn't happen, not me!" I was the Managing Director of a large IT company in Düsseldorf. I really enjoyed the work and the position, despite the responsibility and demands. I loved working with people. The ability to inspire and convince people made it easy for me to hold my own – even in this male-dominated profession.

When the first problems occurred, I put it down to the heavy workload, responsibility and hours of work each week. I was increasingly overwhelmed by the amount of information and requirements. At a conference I met people who spoke to me, but I no longer knew who they were or what their relationship was to me, even though they were long-time customers. In addition,

a German shepherd dog kept appearing, a calm and loving animal – but apparently only I could see him. These seemed to be only temporary – the next day or the day after that everything seemed fine again. Out of shame, desperation and because I didn't know what was happening, I kept everything from those around me and repressed it.

In late 2017, at the urging of my kids, I went to see a neurologist. I thought I was burned out. A neuropsychologist tested me for five days and then told me: it's not just burnout! The family doctor finally gave me the diagnosis: suspected Lewy body dementia.

My big mistake was sending the sick leave I received from my neurologist to my company. No diagnosis was noted but this document bore the stamp of a neurologist. Shortly before Christmas 2017, on 23 December, a letter arrived from my company – I received my notice! I was told that a manager with a supposed neurological disease is not acceptable for the company.

I was shocked and devastated. As the weeks went by, my whole body reacted to the situation – I required multiple surgeries throughout 2018 and after a rehabilitation course, I tried to get back on my feet professionally. However, my only option was to apply for an early pension. After so many successful and beautiful years, my professional career came to an ugly and final end.

I personally lost a lot since 2017 – my health, my career, my social, financial and professional status, many contacts from professional and private life. People often withdraw when confronted with dementia, as it

is too often equated with images of disability, old age, decay and suffering. However, the disease has many faces and different phases. Where one door closes, another opens. After the diagnosis – I had to break new ground and develop strategies to continue living and experiencing my life in a fulfilling, self-determined and meaningful way. My children and people in the German Alzheimer Society in Berlin supported me in this.

It is important to me to draw attention to the stigmatization in society and in the professional world. As a member of the Advisory Board of the German Alzheimer Society and the European Working Group of People with Dementia, I am heard and can contribute my perspective as an affected person.

I'm often asked how I can get by on my own in everyday life? "I'm fighting my way through!" Since

every day feels like a surprise bag, I try to think and act as positively as possible: Radical acceptance, i.e., unconditional acceptance of what is currently, is my motto in life. My backup in all situations are my three children, who support me remotely, i.e., online or coming to my house in an emergency. The distance between Kühlungsborn, Cologne, Berlin and Tokyo does not always make it easy, but so far, we have mastered everything as a team!

I don't want to sugarcoat anything. Dementia is an existential disease both for those affected and their families. So, every day I face the challenges and the question: "What can I do to make myself feel good today". I still love my life.

Sure, it's very different from what I planned, but it's the only life I have – I want to live it actively and self-determined until the last day!

7.5 Iceland - Sigríður Erla Jónsdóttir



Sigríður Erla Jónsdóttir is a current member of the EWGPWD.

My name is Sigríður Erla Jónsdóttir and I live in the land of "Fire and Ice", Iceland. I am 66 years old, happily married, a mother of two wonderful daughters, and a grandmother of four.

If asked to describe myself I could say that I am a talkative extrovert that likes nothing better than being among people, communicating, and helping out – I am bursting with social needs!

Togetherness of all kinds, among family, friends, and partners, is very important to me. Throughout my life, I have been an active citizen in my society and I have a broad spectrum of working experience. I started my career the day I graduated from university and have contributed to our economy in the form of work every day of my life, except for the time I spent acquiring further education.

I was diagnosed with Alzheimer's in 2019, but most likely I developed my disease several years earlier. Due to a mistake by a foreign laboratory, my diagnosis was delayed by at least two years. This was a very difficult period!

When my Alzheimer's started to take its toll, I worked at a large public institution. Having a job is not just

about earning money. It provided me with a rich purpose, a daily routine, satisfaction, and a sense of normality and I benefited from the relationships and connections formed through work. All these factors affected my daily life and well-being.

But as time passed, traditional Alzheimer's characteristics began to surface, it was difficult to keep juggling many things at once, my concentration deteriorated, and things were simply forgotten. Misunderstandings and friction arose between me and my colleagues, and I was always pushed more and more to the side.

Always I was made more and more unnecessary and redundant!

I became more and more isolated at work. By the end, I spent the day alone in a windowless room arranging things in alphabetical order. Nothing was explained to me, nor did I get any consultation. It was just done! No initiative was taken by the employer to investigate what was happening and nothing was

done to encourage communication between me and my colleagues to find an explanation for the change in my behaviour.

Then came the diagnosis and I was immediately ordered to go on sick leave. To cut a long story short, I never returned to the workplace again – that possibility was never discussed or considered. I never met or even heard from my co-workers after I went on sick leave.

Nor did I get any consultation on behalf of my employer on how to guarantee all my financial and social rights.

In situations like mine, we can do much, much better!

By looking at everyone's situation, characteristics, advantages, and ability to work, a way can be found, in cooperation with the employee, to enable them to work considerably longer. The goal must always be to enable the employee to finish their career with pride and in harmony with God and men!

7.6 Ireland – Kevin Quaid



Kevin Quaid is Vice Chairperson of the EWGPWD.

Today, I work with dementia but in a totally different capacity from my old job. My job now has become my advocacy work and I treat it as a job – but my advocacy work is a job that I love.

Before I got my diagnosis of Lewy body dementia, I had been given a diagnosis of Parkinson's in November and I continued to work up to Christmas, however I was noticing that I was making very simple and basic mistakes in some of the work that I was doing.

I was a kitchen designer and dealing with people's future dream kitchens and also their money – any mistake could possibly be very costly to both the company and the clients that I was working for. This was adding so much stress to a life that was already full of stress.

During the Christmas holidays I spoke to my boss and explained exactly what was happening to me and he quite simply said, just let me know what we can do and we will help you in any way – to me that was very reassuring and I felt very grateful to him.

My next visit was to my GP and he suggested that I should consider giving up work completely as I had a lot of medical problems and I was facing lots of more tests. I took a couple of days and discussed it with my wife and we made the decision to give up work completely.

I then informed my boss and he said that he understood completely and if again I needed help with anything, just to let him know. I was actually relieved that I had made the decision and I was delighted with the attitude of my boss. Having made the decision, it felt like a big weight and responsibility had been lifted from me, but it took quite a while for the stress of work to leave me, this was my first time in my life ever being out of work and there were mornings when I would wake up and think that I was late for work or that I had made a mistake at work, but that was my Lewy body dementia playing tricks on me.

During the space of a couple of months the stress of work left me and the more I got involved in advocacy work, the easier my life seemed to be getting, not withstanding the diagnosis that I received.

I began to work with my medical team keeping daily journals for them and it was there that I found a love of writing, something that I could have never imagined, but it did.

Today I am the author of two published books about Lewy body dementia called, “Lewy Body Dementia Survival and Me” as well as “I am KEVIN not Lewy” as well as writing for newspapers and magazines.

My take away message from this is that there is a life after a diagnosis, try and find your passion and embrace it.

7.7 Ireland – Helen Rochford-Brennan



Helen Rochford-Brennan is a former Chair of the EWGPWD and member until 2022.

I am 72 years old and was diagnosed with dementia at the age of 57 in 2007. I was in employment when I was first diagnosed. I was concerned about disclosing the diagnosis and for this reason I didn't share my diagnosis with my employer and instead I opted to take an early retirement. I don't think my employer had an understanding of dementia. After I had retired, staff said that they knew that something was wrong, but you see nobody was talking about dementia back then. There was such a stigma around the disease. However, I have since spoken about my dementia diagnosis openly.

I worked for 5 years after my diagnosis in 2007 until 2012. During this time, I always said that my in-tray was never empty. It was just so frustrating. As a manager, I had to delegate work, but I found this task very challenging during this time.

It meant so much to me to continue working. I developed some coping mechanisms and strategies, although the same ones didn't always work. I loved my work, I was 62 when I left and I had no intention of leaving, but it was too difficult to continue. I really didn't want to leave.

The employed may not know that the person has a problem, so if an employer notices changes or has any concerns, a friendly chat might help initially. I didn't realise I was developing dementia when I was having challenges at work. People with dementia have rights and an employer should be aware of these and perhaps offer flexible hours to the employee or offer them some quiet space which could really help people.

Speak up and ask for support. It's rare that an individual would have a full diagnosis when problems first arise and rather could be in decline before the diagnosis. The focus here is on the employer.

A dementia diagnosis is a daunting issue for any employee. Even if an employee has a dementia diagnosis, they can still have a lot of capabilities. An employee can develop coping strategies to do their job,

can seek support from their colleagues, or they could change jobs. It's important that employees feel secure in their employment and if they need support, seek advice from a doctor. People can also use whiteboards and reminders and tons of technologies.

I'm sure that there is lot more today than when I was diagnosed. An employee needs to know what information is out there as well in terms of courses, social welfare, or the employment office about their options and made to feel supported.

It's a partnership between an employer and valued employee honesty can play a vital part in the employee diagnosis which will enable them to seek appropriate help.

7.8 Malta – anonymous

A carer from Malta described her experience as a carer for her mother.

My mother is diagnosed with dementia. Since her diagnosis, case manager from the Dementia Intervention Team has been assigned who, ever since, has been extremely supportive, professional in her approach, and helpful in providing an overview of the syndrome to make me more aware of expected behaviour, attitudes, and disease's progression.

I am only employed for a few hours a week. Allocating more time for employment is impossible due to my mother's severe state of dementia and since I am the primary caregiver; my other four siblings show little support and my father passed away.

I make use of Respite at Home on Wednesdays and Fridays for four hours, but this is surely not enough since during those hours, I have to make all errands leaving little time, if any, to rest.

I barely sleep four hours every night. In the morning, I wake up feeling enervated and somehow.

I have to cope with low energy and concentration levels at my workplace and to care for my mother which requires strenuous effort. I feel very tired and would like to receive more practical help, particularly respite during the night.

I am aware that residential respite is available in Malta, however utilising such service is not possible since my mother is totally bedridden and very stiff, therefore causing unconceivable stress for her.

Respite one-off interventions during the night are also offered, however such opportunity may only be availed of three times a year which are used only in case of emergencies and to celebrate my birthday.

Relocating my mother to a long-term care facility is not an option for me since informal caregiving, despite the challenges it brings, is a fulfilling vocation; however, my siblings share a different opinion.

Having the possibility of availing myself from respite during the night would be beneficial to relieve me at least a couple of nights a week to be able to rest peacefully over prolonged periods.

7.9 Portugal – Nelida Aguilar



Nelida Aguilar is the daughter and carer of Idaline Aguilar (member of the EWGPWD until October 2022).

I'm 50 years old and live in Madeira, Portugal. I was an executive administrator and businesswoman, but it's as an informal carer that I like to introduce myself, because about a year ago I had to stop working to care for my mother with Alzheimer's and my cousin with vascular dementia.

Receiving support and care from the family has been very important for my mother and cousin, and crucial in the success of their rehabilitation and quality of life. However, caring for a person with dementia is not always a choice and it requires immeasurable effort and altruism. It can be exhausting and tiring. As a carer for two people with dementia, I face enormous challenges both from a physical and emotional point of view. The care model that we have in Portugal is not comprehensive and many relatives, like I did myself, have to take the responsibility for providing care and at some point, leave work.

The negative impact which I am experiencing from having to give up work is immense. Despite being recognized as an informal carer by the public system, the only thing I have received is an "identification card" (which does not have any practical or real use). This card does

not guarantee me access to any of the rights that are legislated. Nor did I have access to any financial support.

Support is only available to informal carers who live on the threshold of extreme poverty. It is a shame that the rights and benefits of informal carers in Portugal are already included in the legislation, but are not operationalized. Many carers do not go through this process as it is very bureaucratic and time consuming, therefore this excludes many carers, and there are still many carers who are not yet recognised in their role. More measures for people who are providing care and are working are essential because many, like it was in my case, have to stop working to take care of their relatives. There should be greater public investment and more formal care available to prevent this or to best support carers who decide / have to leave work.

Despite the legislation in force, support measures are still needed, so that the role of the informal carers is fully recognised and includes benefits and support for those who provide care and those who are cared for. Other existing challenges in my country are related to geographical inequalities (particularly in rural areas), lack of information (many caregivers are unaware of the existence of training opportunities) and organisational issues (related to difficulties in releasing care responsibilities or other commitments)

To improve this situation, I have been part of a group of citizens in Portugal who have been advocating for the creation of a Statute for Informal Caregivers, which we hope would help to recognise the important role of informal caregivers in the provision of care for their loved ones and their rights, and will make the process more straightforward and adequate for everyone.

There is still a lot to do in my country...

7.10 Switzerland – anonymous

Alzheimer Suisse was in contact with a person with early onset dementia. He lost his job because of his cognitive problems at an age of 61. Therefore, he was considered unemployed and was obliged to appointments at the employment agency and to apply

for corresponding offers. With a diagnosed dementia, however, it is not surprising that he did not receive any job offers, especially as the administrative workload was also difficult for him to cope with. Only when he went to the employment office with a case manager was his inability to work recognised by the disability insurance.

7.11 UK (England) – Yvonne Salomon



This example was drafted using a story which was publicised on social media and various news outlets in the UK, and was drafted with permission and input from her family.

Yvonne Salomon began to be affected by Alzheimer's in her early 50s, with her family first noticing some early symptoms in 2009, consulting with doctors in 2010 and finally receiving a formal diagnosis in late 2013.

When she first began to show signs of the disease she was working as a bookkeeper, however, as a result of the condition it became apparent to her and her family that she could no longer do her job effectively.

Yvonne was still able to undertake a less complex role and in mid-2012, she applied for and was offered a job at a Sainsbury's store (a British supermarket chain) as part of their in-store 'picker' team, putting together people's online orders for delivery.

After being diagnosed in 2013 Sainsbury's were made aware of every medical update, with the management in the store taking a number of steps to support Yvonne with her employment, including:

- Offering regular retraining
- Changing hours
- Holding regular welfare meetings between Yvonne and her husband
- Ensuring her colleagues were aware of her condition so they were able to assist

- Adapting her role so there was always something in-store she could do (without changing her job title).

In the last example, Yvonne was given responsibility for the task of cleaning the tote boxes (in which the products and items were gathered for the online deliveries). Her family noted that this was, to her, the most important job without which the store would not be able to function. Her family remarked that the sense of self-worth and pride she had in her role had undeniably helped with aspects of her Alzheimer's, such as giving her something to talk about in social situations.

In addition, her family shared that there were many times when they expected that the store would let her go as a result of the progression of her condition. Yet each time her husband was called in for a meeting because of a noticeable decline, they expressed concern and wanted to know what more they could do to help.

In October 2017, an occupational health assessment showed her Alzheimer's was rapidly advancing and that, in essence, she was unemployable. Despite seeing the report, Sainsbury's continued to be supportive and made accommodations to ensure she was able to continue in employment. In March 2018, Yvonne left her role, with her family stating that this was emotional but also a relief.

Yvonne's family recognised the compassion of senior management throughout the five years of her employment, specifically highlighting how the staff in the store always treated her with dignity, going above and beyond to make sure that she was happy and felt valued.

The family expressed their sincere thanks, noting that Sainsbury's had been an excellent employer but more than that, the people working at the store had shown sensitivity, kindness and care.

8. Good practice examples

Alzheimer Europe asked its members to share good practice examples of activities, programmes, projects or other work taking place in their country in relation to the employment and social protection for people with dementia and/or their carers. This included their own work, projects and resources, as well those of other organisations (e.g. other civil society organisations, academic institutions etc.) or programmes developed by governments.

The examples below aim to give a brief overview of different pieces of work, whilst providing links for further information. The examples vary in scope, with some being dementia-specific and developed specifically to address the challenges faced by people living with dementia (and their carers), whilst others are broader in nature (e.g. focusing on disability) but have relevance for people living with dementia.

8.1 France

France Alzheimer “White Book”

In 2016, France Alzheimer published a resource, the “White book”, examining the position of carers in professional activity. The publication examined the challenges and difficulties faced by carers of persons living with dementia, specifically noting:

- The impact upon the professional lives of informal caregivers (e.g. difficulty balancing the roles, negative impact upon concentration and efficiency)
- The impact on their daily lives (e.g. greater fatigue and stress, less social and leisure time etc.)
- That almost half of carers do not speak about their caregiving role at work
- The vast majority of carers wish to continue their professional activities.

In 2018, France Alzheimer updated this document, highlighting continuing issues faced by carers, and proposing specific recommendations under four headings:

1. Better communication to promote a change of perspective on professional caregivers
2. Act on the financial consequences of a possible work suspension and promote job retention for caregivers
3. Promote good health at work and respond to the need for time by allowing respite for the caregiver
4. Encourage companies and all economic actors to think about how to better support professional caregivers.



National award for companies supporting employees who are carers

Every year since 2016, France Alzheimer has partnered with other workers protection organisations for the national award “Prix Entreprises et salariés aidants” (Companies and carers’ employees Prize), which showcases and recognises the corporate initiatives which have helped employees who also have a caregiving role.

In addition to awarding prizes to companies who have exhibited best practice, the website compiles initiatives by employers and social partners which support employees in caregiving role, with the aim of:

- Supporting employees in caregiving situations, regardless of their situation: employees of large companies, employees of small and medium-sized businesses, employees on short contracts (artists and technicians, temporary workers, etc.), people looking for work, self-employed workers and authors, etc.
- Promoting and giving visibility to initiatives and schemes

- Giving all stakeholders who want to make progress on this topic the possibility of easy access to all the initiatives submitted, to help in the spread good practice.

Further information on this prize, as well as a database of previous initiatives and winners, can be found at: <http://www.prix-entreprise-salaries-aidants.fr/>



8.2 Germany

Dementia Partner – Audi

Under the motto “Dementia needs you”, the Dementia Partners initiative has been committed since 2016 to removing psychological barriers and reducing uncertainty when dealing with people with dementia. The German Alzheimer’s Association (DALzG) is the sponsor of the initiative. The Dementia Partners initiative is supported by the German Federal Ministry of Health and the German Federal Ministry for Family Affairs, Senior Citizens, Women and Youth.

In this example, Audi became the first care manufacturer in Germany to take part in the scheme, first inviting its employees and the public to a series of events relating to dementia in autumn 2019.

Individual Audi employees can also become a Dementia Partner, involving training in which they learn about the disease and how to deal with people living with dementia. In addition, Audi offers its employees sessions on “Career and caregiving” that revolve around the issue of dementia. A caregiving dialogue and caregiving consultation are also offered at Audi, with counsellors available to help affected employees with individual questions.

Whilst “Dementia Partner” is similar in nature to the Dementia Friends scheme seen in dozens of countries around the world, this example is particularly useful

in the context of this yearbook, as many Dementia Friends programmes are principally aimed at the public or public-facing service sectors, where people are likely to come into contact with people with dementia.

By using the scheme to encourage companies to identify how they can support caregivers of people with dementia, we see how such awareness raising and training schemes can help improve the approach taken by businesses and employers.

DALzG has also held a workshop for employees of Porsche, after they heard from the cooperation with Audi. Furthermore, there have been many other workshops for employees of different institutions and companies.

More information on Audi’s participation in the Dementia Partner scheme can be found here: <https://www.audi-mediacycenter.com/en/press-releases/audi-is-becoming-a-dementia-partner-13372>



Government brochure specifically on employment and dementia

The German Federal Ministry for Family Affairs, Senior Citizens, Women and Youth produced a publication "Taking new paths - companies and public authorities as partners for people with dementia" in which it outlines various measures to demonstrate how working life can be maintained for as long as possible, by persons with dementia, as well as by businesses and employers.

The handout was developed as part of the "Local Alliances for People with Dementia" funding program and takes up suggestions from the symposium of the same name held by the Local Alliances for People with Dementia network office.

The following topics are addressed under the heading "Reconciling care and work":

- People affected by dementia as employees
- Legal bases for securing the workplace
- Measures to support caregiving relatives
- Dealing with customers affected by dementia in banks, stores and public authorities.

The brochure can be accessed at:

<https://www.bmfsfj.de/resource/blob/154872/>

[cf8b1834fd66720eca2e120188cbfa68/neue-wege-gehen-unternehmen-als-partner-fuer-menschen-mit-demenz-data.pdf](https://www.bmfsfj.de/resource/blob/154872/cf8b1834fd66720eca2e120188cbfa68/neue-wege-gehen-unternehmen-als-partner-fuer-menschen-mit-demenz-data.pdf)



8.3 Greece

Social worker as a source of advice, support and advocacy

Alzheimer Europe's Greek member shared that Alzheimer Hellas and other Alzheimer's associations are available for contact and information about the benefits and the rights of patients with dementia as well as legal issues that may arise.

More specifically, on a case by case basis, where there is no caregiver to support the person with dementia, the social worker may assist with the submission of supporting documents and/or accompany the individual to an assessment committee or meetings,

to ensure that the person receives the support to which they are entitled.

In addition, Alzheimer Hellas and Alzheimer's associations provide online workshops and events to ensure that people with dementia and their carers are informed about the support to which they are entitled, with around 100-140 people attending these events.

Further information can be found on the Alzheimer Hellas website: <https://www.alzheimer-hellas.gr/index.php/en/>

8.4 Hungary

Dementia Advisor position

As part of another EU supported project, Social Cluster Association Hungary piloted a position called a Dementia Advisor. The Dementia Advisor is available to provide support and advice to people with dementia, families and carers.

The role requires the professional to have specialised knowledge not only about dementia but also the accessible support possibilities in the social and health services, creating a life plan for the person, as well as providing ongoing support according to needs of the person.

As part of this, they will examine and address considerations related to wellbeing and financial matters, before offering and information to the person.

Their task also involves mapping the general state, social connections and environment of the person with dementia, gather all possible information before developing a plan plan (together with the person and family) about how best to cope with dementia.

The pilot project is part of the Margit Slachta National Social Policy Institute, EFOP-1.9.4-VEKOP-16-2016-00001, named "Renewal of the methodological and information systems of the social sector".

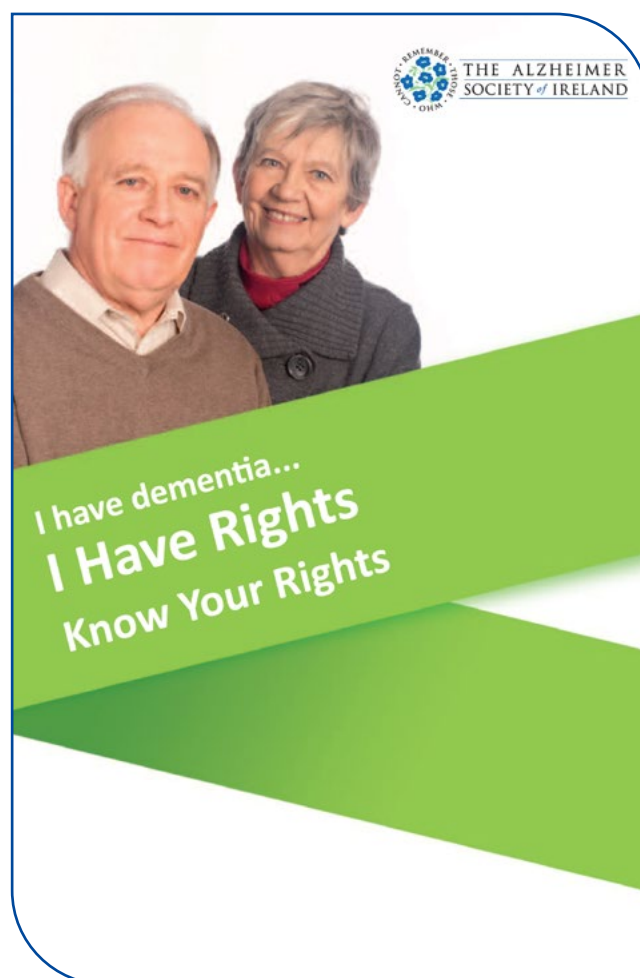
8.5 Ireland

First published in 2012, the Alzheimer Society of Ireland published its "I have dementia... I have rights" publication, setting out the rights of persons with dementia in Ireland, including in relation to employment and social protection.

The guide is written in plain English, providing explanations about what constitutes discrimination, how people with dementia are covered by key legislative protections and an overview of the types of social protection to which a person are that cover people with dementia, as well as detailing what constitute

Dedicated sections within the report explain: It explains:

- That people with dementia have the same civil and legal rights as everyone else. This booklet is for people with dementia and their families. It explains:
- What is contained within equality legislation
- How equality legislation can help a person with dementia
- The rights of persons with dementia in accessing services
- The rights of people with dementia in employment
- The rights of people with dementia to make decisions
- How to make a complaint.



The guide is available at: https://alzheimer.ie/wp-content/uploads/2018/11/ASI-I-have-dementia-I-have-Rights_web.pdf

8.6 Malta

Access to Employment Scheme (A2E)

Whilst not specific to people with dementia or their carers, the Access to Employment (A2E) scheme from the Maltese Government is a good example of how businesses can be encouraged to take on people with disabilities or carers who may face greater challenges when accessing the labour market.

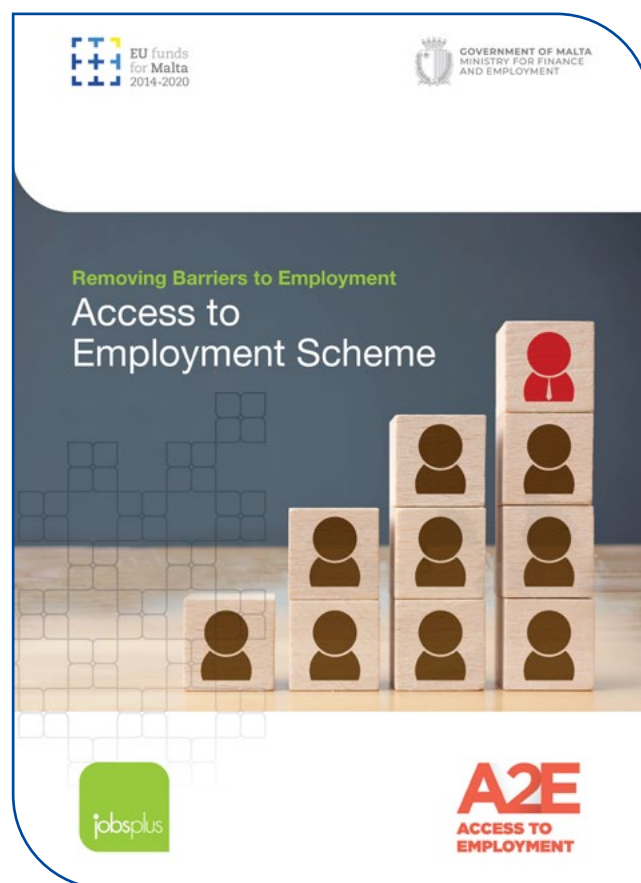
The scheme facilitates integration into the labour market by enhancing opportunities to access the labour market and providing work experience to those furthest away from gainful employment, bridging the gap between labour market supply and demand.

Specifically, it offers employers a subsidy when they recruit someone from a target group, with different levels of subsidy depending on whether the person is employed full or part time, for a period of 52 weeks or 104 weeks, depending on the target group.

In the case of registered disabled persons, the subsidy is slightly higher and is provided for a maximum of 156 weeks is provided. The type of enterprises that can benefit from the scheme are employers having an economic activity irrespective of their legal form e.g. regardless of being a partnership, company, cooperative, NGO etc.

The first call of applications covered from June 2015 and December 2019, with the most recent scheme taking place in 2022.

Completed applications were required to be submitted by end of August 2022, with recruitment needed to take place by end of September 2022.



A2E Scheme is co-financed by the European Social Fund, the Maltese Government, and employers. More information on the scheme can be found at: <https://jobsplus.gov.mt/a2e>

8.7 Netherlands

DemenTalent programme

Whilst not an employment scheme per se, DemenTalent is an innovative scheme in which people with dementia continue to participate as volunteers in meaningful activities in society, in line with their skills, interests and abilities, with support provided where necessary.

The key focus is to focus on what people with dementia can do and the positive role they continue to play in their communities.



DemenTalent aims to empower people with dementia, focusing on their strengths and abilities, allowing people with dementia to use their strengths to volunteer and contribute to and maintain connections with their society, which improves their emotional

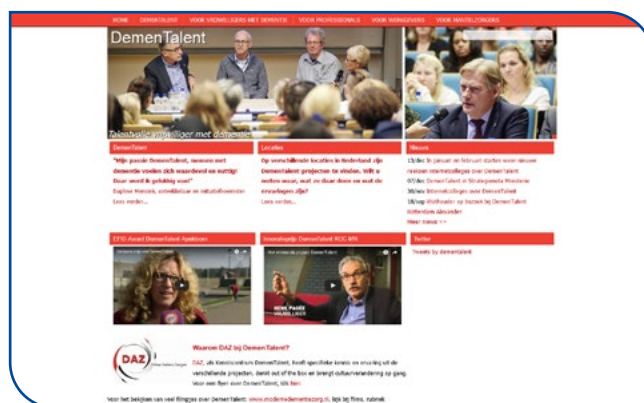
wellbeing. By making use of their talents this preserves the connection with society and they can continue to operate independently for longer.

The concept and programme are run by a care innovation agency Dirkse Anders Zorgen (DAZ) which coordinates and facilitates the national roll-out and “guards” the concept. The key aim goal for the programme is for behind this coordination is that the DementTalent projects run entirely independently at local level, supported by local organisations with local project management. Projects often are linked to local Dementia Meeting Centres, and include activities such as maintaining older people's gardens, refurbishing the clubhouse of the local hockey club, uprooting trees on the moors, teaching students about what it means to have dementia etc.

Experience has shown that a good start for these types of projects is crucial. At the start of every DementTalent project it is important that a number of questions

are answered. To this end, discussions are held with relevant organisations, partly individually, partly in groups. Based on these conversations, DAZ guides the most important choices and the coordination of the project. Municipalities generally act as clients for the start of a DementTalent project. After the start, local DementTalent projects run completely independently.

More information on the DementTalent programme can be found at: <http://dementalent.nl/>



8.8 United Kingdom (England, Northern Ireland and Wales)

The Alzheimer's Society in England, Wales and Northern Ireland has produced two useful resources on the subject of people with dementia and employment, including one for people with dementia and one for employers.

Guide for people with dementia

Published in 2020, the “Living with dementia – Employment” guide for people with dementia is specifically aimed at people who have been diagnosed with dementia while they are still in employment. It explores many of the considerations in relation to whether people wish to continue working, noting that the decision is ultimately a personal one.

This booklet gives advice on talking to employers and outlines some of the ways in which employees can be supported to continue working.

In addition, the resource highlights some of the key legal protections which exist for individuals in

relation to employment matters (and those which are applicable to dementia specifically).

For those who decide that they no longer wish to work, the booklet also covers considerations for what happens when a person leaves work, including benefits and activities.

In total, the resource contains 10 sections:

- Employment
- Working with dementia
- Talking to your employer
- How the law protects you
- Changes to your role
- Leaving work
- Benefits
- Staying involved and active.

The full guide can be downloaded from: <https://www.alzheimers.org.uk/get-support/publications-and-factsheets/living-dementia-employment>



Guide for employers

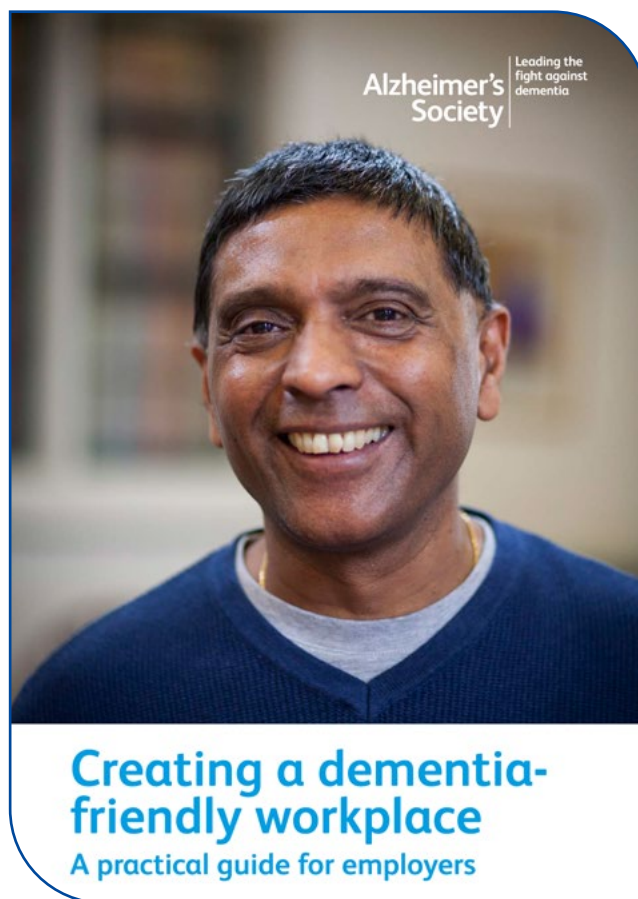
In 2015, the “A dementia friendly workplace” guide for employers was published, aiming to help them provide support for staff members with dementia. It may also be a useful resource for people living with, or affected by, dementia in the workplace.

The guide includes practical tips and examples of situations that managers can use, as well as reviewing existing approaches to support people with dementia in the workplace.

This resource is aimed at all UK employers, regardless of size or sector, to encourage them to provide support for the people with dementia and the carers they employ. The resource covers issues, including:

- Employment information about dementia, its symptoms and common issues faced by people with dementia
- Information about the legal responsibilities of the employer in relation to the protection of people with dementia from discrimination

- Ideas to help develop awareness of dementia in the workplace
- Step-by-step tips on how to support a member of staff who is affected by dementia at different stages of their dementia journey, covering a number of common workplace scenarios
- Information and guidance on making reasonable adjustments to ensure people with dementia are not disadvantaged in the workplace
- A list of organisations that can give further advice and support to an individual as a manager, as well as to employees who either have dementia or care for someone with the illness.



The full guide can be downloaded from:

https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/creating_a_dementia-friendly_workplace.pdf

8.9 United Kingdom (Scotland)

Alzheimer Scotland Centre for Policy and Practice – Research and Resources

The Alzheimer Scotland Centre for Policy and Practice at the University of the West of Scotland (UWS) has carried out significant research in this area, seeking to understand the experience of people with dementia who are diagnosed whilst still in employment, including the support required for them as employees, their employers, work colleagues and families, whilst using this information to develop toolkits and resources to support people diagnosed with dementia whilst of working age. To date three applied studies have been completed.

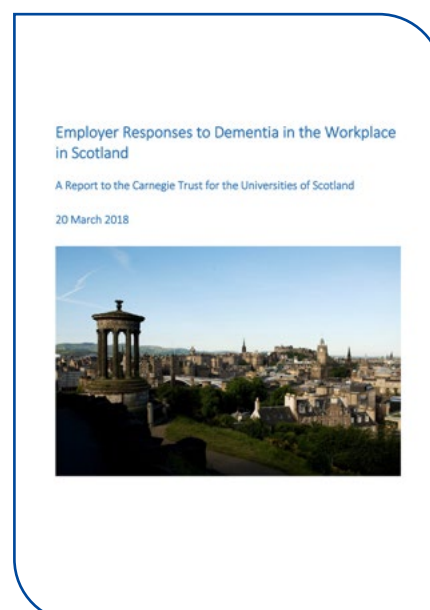
Study 1: Dementia in the workplace

A case study research, carried out by UWS and Heriot Watt University (HWU), explored the potential for continued employment post diagnosis and was completed between 2013 -2015 and was funded by the Alzheimer's Society UK.

The study has identified that continued employment post diagnosis of dementia is possible, although could be complex to support. The supports required to continue working will depend on the type of job a person does, the insight they have into their symptoms and the culture of the organisation they work in as to whether they have the resources to support them.

This project has highlighted the potential impact employment issues have on the lives of people with dementia, their families and their employers. The study made six recommendations:

1. An enhanced dissemination strategy for this research is required in order to raise awareness of the issues surrounding dementia in the workplace to the general public and in particular with employers.
2. Resources for employers, employees and other key stakeholders need to be developed which provide accessible information on relevant employment law.
3. Practitioners who work with individuals from the first point of contact through to post diagnosis of dementia need to consider the implications for employment and the potential financial and social impacts on the individual.
4. The post diagnostic framework needs a review of the implications of employment issues for individuals with dementia, in particular work with national work and pension agencies to ensure timely access to appropriate benefits, pensions and supports.
5. Further research is required to fully understand the problems relating to the employment of people with dementia.
6. Reflecting on the recent changes in the employment of older people and the changes in state pension ages across Europe, we urgently need a stronger understanding of the international landscape for employment of people with dementia.



A summary of the findings from the report can be found at: <https://www.uws.ac.uk/media/4021/ritchie-dementia-workplace-booklet.pdf>

Study 2: Employers' responses to dementia in the workplace

This mixed method survey and interviews with employers highlighted gaps in knowledge and understanding of dementia and in the workplace was funded by Carnegie Trust Scotland/UK and led by Edinburgh Napier University with UWS and HWU collaboration.

The study sought to discover the extent to which employers are currently meeting their legal, equality and human rights duties, as well as identifying good practice examples. The report made a number of recommendations, including:

1. There is a need for increased employer awareness that dementia is a disability and that they therefore have legal and human rights obligations to support employees with dementia.
2. There must be clear guidance and training on the legal and human rights position of employers and employees in relation to dementia in the workplace.
3. There must be clear pathways in workplaces to enable employers to support employees with dementia, or with potential symptoms of dementia, that allows such employees to either continue in employment or to leave it in a dignified manner that fully respects their legal and human rights.
4. In order to effectively implement such pathways there is an urgent need for an integrated approach with management, the employee concerned,

Occupational Health, vocational rehabilitation and all others involved in the implementation of the pathways.

5. There is a need for awareness raising amongst health care professionals to consider the implications for employment where a person is diagnosed with dementia.

The fully project report can be accessed at: <https://www.napier.ac.uk/~media/worktribe/output-1154874/employer-responses-to-dementia-in-the-workplace-in-scotland.pdf>

Study 3: Dementia, Work and Employability

The third study was a secondary analysis of data sets collected across the two previous projects, providing a theoretical perspective on dementia in the workplace. The findings of this study outline the range of personal resources, supports and environments required to enable positive employment-related experiences and practices for people with dementia.

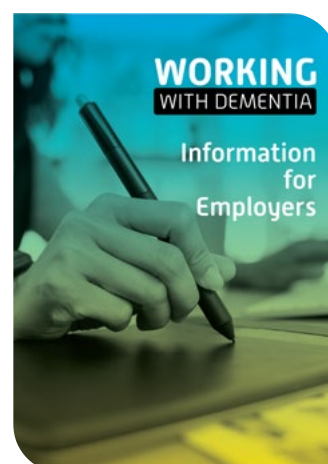
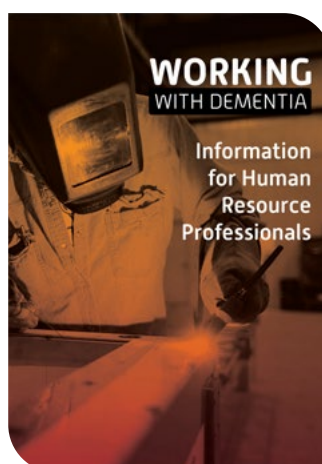
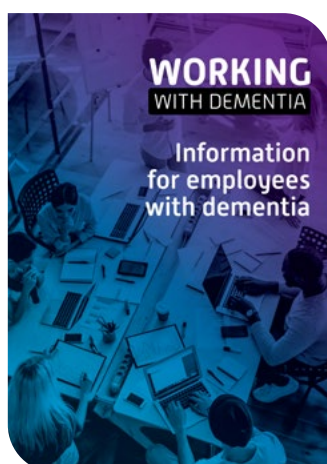
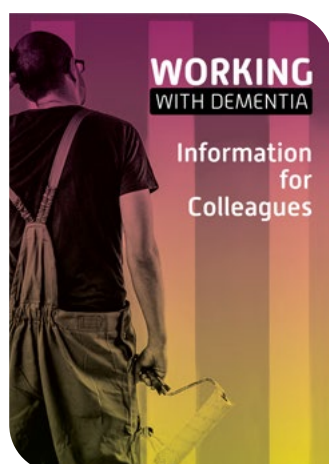
Through a dissemination grant provided by the Alzheimer's Society, a series of short evidence-informed resources were produced to provide information and signposting to support people with dementia, their employers and family members with employment post diagnosis.

Information for colleagues

<https://www.uws.ac.uk/media/4994/todd-wwd-information-for-colleagues-003.pdf>

Information for employees

<https://www.uws.ac.uk/media/4995/todd-wwd-information-for-employees.pdf>



Information for employers

<https://www.uws.ac.uk/media/4996/todd-wwd-information-for-employers.pdf>

Information for HR

<https://www.uws.ac.uk/media/4997/todd-wwd-information-for-hr.pdf>

More information the work done by the Alzheimer Scotland Centre for Policy and Practice can be found at: <https://www.uws.ac.uk/research/research-institutes-centres-groups/alzheimer-scotland-centre-for-policy-and-practice/our-research/>

Action on Rights service

Launched in 2021, Alzheimer Scotland developed a service called Action on Rights, which includes a team which works on complex issues relating to the rights of persons with dementia and carers in day to day life. Originally conceived in relation to the rights of persons with dementia living in care homes during the COVID-19 pandemic, the expanded remit of the team has meant that it now provides support and advice in a broader range of scenarios, as well as being able to act as mediators, advocates, or provide guidance on interpreting legal frameworks.

This includes on matters relating to:

- Welfare rights (i.e. social protection)
- Human rights and equality issues
- Understanding relevant legal frameworks.

More information on the Action on Rights service can be found at: <https://www.alzscot.org/action-on-rights>



Action on Rights

The Action on Rights team will work alongside colleagues, people living with dementia and their families and carers on some complex issues. The team can act as mediators, advocates, or provide guidance on interpreting legal frameworks. For example the team could help with:

- Complaints processes with Health and Social Care Services
- Hospital visiting and discharge
- Power of Attorney and Guardianship
- Difficulties arising from pre and post-diagnosis
- Challenging decisions
- Paying for care
- Welfare rights
- Community Care Assessments
- Human rights and equality issues
- Understanding relevant legal frameworks, for example: Adults with Incapacity Act, Adult Support and Protection, Mental Health Care and Treatment, Self-directed Support legislation etc.

This list is not exhaustive.

If you are experiencing difficulties with any of the above and would like support from our team, please contact our 24 hour Freephone Dementia Helpline on **0808 808 3000** or email actiononrights@alzscot.org

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9. Conclusions and recommendations

Taking together the information presented in this report, it is evident that a mixed picture exists across Europe, in relation to employment and social protection for people with dementia, their families and carers.

Current state of play across Europe

At the international and European levels, a strong framework exists for the protection of the rights of persons with disabilities, well-articulated under the disability rights framework, through the Charter of Fundamental Rights (CFR), European Pillar of Social Rights (EPSR) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

The degree to which these frameworks also apply to people living with dementia depends on the countries. It is also worth noting that the rights of informal caregivers are not clearly defined or outlined in the same way. Whilst, CFR and EPSR reference many of the issues faced by informal carers (especially in relation to employment and gender imbalances etc.), the role of informal carers in caring for a person with dementia is not acknowledged or defined, with the distinct challenges not directly addressed (compared to, for example, a parental role which does feature in these documents).

At a purely European level, the legislative and policy measures are inevitably inconsistent and limited in scope, owing to the varying competencies between the EU and Member States, across different policy areas. It is welcome to see the expansion of the Social Score Board to monitor these matters relating to employment and social protection (feeding into a growing social dimension of the European Semester), as well as actions set out within the ESRPD. Additionally, the Action Plan on the EPSR, shows a clear commitment from the European Union to ensure that the rights of all citizens, including those with disabilities, are upheld and given effect through the policies, legislation and activities undertaken by the European Union.

At a national level, the approach to ensure that people with dementia are supported in policies and legislation relating to employment or social protection

(whether in its own right or within the definition of disabilities) vary considerably, reflecting the different policies and approaches to different welfare systems. Perhaps most surprisingly, few countries referred to the Work Life Directive being transposed into their laws, despite Member States being expected to have done so by this year. It is not clear why this is the case.

Countries may already meet or exceed the Directive, may not yet have transposed the law and in some cases our members may not be aware of the status of the work in the country.

However, an overarching theme which is missing from much of the policy work in this area relates to persons who acquire/develop disabilities later in life, as a result of illness or other causes. At both a European and national level, a greater emphasis is placed on how to ensure people with disabilities can access the workplace, as well as receiving training and education which allows them to participate in the labour market. Whilst this is unquestionably important, it overlooks the need to support people whose circumstances change whilst in work, especially where they have a progressive condition such as dementia.

As part of this, eligibility criteria for social support are incredibly restrictive for both persons with dementia and carers. There is little flexibility or accommodation in systems for persons to continue in employment, even at a significantly reduced rate, without a significant risk to their eligibility for some form of support.

Whilst welfare benefits between countries differ considerably, the recurring barriers and challenges associated with them are common across many countries. In particular, issues of time consuming and bureaucratic application processes were noted by many countries, whilst only a few benefits were felt to offer sufficient amounts to allow a person to live a good quality of life.

Reflections from people with dementia and carers

The inclusion of references from people with dementia and carers is intended to demonstrate some of the difficulties and the real-life shortcomings of policies and practice in this area.

For people living with dementia, their own experiences of a lack of formalised policies either in statute or in their own companies, is outlined in many of the examples provided, whereby companies have often provided little in the way of support, either in making accommodations to allow people to continue to work, or to support a gradual transition in to retirement. The good practice example from England showed how this can work in practice, however, from the responses of our members, it is seemingly not commonplace.

Similarly, the experience of carers is largely disappointing. Carers clearly expressed in these examples that the support (financial or otherwise) available to them is insufficient – as such, they are placed in hardship, unable to continue working owing to their caregiving role and restrictive eligibility criteria to access support.

However, one recurring theme which should be reflected upon are the way in which employment is described by the people who contributed. Whilst the financial considerations are evident, the focus in the testimonies was also on the meaning and value that their role provided in their life – where this was lost or diminished, it is evident that this affected the person. As such, it is important to recognise this broader view of the employment, beyond solely a financial means to an end.

Report recommendations

It is evident from the report and from the information provided that there remains much work to be done in this area to ensure that the experience of people living with dementia and their carers, in both employment and in accessing support, is as positive as possible and affords them the rights set out in the CFR, EPSR and UNCRPD.

Under the following heading, we set out policy recommendations for different actors under three key areas, which we believe would support the upholding of the rights of persons with dementia, their families and carers in relation to employment and the workplace.

European rights/protection

In relation to European rights, it is the view of Alzheimer Europe that:

- The Commission should explore how specific protection and rights can be provided to caregivers which distinctly acknowledge their role in support individuals (who have ill health, a disability, additional support needs etc.)
- As with the social scoreboard for the EPSR, there should be a scoreboard (or expanded social scoreboard) with metrics to measure the implementation and adherence to the UNCRPD and CFR
- The implementation and impact of the Work Life Balance should be closely monitored and, if needed, the legislation should be expanded to provide greater guaranteed support for caregivers
- Based on the European Semester, the Social Scoreboard and the findings of bodies such as the CRPD, where the Commission identifies shortcomings, they should proactively identify and share good practice with the Member States, as well as proposing available resources and funding through EU programmes to support improvements.

Social protection

In relation to social protection, it is the view of Alzheimer Europe that:

- National governments should ensure that working-age earnings replacement benefits:
 - Provide sufficient levels of monetary support reflecting the loss of income and additional challenges faced by persons with dementia (or disabilities more broadly).
 - Are streamlined, easily accessible and require only the minimum required bureaucracy
 - Adapt eligibility criteria to allow people with dementia and carers to be able to continue some level of work, if this is something they wish to do, without complete loss of entitlement to a benefit
- Ensure that the role of carers is adequately supported, recognising and reflecting that carers will often be unable to work as a result of their caregiving role
- Ensure that information, advice and support to access benefits is available in accessible formats, including easy read.

Employment protection

In relation to employment protection, it is the view of Alzheimer Europe that:

- Member States must take greater steps to ensure the implementation of the EPSR, CFR and UNCRPD rights relating to employment, especially where individuals receive a diagnosis of dementia (or other illness) whilst they are in employment
- Support the development and distribution of awareness raising programmes and resources, such as those developed by national Alzheimer's associations, to make employers aware how they can and should support persons who develop dementia during the course of their working life
- Greater support and flexibility should be given to informal carers to allow them to continue to work (where they wish to do so).

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