

ACT ON DEMENTIA

FINAL REPORT
SUMMARY VERSION

WORK PACKAGE 5 **Crisis and Care Co-ordination**



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Acknowledgements

This summary is based on the Work Package 5 ***Crisis and Care Co-ordination: Final Report***, which will be available on the Act on Dementia website (<https://www.actondementia.eu/>).

Organisations from Italy and the Netherlands were in the lead of Work Package 5. The Scottish Government, Bulgaria and France were involved as associated partners, while Greece (Dr Antonio Politis), Alzheimer Europe (Jean George) and the Italian Ministry of Health (Dr Teresa Di Fiandra) were involved as collaborating partners. The Dutch Ministry of Health, Welfare and Sport (Dr Jacqueline Hoogendam), with the Trimbos Institute as a subcontractor, and the Italian National Health Institute (Dr Nicola Vanacore) were the main lead organisations of this Work Package.

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

Many health-care systems need guidance on effective, ethical and evidence-based ways to care for people living with dementia, including guidance on crisis-response services and care management programmes. Research has shown, however, that written guidance is only part of what is required to help health-care systems and care practices to change. More is needed, including resource-sharing, education on implementation models and tailored implementation support. Combining evidence-informed recommendations and implementation support has been shown to increase the use and sustainability of interventions in health care.

The overall objective of Work Package 5 (WP5) was to provide clear, evidence-based and tested information and recommendations on how to effect change and improvement in care co-ordination and crisis-response services for people with dementia. The objective was met through the development and dissemination of good practice recommendations for care co-ordination and crisis-response services for people living with dementia, and through tailored, timely and evidence-informed implementation support for pilot projects in Bulgaria, France, Italy, the Netherlands and Scotland to improve how dementia care co-ordination and crisis-response services for people with dementia are delivered.

Care co-ordination and crisis management

WP5 defined **care co-ordination** as: “the deliberate organisation of patient care activities between two or more participants (including the patient) involved in a patient’s care to facilitate the appropriate delivery of health-care services. Organising care involves the marshalling of personnel and other resources needed to carry out all required patient care activities and is often managed by the exchange of information among participants responsible for different aspects of care”.

Crisis in the lives of people with dementia has been defined as “a process where there is a stressor(s) that causes an imbalance requiring an immediate decision which leads to a desired outcome and therefore crisis resolution”. In the case of dementia care, crisis resolution can be seen as crisis-response services, as dementia is a chronic condition with no curative treatment or curative resolution.

These definitions ensured that all parties involved had a consistent understanding of crisis-response services and care co-ordination.

The WP5 report on which this summary is based – ***Crisis and Care Co-ordination: Final Report*** – describes the process of developing and disseminating the good practice recommendations, the translation of aspects of the recommendations into pilot projects and the tailored implementation support given to the projects. This paper provides a brief summary of this process.

WP5 tasks and deliverables

The WP5 team was commissioned to complete the following tasks and deliverables with support from, and collaboration with, other members of the Act on Dementia Joint Action:

- report on existing practices in care co-ordination and crisis-response services;

- report on identified best practices;
- develop materials for implementation planning and support; and
- report on the outcomes of the pilot projects.

The process began by reviewing the literature and guidelines on existing practices in dementia care. These activities are described in detail in the *Evidence and Recommendations* report, *Overview of Best Practice Recommendations* report, and in the *Implementing Programs in Healthcare Systems: Tips and Tools* materials, all of which appear as appendices to the *Crisis and Care Co-ordination: Final Report*.

WP5 thereafter devised recommendations for health-care centres to support the development and implementation of programmes focusing on crisis-response services and care co-ordination, especially related to behavioural and psychological symptoms of dementia (BPSD). The recommendations were developed through an in-depth review of existing practices and were guided by evidence and recommendation selection criteria. They were used, in part, to implement the pilot projects in Bulgaria, France, Italy, the Netherlands and Scotland.

In addition to reviewing literature related to existing practices in care co-ordination and crisis management in dementia care, WP5 developed and disseminated a survey among European Union (EU) Member States and relevant organisations. The online survey was sent to experts on dementia in 29 countries, with 20 completions. It focused on national dementia policies, implementation of Joint Action on Alzheimer Cooperation Valuation in Europe (ALCOVE) recommendations,¹ and use of care pathways and multidisciplinary care teams for people with dementia. The survey data provide an overview of the current status of national dementia policies and information on how services for people with dementia are organised.

Pilot project planning and ongoing support

Each pilot programme needed general implementation guidance and tailored implementation support to successfully meet goals and objectives. In summary, this consisted of:

- guidance on development and implementation of programmes for crisis and care co-ordination and implementation science, offered to project leaders in the pilot sites between December 2017 and April 2019;
- dissemination of the good practice recommendations and other materials to the project sites in December 2017;
- experts from the Trimbos Institute from the Netherlands² giving a presentation on implementation strategies to pilot-site representatives at the Act on Dementia meeting in Rome in March 2018, focusing on issues such as developing realistic implementation strategies through clear documentation, goal-setting and creating a timeline of actions;
- experts from the Trimbos Institute developing an implementation reporting template to enable pilot sites to collect consistent information on their projects

¹ European Commission (2014). Implementation Report on the Commission Communication on a European Initiative on Alzheimer's Disease and Other Dementias. Brussels: European Commission (https://ec.europa.eu/health/sites/health/files/major_chronic_diseases/docs/2014_implreport_alzheimer_dementias_en.pdf).

² See: <https://www.trimbos.nl/>

to support further implementation: the template included items on project metrics, support needs, outcomes, and ethics and equity; and

- customised one-on-one support being available for project leads through in-person meetings, phone/Skype meetings, emails, comments on project plans and shared materials.

One of the objectives of offering support was to enhance motivation and confidence, which can be of great value to project leaders.

2. Pilot projects

Bulgaria

Management of severe BPSD in people with dementia in Bulgaria usually involves referral of patients to emergency psychiatric units by their general practitioner (GP). This pilot study aims to make a relevant impact on GP practice in Sofia by reducing inappropriate referrals and use of emergency departments.

The project is designed to improve the efficiency of management, treatment and support for people with dementia with BPSD. Its aims include increasing the knowledge and self-confidence of GPs and carers dealing with BPSD and coping with challenging behaviour, and reducing inappropriate use of emergency departments.

Psycho-educational programmes represent the first-line care option for BPSD prevention and management. The project therefore focuses on implementation of a psycho-educational training programme for the management of crises related to BPSD in people with dementia through training GPs and groups of carers in Sofia.

Two educational sessions were organised for GPs (in May 2018 (with 23 GPs) and October 2018 (15 GPs)). For carers, two support groups were organised: 10 carers had six meetings in October, November and December 2018; and 10 carers had six meetings in February, March and April 2019. Pre-training and post-training questionnaires were provided for both GPs and carers. The planning and organisation of the education/training and support sessions were coordinated by the Bulgarian Society of Dementia team with partners.

A three-month implementation period was created to allow GPs to evaluate and manage BPSD in people with dementia referred to them by families. The GPs assessed BPSD in the people with dementia using the Neuropsychiatric Inventory (NPI). They helped those with dementia and their carers cope with mild symptoms by applying non-pharmacological interventions and, for those with more severe BPSD, arranging specialist consultations. Follow-up assessment of BPSD using the NPI was performed within one month of the evaluation.

Several types of data were collected and analysed to evaluate the impact of the pilot project, including information about GPs, carers and people with dementia and BPSD (such as the number of cases managed by GPs with non-pharmacological treatment approaches, referrals to specialists and inappropriate use of emergency departments), and results from the pre- and post-training questionnaires. The data analysis revealed that:

- GPs and carers had insufficient knowledge, skills and competence related to dementia, BPSD, person-centred care approaches and non-pharmacological treatment approaches before the training;
- training and education increased GPs' knowledge and self-confidence on BPSD and non-pharmacological approaches;
- feedback from GPs concerning detection and assessment of neuropsychiatric symptoms through NPI was very positive;
- the support groups increased carers' knowledge of dementia, psychological symptoms and non-pharmacological approaches for coping with BPSD; and
- both GPs and carers reported relatively high levels of satisfaction: the education programmes were seen as being very useful by both target groups, especially the case presentations and discussion of practical issues.

Thirteen of 18 people with dementia and BPSD with mild and moderate psychological symptoms were successfully helped by GPs, and five with severe BPSD were referred to specialists, with collaboration and care co-ordination between the GPs and specialists. Formal and informal communication with GPs revealed their willingness to continue to apply their knowledge on BPSD and coping skills in future in their everyday practice.

Next steps for the project include follow-up communication with GPs and carers, preparation of dissemination materials (such as publications, presentations, meetings, leaflets and websites) and the development of a proposal for inclusion of educational programmes on BPSD and crisis interventions for GPs. In addition, a national dementia strategy that includes results from the Bulgarian pilot is being developed.

France

Two pilot projects were taken forward in Lyon:

- the Alzheimer's Disease Mobile Team (EMMA); and
- a collaboration pilot project between a nurse and GPs (INFIMEGE).

The Alzheimer's Disease Mobile Team (EMMA)

The EMMA pilot project uses a mobile team to address BPSD, as recommended by the WP5 *Overview of Best Practice Recommendations* report. It takes a multidisciplinary approach, in line with the good practice recommendations. The project's aims include:

- facilitating access to care and structures/organisations dedicated to BPSD to avoid inappropriate emergency room and hospital admissions;
- proposing at-home and nursing-home-specific interventions; and
- reducing carers' anxiety levels.

EMMA comprises a geriatrician and psychiatrist, psychologist, co-ordinating nurse, research officer and secretary. It collaborates with co-ordinated services for the elderly, such as home-care nursing services and home-help and support services.

The team works closely with GPs, neurologists, geriatricians and other health-care professionals to provide clinical expertise and practical support to people living with BPSD at advanced stages and their carers. At the request of one of these (or any

other) health-care professionals, the multidisciplinary team performs a clinical evaluation at the patient's home (whether at home or in a residential setting), including the BPSD inventory and an evaluation of factors contributing to BPSD. The EMMA then makes recommendations for interventions such as non-pharmacological approaches, pharmacological therapies and/or medico-social therapies, in agreement with the patient's GP.

The team strives to provide comfort, explain the origins, symptoms and signs of the disorders, and offer tools to help the cared-for person and carer to better respond to crisis episodes. The NPI behavioural scale is used to evaluate the frequency, severity and occupational disruptiveness of 12 symptoms related to Alzheimer's and related diseases.

EMMA takes an educational approach that includes patient data-collection, communication of challenges, understanding of older people's refusal to seek help and care, and essential principles of know-how and soft skills. The team spends time with the elderly person and family to listen to their needs and opinions and briefly assess their cognitive and behavioural abilities. Evaluation measures in place include parts of the State-Trait Anxiety Inventory self-administered questionnaire for carers, which enables the implementation team to evaluate the effect of EMMA's intervention on caregiver distress, and the NPI (nursing home version) to assess patients' behavioural and psychological symptoms before and 60 days after the EMMA intervention.

Collaboration pilot project between a nurse and GPs (INFIMEGE)

The INFIMEGE project was created to improve detection and diagnosis rates of neurocognitive disorder (NCD). It encompasses a multidimensional assessment by a nurse followed by medical investigation leading to a diagnosis by the GP. The nurse also assesses behavioural disorders using appropriate tests to identify at-risk situations, such as the patient continuing to drive, preparing hot meals or struggling to handle finances. The nurse may propose that the GP contacts the EMMA for care and follow-up of the patient.

Preliminary results from INFIMEGE suggest that GP–nurse collaborations may help to better detect and manage patients with BPSDs in primary care, and better organise diagnosis and care pathways. Feedback from GPs on the usefulness of collaboration with the nurse for detection of NCD and/or behavioural disorders has been positive. To date, a number of additional examinations (such as brain imaging and neuropsychological testing) have been performed following the initial assessment to corroborate the nurse's conclusions.

The next steps are to try to disseminate these two pilots elsewhere in France and in other European countries, based on the positive results received so far.

Italy

The project in Italy focused on implementation of a management system for emergencies in patients with dementia in the local health unit of Modena. Using recommendations from ALCOVE and the WP5 *Overview of Best Practice Recommendations*, a specific management model was designed to improve co-operation between GPs and specialists in the centres for cognitive disorders and

dementias in the local health authorities of Modena. The model aims to improve efficiency and effectiveness in the management of people with dementia, including those with BPSD.

The pilot project aimed to improve dementia care at GP level to reduce unnecessary hospitalisations, and improve care through providing home visits for those who are housebound and making referrals to specialist outpatient care at the centres for cognitive disorders and dementias. Co-operation between GPs and specialists was formalised through official agreements, boosting the potential for the model to have long-term impacts.

The project was implemented in the local health unit of Modena, which has an estimated population of 3,400 people with dementia. It ran from January 2018 to May 2019, using a five-step approach.

During the first phase, information on current practice in BPSD management in the Modena area was collected. Prior to the project, the local health authority had adopted a protocol for the co-ordinated care and management of people with dementia and BPSDs that involved GPs and specialists. The formalised network between GPs and specialists provides people with dementia with outpatient visits or home visits within 7–10 days from the initial call.

The second phase was about training. GPs were trained on the management of BPSD by participating in a two-phase training course:

- a face-to face course aimed at explaining the objectives of the project and providing the most important information on management of BPSD; and
- an e-learning-course targeted at all 138 GPs who had participated in the face-to-face course: the course lasted four hours and had modules on legislation (including guidance on integrated care pathways and information systems on dementia) and operational issues (with a tutorial on the identification and management of BPSD in clinical practice and three clinical cases specific to the management of BPSD).

Phase 3 was dedicated to the implementation and monitoring of best practice. GPs were monitored through phone calls from the National Institute of Health and local health authorities and a structured interview that aimed to identify and ultimately overcome obstacles to participation in the e-learning course.

Phase 4 focused on data collection and analysis, including data on people with dementia, e-learning course registration and participation, and user satisfaction with the e-learning course. Phase 5 will involve drafting the final report, which will include the final evaluation, strengths and limitations of the implementation process, and planning of new projects.

A pilot study was carried out to evaluate the qualitative impact of the project. It used a Strengths–Weaknesses–Opportunities–Threats (SWOT) analysis approach and involved a sample of 20 GPs and 10 specialists. Additional data were collected on numbers of GPs attending the courses, telephone calls between GPs and specialists, and inappropriate use of emergency departments. A focus group interview was also carried out with 11 GPs to evaluate the qualitative impact of the project. Results of

the pilot study are reported in full in the *WP5 Crisis and Care Co-ordination: Final Report*, but highlights include:

- the e-learning course was undertaken and completed by 59 of the 138 GPs who attended the face-to-face course;
- 22 of the 25 GPs who completed the optional satisfaction questionnaire indicated that the programme was relevant or highly relevant, especially in relation to content and acquisition of skills;
- the number of calls from GPs to specialists increased from 123 before the implementation phase (January–September 2017) to 173 after (January–September 2018);
- the most frequent reason for calls was a BPSD episode (122 of 173 calls, 70.5%), followed by other requests (such as requesting information) (35 calls, 20.3%) and calls regarding delirium episodes (17 calls, 9.8%); and
- referrals to emergency departments decreased from 161 in 2017 to 153 in 2018, a decrease of 5.5%.

The positive outcomes of the implementation process will inform future implementation of this training project in all Italian local health authorities as representing best practice in management of BPSD. Learning about the barriers encountered during the implementation process, particularly the concern of GPs about the time needed to complete the e-learning course, can be used to tailor the training programme.

Future steps include better tailoring of the two phases of the training process to promote dissemination of this best practice example of improving management of BPSD.

The Netherlands

The multidisciplinary care group manager in North Limburg oversees the Dutch pilot project, which is part of the national programme on dementia focusing on care management and support around difficult behaviour at home. The North Limburg multidisciplinary care group consists of three regions (Venlo, Venray, and Peel en Maas) and is an active network in which case managers have a key role in supporting people with dementia and their carers. The case manager is the link between the GP and multidisciplinary care services.

A multidisciplinary team is also closely involved in organisation and supportive care as part of the Diagnostic Expertise Centre (DEC). The DEC team consists of five professionals, including an elder-care specialist, an elder-care mental health professional, a psychologist, a psychiatrist and case manager(s).

The pilot project aims to evaluate the current role and functioning of the DEC team by looking at:

- how support for managing difficult behaviour is experienced by carers;
- the support given by case managers and whether they feel sufficiently equipped to be able to offer appropriate support; and
- the current role of the DEC team.

Evaluation data will be used to improve DEC care and case management for people with dementia. Data from interviews, focus groups with DEC teams, meetings with representatives of DEC and discussions with the multidisciplinary care group manager so far show that:

- case managers need more tools for, and knowledge about, analysing difficult behaviour at home and how to explain it to those with low literacy levels;
- DEC team members need more education on difficult behaviour in people with a psychiatric condition;
- the roles, ways of working, connections and potential support to be accessed from the DEC team are not clear and visible to relevant professionals, such as GPs; and
- work processes and workflows differ among the three DEC teams.

As of June 2019, the project team has been focusing on improvement activities. The exploratory evaluation has provided insight into improvement activities related to how:

- carers experience support in the event of challenging behaviour (evaluation data show that carers are positive about accessibility and having a permanent contact person but feel that clear information about challenging behaviour is needed);
- case managers feel comfortable in providing guidance on challenging behaviour (data from the evaluation show that case managers feel sufficiently equipped to offer guidance, and that experience and training has contributed to this); and
- multidisciplinary co-operation is experienced in the DEC team (collaboration has been experienced very positively by the team, but the data show that the visibility of the DEC team could be improved).

Scotland

The Focus on Dementia team, the national improvement programme for dementia in Scotland, oversaw the Post-diagnostic Support in Primary Care project in GP clusters³ in three parts of the country – East Edinburgh, Nithsdale and Shetland.

Scotland remains the only country to have a governmental guarantee that anyone with a new diagnosis of dementia will have a minimum of one year's post-diagnostic support, but there is still work to do to ensure timely access to post-diagnostic support and that the support is consistently of high quality across the country.

The project aims to support improvements and redesign of community-based post-diagnostic support services to improve experience and outcomes for people with dementia and their carers. Post-diagnostic support helps build resilience in individuals and communities and enables people to plan for the future. The emphasis is on supporting people to stay well at home or in a homely setting for as long as possible. The project is based on the idea that improved diagnosis and post-diagnostic support services will help prevent unnecessary hospital admissions by increasing individual resilience and community support.

³ GP clusters typically are groups of 5–8 GP practices in a close geographical location.

Project objectives include implementing and evaluating the delivery of dementia post-diagnostic support from the three sites (27 GP practices in total), engaging the wider primary care team, social work, housing bodies and the voluntary and independent sectors, and understanding which groups of people benefit from post-diagnostic support in primary care.

The project is being conducted through a range of means, including:

- ensuring each site has identified someone locally who had the skills, expertise and dedicated time to project-manage the initiative (“practice champions”);
- providing training to primary-care providers on aspects of delivery that best suit local contexts;
- supporting monitoring through the development of a measurement framework and data-collection tools to obtain and share data across the sites;
- developing and disseminating the dementia-friendly GP toolkit (in collaboration with Alzheimer Scotland and the Alzheimer’s Society); and
- developing a quality improvement framework for post-diagnostic support with the support of people with dementia, carers, staff and partner organisations to set a vision for high-quality post-diagnostic support and enable services to self-assess to identify service improvements.

The approach provides implementation support for each of the project sites. This includes regular learning sessions to share experiences, challenges and progress, monthly reporting with the project team, implementation of a quality-improvement methodology, opportunities for practitioner/project leads to be physically situated in the GP practices, robust project management to keep projects on track and within timescales, and co-ordination between sites.

The pilot sites have conducted a variety of activities. As of November 2018, these included the following:

- the East Edinburgh site appointed a full-time Dementia Support Facilitator who is providing one-to-one support and helping to run post-diagnostic support group-work sessions (three courses have been run and have been evaluated positively);
- the Nithsdale project site’s main focus is on changing their systems and making them sustainable after the project ends, with a key aim of GPs diagnosing dementia for non-complex cases and/or referring on, with a clearer route from primary care into accessing post-diagnostic support, occupational therapy and, specifically, home-based memory rehabilitation; and
- the Shetland site has used the project to transform the whole post-diagnostic support service, with a senior occupational therapist seconded to the programme for two days a week supported by a health and social care worker who focuses solely on post-diagnostic support (35 hours per week).

Other project outcomes include:

- reduced waiting times for post-diagnostic support, with wait times down by nine months in some cases;
- people with dementia and carers experiencing high-quality post-diagnostic support in primary-care settings;

- staff having improved knowledge, understanding and confidence in supporting people with dementia and carers: one area has seen a 58% increase in staff confidence following dementia training and an 86% increase in diagnosis rates; and
- improved anticipatory care planning⁴ and key information-summary completion, with one area recording a 100% anticipatory care-planning completion rate.

This work will continue until September 2021 to ensure it is embedded in practice and achieves longer-term outcomes.

3. Conclusions

The focus of WP5 was to improve crisis-response services and care co-ordination for people with dementia. To this end, evidence-informed recommendations were developed and shared with each of the pilot projects in Bulgaria, France, Italy, the Netherlands and Scotland. While each project had a unique aim and worked to improve different aspects of crisis-response services and care co-ordination, common themes can be seen across the projects.

Central role of primary-care providers

Each of the pilot projects worked to improve crisis-response services and care co-ordination for people with dementia at primary-care level. In doing so, the projects aimed to reduce unnecessary emergency department and hospital admissions, improve quality of life for people with dementia, reduce stress in carers, and establish systems to enable people with dementia to stay at home longer.

The projects in Bulgaria, Italy and Scotland developed educational and training programmes to improve GP knowledge of dementia, dementia care options and the management of dementia symptoms. The programmes included online and in-person options and featured ongoing educational and peer-support sessions.

The pilot projects in France focused on strengthening the knowledge and confidence of GPs by connecting them to multidisciplinary mobile dementia care teams and/or to a nurse specialist, who provided support and assessments. The projects in France and Italy connected GPs to dementia specialists to increase and improve dementia care at primary-care level. The dementia specialists provided support, answered questions and/or conducted assessments.

Primary-care practices in Scotland were supported through dementia care coordinators at the practices and learning and peer-support sessions. The pilot project in the Netherlands sought to understand the needs of primary-care providers, especially in relation to the support provided by specialists at a dementia care centre.

⁴ Anticipatory care-planning enables people to use services better and make choices about their future care. Planning ahead helps the person to be more in control and able to manage any changes in their health and wellbeing.

Supporting carers

As each of the projects sought to improve dementia care for those living at home, most worked to support informal carers, such as family members. The pilot project in Bulgaria provided this support by developing and implementing carer education and support groups aimed at improving carer knowledge of dementia and promoting techniques to cope with challenging behaviour. The French projects aimed to reduce carer stress through home visits that included information, support and tools for carers to equip them to better respond to crisis episodes.

Project teams in the Netherlands sought to learn how care and support for people with BPSD is viewed by carers and family members of people with dementia. This information will be used to develop and implement improvement strategies in dementia care co-ordination. In Scotland, the project team worked to reduce carer stress and burden through “practice champions”, who were contact points for carers seeking additional information and support.

Pilot project overview

In general, the work of the pilot projects shows the desire and need to:

- connect primary-care providers to external support from dementia care specialists;
- train primary-care providers in the tools and techniques needed to provide care for people with dementia;
- co-ordinate care between primary-care providers and dementia specialists;
- develop dementia care pathways in primary-care settings through, for example, care co-ordination by nurses or other care providers;
- reduce carer burden and stress, especially in relation to care for people with dementia and BPSD;
- provide support for people with dementia so they can live longer at home;
- tailor dementia care approaches and improvement strategies to each pilot site context; and
- conduct ongoing evaluation of care to improve care co-ordination and crisis-response services for people with dementia.