

# ACT ON DEMENTIA

FINAL REPORT  
SUMMARY VERSION

## **WORK PACKAGE 6** **Residential Care**



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## **Act on Dementia**

**Act on Dementia** is a 44-month European Union Joint Action which began in March 2016 and ends on 31 October 2019.

The aim of the Act on Dementia Joint Action is to promote collaborative actions among Member States to improve the lives of people living with dementia and their carers. It provides practical guidance for policy-makers developing and implementing their national dementia plans, policies and strategies, and provides cost-effective and practical examples of the core components of good dementia diagnosis, care and support.

Act on Dementia consists of seven work packages:

- Work Package 1: Co-ordination
- Work Package 2: Dissemination
- Work Package 3: Evaluation
- Work Package 4: Diagnosis and Post-Diagnostic Support
- Work Package 5: Crisis and Care Co-ordination
- Work Package 6: Residential Care
- Work Package 7: Dementia-Friendly Communities

For further information on the work packages, reports and other resources, access: <https://www.actondementia.eu/>

# 1. Introduction

The purpose of Act on Dementia Work Package 6 (WP6) was to provide European Union (EU) Members States with clear, evidence-based and tested information and recommendations on how to make changes and improvements in quality of care for people with dementia in residential care.<sup>1</sup>

## Residential care

There are many types and forms of residential care for older people in Europe, from clusters of private flats with some common space and activities, to hospital-like nursing-home wards. Dementia-specific residential services have been developed in recent decades as group living spaces for people with dementia. Institutions or residential care facilities that are not dementia-specific also have a large proportion of residents with some degree of dementia.

## Challenges for people with dementia in residential care

A number of challenges face people with dementia in residential care settings.

- **Psychoactive medication** to manage stress and distress behaviours can be overused in residential care settings. A range of alternative psychosocial interventions is available.
- The state of the art in dementia care is **person-centred care** (PCC). PCC may be challenging to implement in residential care settings.
- **Meaningful activities** to reduce everyday boredom, such as individualised recreational activities and reminiscence therapy, provide benefits for people with dementia living in residential care, but may be in short supply in some settings.
- **Optimal medical treatment**, including the reduction of pain and discomfort, is important for people with dementia, in whom the prevalence of comorbid conditions may be high.
- Behavioural and psychological symptoms of dementia (BPSD) are distressing to people but can be averted through **psychosocial approaches**. BPSD nevertheless can arise as a result of lack of success in addressing the challenges above.
- At the end of life, elderly people with various diagnoses and at different stages of dementia should be able to rely on professionals providing **skilled end-of-life (or palliative) care**, which may be challenging to provide in residential care settings.

## WP6 focus

WP6 has six projects: five about BPSD in residential care, and one about palliative care in nursing homes:

- projects on translating, adapting and further developing BPSD models and testing their feasibility and usefulness in residential care homes in Bulgaria, Greece and Romania;

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<sup>1</sup> Residential care refers to all facilities providing a 24-hour service that people move to or are hospitalized in due to cognitive, mental or physical needs.

- projects on promoting larger-scale implementation of recommended models for BPSD in the Netherlands (the GRIP model<sup>2</sup>) and Norway (the TIME model<sup>3</sup>); and
- a project to evaluate an e-learning programme about palliative care in nursing homes in Norway.

The projects in Bulgaria, Greece and Romania were considered pilot projects, while those in the Netherlands and Norway were about promoting larger-scale implementation of existing initiatives.

## Evaluation

The approach to evaluation of the interventions was not about measuring the effect on a defined outcome, but about evaluating:

- feasibility in clinical practice;
- to what extent the staff and organisations worked according to the new method; and
- the sustainability of this way of working.

The WP6 partners agreed to use the **RE-AIM Framework** as a basis for evaluation of the different pilot projects. RE-AIM is an acronym for five elements that relate to health interventions: **reach, effectiveness or efficacy, adoption, implementation and maintenance**.

## 2. Interventions

### The pilot projects

#### *Bulgaria*

The Bulgarian project aimed to test the use of a learning programme, Implementation of Advanced Care Training (IMPACT). IMPACT was adapted to, and tested in, a residential care home with 26 staff members, none of whom had had special dementia training.

The intervention consists of 16 hours' face-to-face advanced care training, with four hours of lectures and four three-hour training sessions in which cases of people with dementia with different BPSDs were presented. Guided reflection meetings with videos, case presentations and role play were included.

The aim was to heighten staff awareness of different aspects of challenging behaviour exhibited by people with dementia, their personal needs, communication difficulties and possible solutions and actions. Issues about resources, barriers and benefits were addressed, and improvement of individual care plans was discussed.

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<sup>2</sup> The GRIP model (full name GRIP on Challenging Behaviour) consists of four steps: detection, analysis, treatment and evaluation.

<sup>3</sup> TIME stands for: Targeted Interdisciplinary Model for Evaluation and Treatment of Neuropsychiatric Symptoms. It is an interdisciplinary multicomponent intervention based on the theoretical framework of cognitive behavioural therapy and PCC.

## **Results**

The pilot measured knowledge, awareness and attitudes before and after the study. It found increased general and specific knowledge about psychological symptoms and how to manage BPSD, and staff had also become more aware of different types of BPSD, gained confidence and developed improved attitudes. The methods were used with 15 of 17 patients with BPSD, indicating that IMPACT had been implemented at both carer and organisational levels.

The main facilitators for implementation included:

- discussions with, and feedback and supervision from, the training team;
- clear definition of staff roles and responsibilities, establishing the team leader and key person; and
- support from the home administration for some organisational aspects, and changes to the environment and schedule of daily activities.

The main barriers were:

- time limits and insufficient staff;
- different levels of staff education and experience; and
- lack of formal recognition or reimbursement for efforts and improved skills.

Staff continue to have twice-monthly one-hour meetings to discuss issues (this was ongoing five months after the project completed).

## **Dissemination**

The IMPACT programme has created plans for dissemination to the general public through media coverage and websites, to professionals by publications in journals, continuing education activity, courses and presentations (it has been presented at a national congress of neurology), and to policy-makers through a report to the Ministry of Health and Ministry of Labour and Social Affairs. Experiences from IMPACT will also feed into a developing national dementia strategy.

## **Discussion**

The residential care home in the study was “hand-picked” by the WP6 team, so staff motivation was never likely to be a problem. The results nevertheless show that it is feasible to arrange courses, practical training and case meetings that involve nearly all staff of an institution.

## **Greece**

The Greek team implemented a multi-component biopsychological educational approach by means of a train-the-trainer approach. The main aim was to raise staff awareness of dementia, change nursing-home staff behaviours, and develop on-site BPSD Care Coaches.

The Antipsychotic Review Implementation Strategy (ARIS) consists of three educational pillars:

- PCC;
- an introduction to BPSD through lectures from experts, handouts, texts and videos, including practical guidelines and training in mapping BPSD using the Neuropsychiatric Inventory– Nursing Home version (NPI-NH); and

- “Recognise Antipsychotic Drugs” (RAD), a review of psychotropic and other drugs used in residential settings with people with dementia.

ARIS was implemented in two nursing homes and a specialized care unit for patients with dementia. At least one trainee from each institution (a total of seven) participated in the train-the-trainer approach, which included two hours of face-to-face or teleconference sessions twice a week for two months. The trainees become BPSD Care Coaches in their respective institutions.

### **Results**

The seven BPSD Care Coaches have used the NPI-NH. All participants reported that the education course had given them sufficient competence to understand BPSD, recognise antipsychotics and use psychometric scales. They used the tools from the project in clinics after implementation.

The seven participants used most of the elements in the educational pack (items focusing on probable diagnosis, demographic information, overall medication use rate, comorbidities, falls, sensory deficits, BPSD measures, antipsychotic drugs review and length of use), with 55 patients being evaluated during the follow-up period. Two institutions adopted the programme and continue to educate staff through it.

Facilitators for implementation described by participants included:

- motivation to understand more about personalised care;
- development of expertise in complex pathological cases; and
- commitment to the work.

The barriers included:

- the use of different nursing therapeutic strategies;
- nursing home organisational issues;
- insufficient training of nursing-home staff; and
- unhelpful attitudes (such as that antipsychotics are not harmful, psychometric scales are not necessary, and any behavioural disturbance can be described as “agitation”).

The ARIS project in Greece is the only WP6 project to have been maintained for more than six months (one institution reports that the effect has been sustained for eight months).

### **Dissemination**

The ARIS framework and its objectives were presented at a long-term-care school held in Athens, with participants describing the acquired experience of personalised care and appropriate use of antipsychotic and other psychotropic medications. This meeting led to the development of national recommendations and an adoption statement.

### **Discussion**

The ARIS project aimed to expand knowledge and change attitudes in a limited number of institutions. While there are little data on the extent to which the rest of the staff were influenced by the BPSD Care Coaches, it seems the train-the-trainer

approach adopted in the project has been successful in ensuring most of the patients were reached.

### ***Romania***

An educational project for better management of BPSD in residential care inspired by the TIME model was tested. The theoretical component comprised two days with staff divided into three groups (doctors, nurses and carers), and a third day for practical training in mixed teams where patients were evaluated by means of the tools introduced during the theoretical part of the training.

All 60 staff who were defined to be in the target group participated both in the theoretical and practical training. Fifteen patients with dementia were involved in a practical activity (developing a patient's diary).

### **Results**

A focus group interview with staff after the implementation period concluded that the implemented approach to BPSD had increased the quality of care interventions, and patients who have been approached in this way had had less problematic behaviour.

### **Dissemination**

The project was presented at national conferences of the Romanian Alzheimer Society and Romanian Geriatrics Society in 2019. Plans are in place to provide support for dissemination of the results of the pilot study to psychiatric hospitals and mental health centres. A guide is under development and will be disseminated by the National Mental Health and Anti-drug Centre to all residential centres for the elderly nationwide.

### **Discussion**

Like the IMPACT training project in Bulgaria above, it was not difficult to reach the target group for the Romanian programme, where the institutions had been “hand-picked” by the WP6 team.

## **The larger-scale implementation projects**

### ***Norway (TIME model)***

The Norwegian TIME model has been scientifically tested and shown to have a good effect on BPSD. A train-the-trainer course was designed to spread and implement the TIME model, targeting registered nurses and other health professionals with at least three years of college or university education. Participants attended two-day courses comprising lectures, role play and case conferences in accordance with the TIME manual. The aim of the project was to perform a process evaluation of this method of dissemination and implementation of an evidence-based model.

There have been four courses so far, and one new course is planned. The first course had 25 participants, and courses 2–4 had 30 each.

### **Results**

Fourteen people answered a questionnaire evaluating the effectiveness of the course. Of these, 13 (93%) answered that the course had given them sufficient

competence to conduct a basic TIME course in their workplace, and the same number reported that the course had met their expectations for learning.

A more detailed evaluation was performed among the first 25 participants. Twenty-four sent in a written report after the course. Of these, six had conducted at least one basic TIME course for staff members and five had planned a date for a basic course.

The fact that organisations pay for the nurses to attend the courses can be seen as positive support for implementation but is not conclusive evidence of support.

### **Dissemination**

The TIME project has been presented through a paper in an international scientific journal<sup>4</sup> and national publications for professionals, including online options.

### **Discussion**

The train-the-trainer courses were fully subscribed, but with 30 attendees at each course and a maximum two courses each year, it will take some decades to cover all of Norway. Effective distribution will depend on the capacity of train-the-trainer courses and the TIME model becoming endorsed in national recommendations.

### ***Netherlands***

The Dutch Ministry of Health, Welfare and Sport introduced a programme to reduce the use of psychotropic medication and reduce their misuse among institutionalized people with dementia or mental disabilities in 2016. The programme, called “Less is More”, comprises an online toolbox designed to heighten health-care professionals’ awareness of use of psychotropic drugs. The GRIP model, which has been scientifically tested and shown to be an effective approach to BPSD, is one of the toolbox interventions.

Health-care providers who participated in “Less is More” could use the tools to tailor an improvement programme in their own organisation. The objective of the Dutch part of WP6 therefore was to gain insight into the obstacles some of the nursing homes in the “Less is More” programme experienced in selecting and using GRIP.

### **Results**

It was found that some places were already working with a methodical approach that was in line with national guidelines, and these approaches were considered effective and sufficient. Participants could see no reason to replace their current model with a new method (GRIP), even if GRIP had been scientifically proven to be effective.

Three main factors were found to be influential in adoption of the model:

- the need for support from various levels of the organisation;
- the person who initiates the intervention should have a prominent position in the treatment or care of patients and in the organisation more widely; and

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<sup>4</sup> Lichtwarck B, Selbaek G, Kirkevold O, Rokstad AMM, Benth JS, Lindstrom JC, et al. Targeted Interdisciplinary Model for Evaluation and Treatment of Neuropsychiatric Symptoms: a cluster randomized controlled trial. *The American Journal of Geriatric Psychiatry*: official journal of the American Association for Geriatric Psychiatry. 2018; 26 (1): 25–38.

- positive experiences from colleagues or other departments strengthen the motivation of staff to implement the programme.

Providers who implemented the model indicated that:

- GRIP aligns well with their practice and follows the guidelines for dealing with challenging behaviour; and
- the training ensures staff learn to work with GRIP and learn more about challenging behaviour in dementia and possible ways to deal with it.

Providers that did not implement the model cited reasons such as too great an investment of time, extra administrative burdens for staff, and too much emphasis on working in accordance with protocols.

### **Dissemination**

The GRIP project has been presented through a paper in an international scientific journal<sup>5</sup> and national publications for professionals, including online options. It remains one of the tools of the “Less is More” programme in the Netherlands.

### **Discussion**

Some concern about implementation of the GRIP model was reported before the project, but an average 81% of the staff from the 17 nursing homes participated in the training at the first attempt. It nevertheless was difficult to implement the GRIP model further, even with positive results from the first implementation.

Participants who were not inclined to replace their entire approach with another method, even though the new method had been scientifically proven, highlight the importance of analysing the need for change before implementing new procedures. It is also useful to compare the GRIP model with TIME in this regard. The GRIP model introduces some new tools and forms, while TIME recommends the same tools and documentation as the standard recommendations for nursing homes from the Norwegian Health Directorate. Nursing homes adopting the TIME approach may therefore not need to adopt any new tools for observation or any additional documentation.

### ***Norway (palliative care)***

The Directorate of Health instructed the Norwegian National Advisory Unit on Ageing and Health to develop education and training material for health personnel on palliative care for people with dementia. An e-learning programme was developed and made freely accessible to health staff.

Two versions of the programme exist, one for doctors and one for nurses/auxiliary staff, as pre-existing competency and needs were judged to differ between these groups. The version for nurses/auxiliary staff consists of three modules with 23

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<sup>5</sup> Zwijsen SA, Smalbrugge M, Eefsting JA, Twisk JWR, Gerritsen DL, Pot AM, et al. Coming to grips with challenging behavior: a cluster randomized controlled trial on the effects of a multidisciplinary care program for challenging behavior in dementia. *Journal of the American Medical Directors Association*. 2014;15 (7): 531. e1–e10.

10–20-minute lessons on palliative care for people with dementia. The relevance, acceptability and feasibility of implementing the e-learning programme was the focus of the WP6 intervention.

### **Results**

The leaders of four nursing homes agreed their staff could be involved in the pilot. The aim was to have at least five carers from one ward in each institution, with two of them holding reflection groups. Only one ward was able to arrange meetings for the reflection group, however, and not all the nursing homes managed to include staff from one ward.

No information was gathered about the use of the knowledge gained after the programme, but most participants found it relevant as a tool for monitoring of patients' pain and in procedures for advanced care planning.

Most participants chose to undertake the programme from their private computers at home. This indicates that even with some support from leaders, more active facilitation is necessary to support staff through such programmes.

### **Dissemination**

There are 1,050 registered users on the webpage, and about 250 have completed more than 50% of the programme; 151 users were registered between April and June 2019, with 105 starting the courses and 24 completing all lessons.

### **Discussion**

Norway has an extensive teaching programme on geriatric and dementia care (the ABC programmes), comprising textbooks, group meetings and seminars and having more than 20,000 participants. There are plans to replace the textbooks in the ABC programmes with e-learning sources: the programme in the project will fit well into such a programme and therefore has the potential to reach a much larger group.

## **3. Conclusion**

The results of the main report from which this summary is drawn should not come as a surprise. They are in line with several studies focusing on implementing best practice in residential care.

The facilitators and barriers described in the projects are mainly in line with factors described elsewhere. These projects can add to the list of established facilitators a defined need for change as a motivator, and staff seeing improvements quickly.

Lack of time was found to be an important barrier, but lack of resources was not. This indicates that it should be possible to implement these kinds of intervention without new resources other than those connected directly to the implementation period.

Barriers that need to be removed either before or as part of implementation will vary among countries, health-care systems and even units. It therefore is important to conduct pre-intervention mapping of needs and identify possible barriers before commencing implementation.

Sustainability of the programmes is the most challenging part, both to maintain the new and better practice, and to evaluate effectively to develop strong recommendations on how to maintain good practice. All three projects that focused on testing a new approach to BPSD have decided to continue the practice.

In the train-the-trainer programmes (ARIS and TIME), local BPSD Care Coaches, or “superusers”, have been trained and hold special responsibility for implementation and maintaining good practice. This is in line with the notion of a named “responsible employee” suggested in the GRIP evaluation.

In all of the projects (except for the e-learning programme), external experts introduced the programmes and were responsible for teaching theoretical and practical components. It is reasonable to assume that access to external experts to help to solve problems will be a key element in maintaining implemented practice.

There is insufficient information from the projects to recommend that teleconferences should replace face-to-face meetings, but experience from the ARIS project in Greece is positive in relation to use of teleconferencing. This should be explored further. The same is true for the train-the-trainer approach. Experiences from ARIS in Greece and TIME in Norway indicate that this is an effective and time- and cost-saving approach, but more evidence is needed to indicate how and when train-the-trainer approaches offer the best solution.

It is possible to implement evidence-based approaches to BPSD and improve the quality of care in residential settings in the short term through teaching programmes, supervision and coaching. It takes significant effort, and staff need support from their leaders and employers to change practice as a result. Even successful implementation, however, provides no guarantee of improvement being sustained over time (the pilot projects provide little data on sustainability).

The reports from the project sites, which are presented as appendices to the main WP6 report from which this summary is drawn, show that even with programmes that have known scientific evidence of effect (improving quality) and are implementable in practice, it can be a challenge to spread such programmes to services. This is well analysed in the GRIP report. This means motivation must come *before* providers take the decision to implement a new method.

The results from the WP6 projects provide no definitive evidence for which theory or method should be selected for implementation, or which methods should be used to evaluate and follow up implementation and maintenance processes over time. The results nevertheless show that a systematic approach is necessary; starting a programme to implement new practices in residential care without looking deeper into the literature about implementing complex interventions will increase the risk of failure.

## **4. Recommendations**

The main report from which this summary is drawn recommended the following.

Each European country should develop an evidence-based teaching and training programme for approaching BPSD in residential care. Before implementation, special

consideration should be given to limitations of change, known barriers and how to overcome these at each site.

The programme should include:

- methods for mapping and analysing staff knowledge and attitudes and residents' needs;
- a theoretical introduction to person-centred care, understanding of BPSD and psychotropic medication, and alternative approaches to BPSD; and
- activities and actions to prevent BPSD.

Commitment to the programme by the owner(s) of the residential care setting and the participation of managers and leaders in the units are prerequisites for successful implementation. The programme should be tested on a small scale (a few sites), then evaluated and adapted to national requirements.

Many residential care units will be unable to implement the described methods without external support. External support can include teams going into the institution to provide intensive training courses for all staff and train-the-trainer courses. Institutions should also have access to supervision after an implementation period. This can be provided by supervisors or coaches visiting the institution regularly or on request, or through telephone support.

A named employee in each residential care unit should be given the role of "superuser", BPSD Care Coach or supervisor, to assume special roles in relation to follow-up of the implemented methods. These employees should have easy access to external support.

To spread the programme and implement it on larger scale, the programme should be made part of wider dementia plans, national standards, regulations or other guidance that lays obligations on residential care providers to implement programmes for approaching BPSD. How this is done must reflect different national health-care systems.

E-learning can offer an efficient option for distributing the content of the teaching programme but is not the only approach necessary; e-learning should be a part of the programme, alongside practical training, discussion of concrete cases and supervision.