

FAMILY CAREGIVER SUPPORT

Strategies and Tools to Promote Caregiver Mental
and Emotional Support

*Apoio ao Cuidador Informal - Estratégias e Ferramentas para Promover a Saúde
Mental e Emocional dos Cuidadores*

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Resumo

Introdução: O cuidado de familiares com doença mental grave acarreta um grande risco para a saúde dos cuidadores, estando associado ao desenvolvimento de problemas emocionais, mentais e de saúde física. O Projeto Family Caregiver Support visa capacitar os cuidadores informais, através do acesso a informações médicas relevantes, que promovam a autoconfiança e as competências, quer no cuidado dos familiares quer relativamente às suas próprias necessidades.

Métodos: Participaram neste projeto parceiros de oito países europeus, incluindo a ESS|P.PORTO, no período compreendido entre 01/11/2018 e 31/10/2020.

Resultados: Este projeto resultou na criação de um Guia e Pacote de Recursos para capacitação dos cuidadores informais, acessíveis através de uma plataforma online gratuita que pode ser acedida por uma aplicação móvel. Todos os materiais foram produzidos em vários idiomas e amplamente divulgados.

Conclusão: Os produtos e conteúdos continuam disponíveis, estimando-se um forte impacto na capacitação dos cuidadores informais, com melhoria da sua qualidade de vida.

Abstract

Introduction: Caring for family members with severe mental illness poses a great risk to the health of caregivers, being associated with the development of emotional, mental and physical health problems. The Family Caregiver Support Project aims to empower informal caregivers, through access to relevant medical information, which promotes self-confidence and skills, both in the care of family members and in relation to their own needs.

Methods: Partners from eight European countries participated in this project, including ESS|P.PORTO, in the period between 01/11/2018 and 31/10/2020.

Results: This project resulted in the creation of a Guide and Resource Pack for training informal caregivers, accessible through a free online platform that can be accessed through a mobile application. All materials were produced in multiple languages and widely disseminated.

Conclusion: The products and contents are still available, with an estimated strong impact on the training of informal caregivers, improving their quality of life.

Introduction

Mental disorders are highly prevalent in Europe and place a heavy burden on individuals, the society and the economy. These types of disorders represent 22% of the disability burden in the EU, measured as Years of Life with Disabilities (YLD). The responsibility for these types of disorders for individuals, society and the economy is associated with the high prevalence of mental health problems, in which the majority of cases start at an early stage of life - in many cases before the beginning of adulthood, and at the fact that about half of people with mental health problems do not receive evidence-based treatments. Furthermore, in 2015 there were an estimated 9.6 million people in EU countries living with dementia, equivalent to almost one in 50 people. Higher life expectancy will undoubtedly lead to an increase in these numbers in the coming years. Family caregivers play a central role in the care of persons with severe mental illness. This is an important fact and the result

is that the majority of caregivers live with the illness of their affected relative 24 hours of the day, each day of the year.

Moreover, we found that in all EU countries the support provided to family caregivers only refers to economic and insurance aspects. In addition to information on monetary or insurance matters, family members are left alone without the possibility of having immediate access to social and psychological support.

Research shows that family members who provide care to individuals with chronic or disabling mental conditions are themselves at risk. Emotional, mental, and physical health problems arise from complex caregiving situations and the strains of caring for frail or disabled relatives. Medical advances, shorter hospital stays, and expansion of home care technology have placed increased care responsibilities on families, who are being asked to shoulder greater care burdens for longer periods of time.

As a response to this situation, this project intends to empower family members as caregivers and to give them access not only to relevant medical information, but also to psychological support for their own needs.

Aims and target-audience

The main objective of this project is empowering citizens to develop self-confidence and skills in caring for family members with mental illness and to give them instant and easy-to-understand access not only to relevant medical information, but also to psychological support for their own needs. To this end, the project aims to develop a Guide and Resource Pack to provide caregivers with helpful tips, tools and information. Two of its main sections will focus on “Caring for YOU” and “Caring for the Individual”; ensure immediate access to these developed products anywhere, anytime and in all languages of project partners. The products will be available not only as interactive web-based content, but also as mobile applications; include refugees, asylum seekers and migrants who do not or have little command of the language of the host country. To this end, we will also produce translations of the materials in Arabic and Pashtun.

The main target groups of the project are adults caring for a family member with a mental illness. The secondary target group are people working in health and social care organizations who can inform family members about the existence of the Guide and Resource Pack or use these materials in their information and counseling activities. Also other stakeholders and counselors, as well as other institutions dealing with migrants and refugee integration, that can disseminate the materials among their clients. The project fits into

the partners' common strategy as it is in line with their general research or teaching activities.

Profile of the partners

The partnership comprises partners working in psychiatric, psychological or social research and/or as providers of adult education will enrich the quality of the results, making them immediately applicable to exploitation. Moreover, it includes ICT and multimedia specialists, where only the combined efforts made possible the results of the project. This transnational cooperation develops the best practice approaches and transfer them into localized solutions in the eight European states of the partnership and beyond.

The group of social and medical research organizations specialized in various aspects of health care consists of: 1 - MEDRI - Department for psychiatry and psychological medicine of the Faculty of Medicine, University of Rijeka (Croatia), offering education programs in the field of psychological medicine, psychiatry and communication skills; 2- NUIG - Health Promotion Research Centre at the National University of Ireland, known by producing high quality research that supports the development of best practice and policy in the promotion of health; 3- IUL - Italian University Line, is a non-state public university of telematics; 4- ESS|P.PORTO - School of Health (Portugal) is an applied sciences higher education institution with a strong human, technological and ethical capital dedicated to the development of health technologies; 5- INTEGRA Institute for Development of Human Potentials (Slovenia), with specialized counsellors from the field of special pedagogy, psychology, speech therapy, social work and systemic humanistic psychotherapy; 6 - E-C-C - Association for Interdisciplinary Education and Consulting (Austria), has extensive experience in the design of learning and information materials for ICT communication in virtual environments; 7 - QUALED Qualification and Education (Slovakia) is active in the field of innovative learning technologies for supporting learning processes in different settings for different target groups; 8- CSI (Cyprus), Center for Social Innovation, with expertise in the development and provision of advanced ICT services and applications in teaching and learning.

Activities and Results

- *Needs assessment and strategy*

To reach the objectives there is place for a state of art in Europe and in individual countries of the partnership, analyzing them and find a common starting point for developing the educational materials. The transnational meetings performed

made possible the distribution of activities according to the know-how of the partners, as well as the monitoring and follow up of the project.

- *Guide and Family Caregiver Support Resource*

The Guide aimed to provide safe information, support and resources for family caregivers of adults with chronic mental illness and cognitive conditions to better understand their health and their diagnosed disorders. This Guide gives background information about each disorder, explains which behaviour of the patient can be expected, focuses on concerns which the caregiver may have, and presents strategies what can be done and how to deal with this disorder (**Figure 1**).

The Family Caregiver Support Resource consists of two main sections: caring for YOU and caring for the individual. This resources pack provide learning and information material about mental disorders in an easily understandable way.

This Guide provides the complement to the Resource Pack which is available in the Internet (<https://www.family-caregiver-support.eu>). On the online platform, interested readers will find modules with information for the following nine mental disorders: **Dementia, Substance abuse, Schizophrenia, Common mood disorders, Intellectual disability, Attention deficit hyperactivity disorder (ADHD), Autism, Eating disorders and Post-traumatic stress disorder (PTSD)**.

For each module/disorder, specific contents were developed covering aspects about understanding the respective disorder, the concerns of the caregiver, the role of nutrition, activities to support and empower the caregiver and activities for the person receiving the care (**Figure 2**).

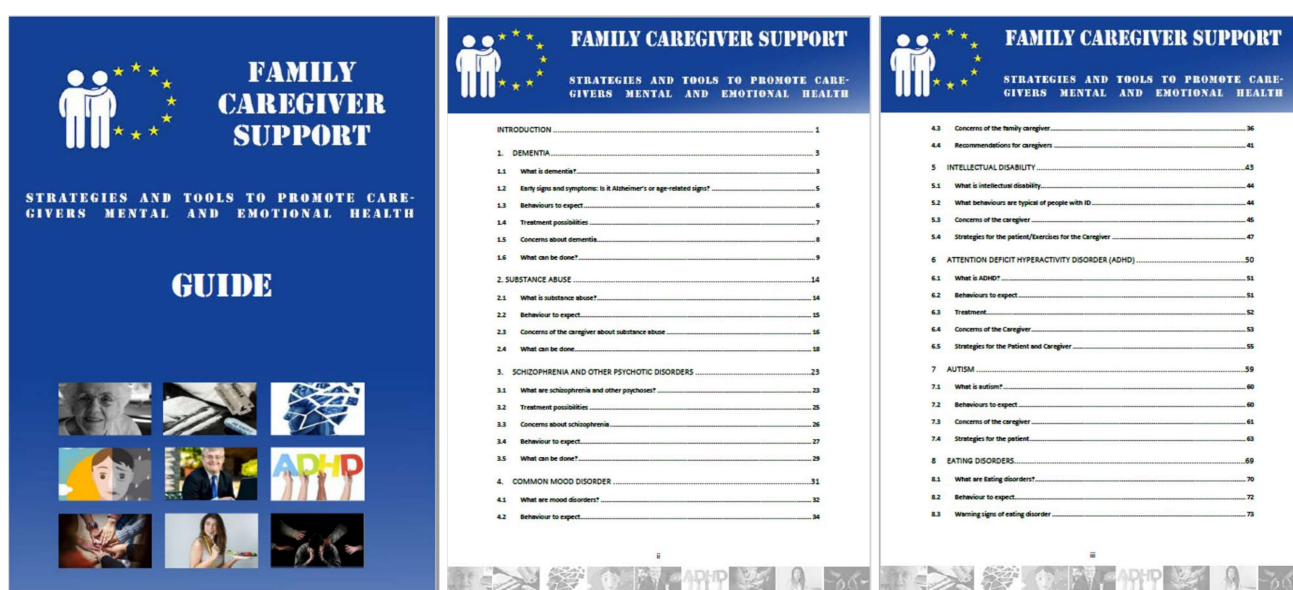


Figure 1. Guide and Family Caregiver Support Resource

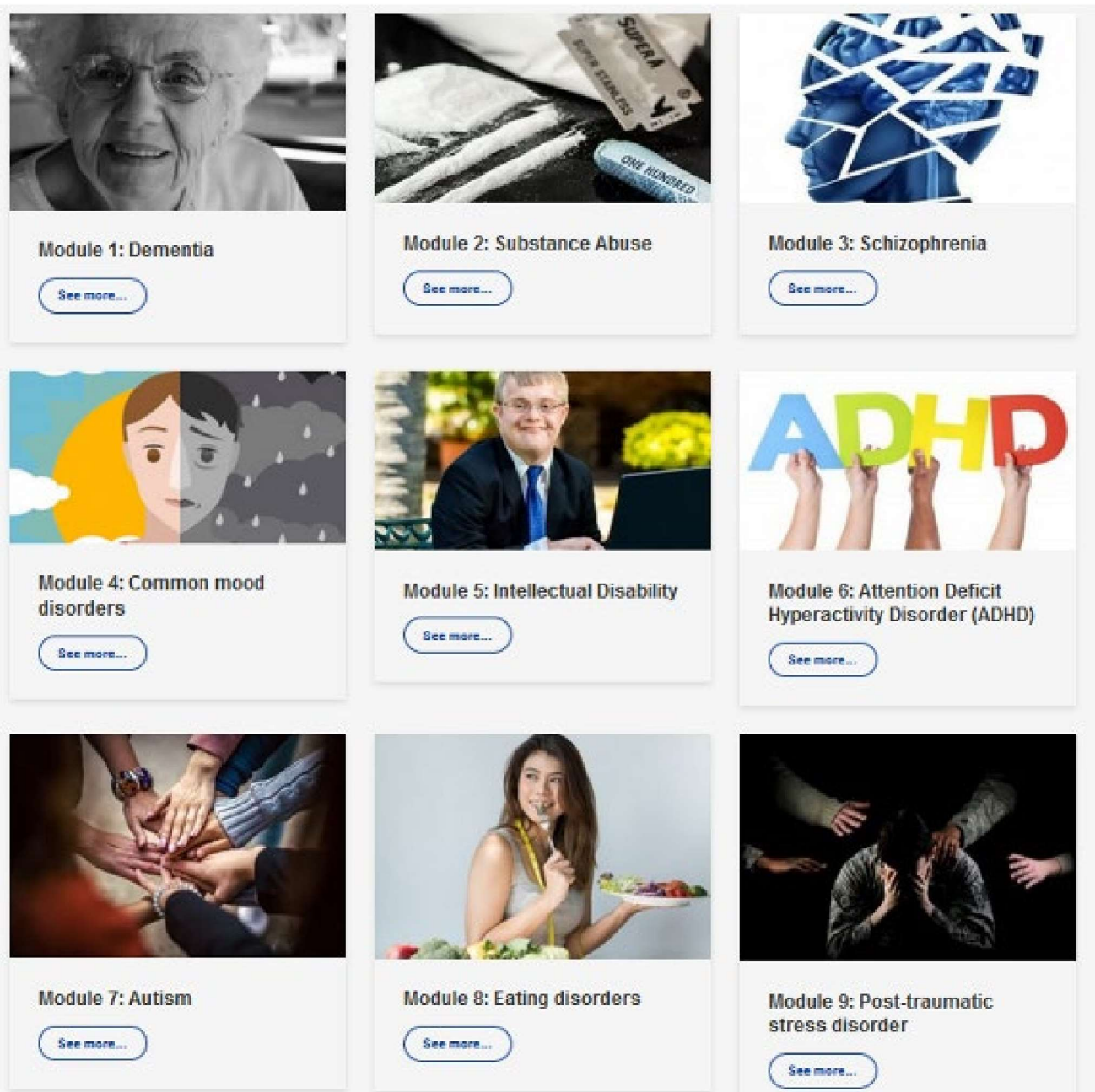


Figure 2. Illustration of contents displayed in the online platform in respect to 9 different mental disorders.

- *The platform and mobile application*

Materials were developed as power point files support that were uploaded after the validation and translation, on an online platform that was created and installed on the project’s website. An example of the appearance of the website is showed on **Figure 3**. These developed materials can be consulted anywhere at any time through an App produced for android mobile devices.



Figure 3. Illustration of the website of the Family Caregivers Project, translated in different languages.

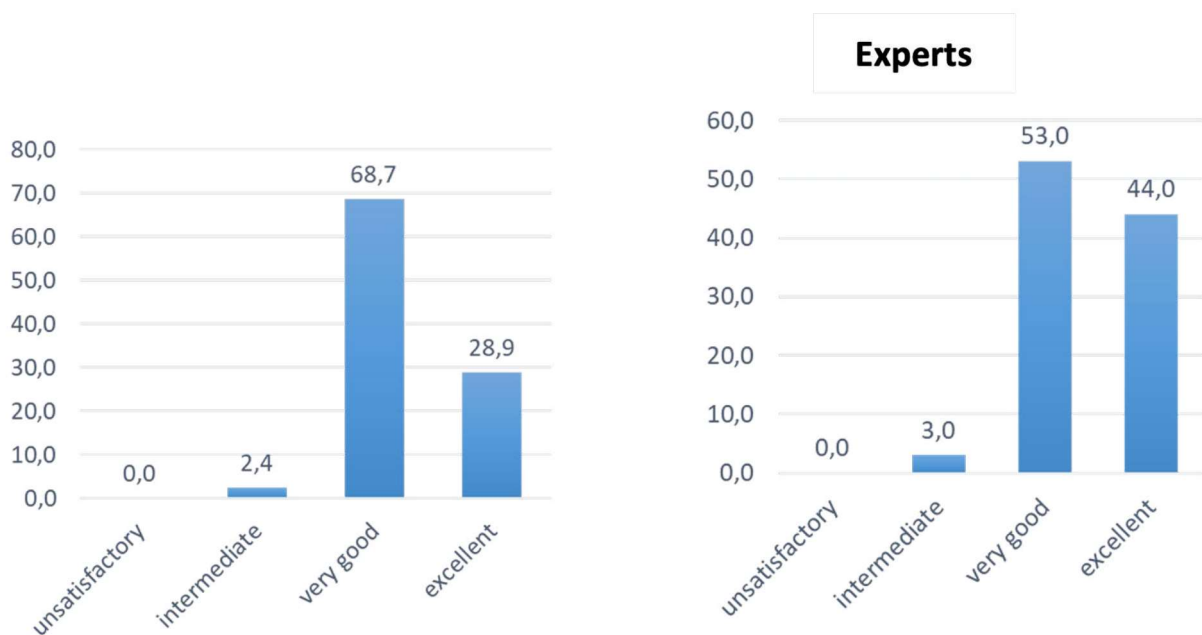
- *Validation of the products*

The Resource e-platform needed to be tested thoroughly to ensure that it is stable and fully functional to be used by experts and the targeted end users. Thus, the contents of the Resource Pack were externally evaluated within the platform in order to ensure that they perform as intended and that they are well integrated in the virtual environment. Moreover, the platform was evaluated to ensure that it is fully functional on all the widely used operating systems, browsers and mobile phones. The validation of the materials was carried out in each country within experts and family caregivers focus groups to register the outcomes of the validation and the suggestions and feedback from the participants, in order to reach the most useful approaches.

Online questionnaires were developed by the project team and translated in different languages. Participants of the focus group consisted of family caregivers and citizens interested in caring and Health and Social Services Professionals - Experts. Data were collected and processed anonymously and

confidentially. As an example, **Figure 4** represents the validation results in Portugal concerning the Website and Online Platform (Layout; Registration process; Navigation system, Accessibility to content, Attractive) (**Figure 4A**) and concerning the contents produced (Are the modules useful/informative to support skills and competence development in Family Caregivers?), for both participant groups (**Figure 4B**).

A



B Family Caregivers / Citizens

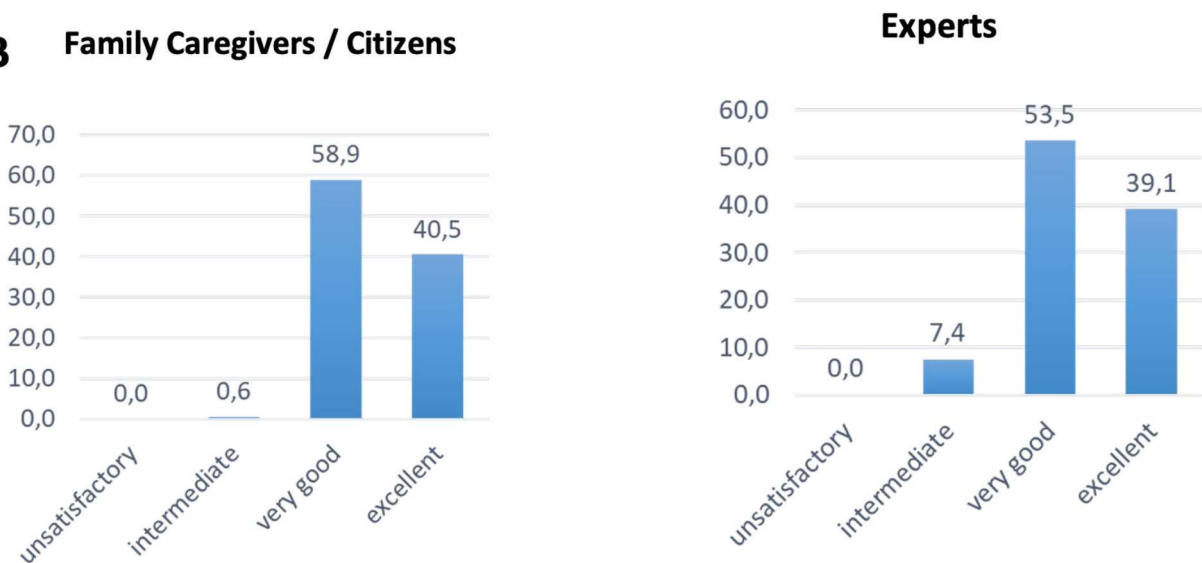


Figure 4. Illustration of the validation results in Portugal concerning the Website and Online Platform (**A**) and the contents produced (**B**), for both Family Caregivers/Citizens and Experts.

In general, the online platform comprising the materials is appealing and very easy to use. The mobile application runs smoothly, and the contents can be accessed anytime and anywhere. However, the necessary changes were performed to the online platform according to the suggestions made by the participants of each country.

Platform contents are generally suitable for their purpose - citizens consider contents well designed and enough for them and consider the platform attractive and easy to use. The platform comprising the materials is appealing and very easy to use and the mobile application runs smoothly, and the contents can be accessed anytime and anywhere.

- *Dissemination of developed materials/contents*

Taking into account the results of the validation results, partners proposed to apply some activities with the aim of dissemination of the results. Thus, some multiplier events of the products were conducted with the objective of publicizing the Family Caregiver's project products. Dissemination activities were made within care providers and social support institutions, through social media, secondary schools, higher education institutions, community and technical-scientific events.

Conclusion

As a conclusion, this project essentially allowed the empowerment of Family Caregivers encouraging them to take care of their physical, mental and emotional health. Family Caregivers and citizens can thus develop their self-confidence and competences in caring of family members with mental illness, including refugees, asylum seekers and migrants who have no or only little command of the host country's language. Moreover, there is a possibility for the immediate access to helpful to the contents and information at any place or any time in all languages of the partnership countries - products of this project are available not only as interactive web-based contents, but also in mobile apps.

The project was concluded and all the objectives were successfully reached. The validation and dissemination phases allowed us to conclude that the materials produced in the context of this project were generally well received and highly appreciated by the inquiries.

It would be interesting to update and improve the materials throughout time, in order to have access to the needs of professionals working in the areas of counselling and therapy. In the upcoming years, it will be important to follow the stakeholders and the experts who are linked to the project in order

to promote online interventions and, consequently, the online materials.

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