

FINAL PUBLICATION OF THE MONUMENT PROJECT



With the support of The European Regional Development Fund

INTRODUCTION

The professional healthcare system of the last few centuries has brought us to where we are today: a planet populated by more than 8 billion people. While this system has effectively cured diseases and prevented death, we are now faced with a new challenge. We live longer. At one point or another in our lives, we will all need (daily) care. In other words, our healthcare systems that we know today, can't keep up anymore with the demand of tomorrow.

But where to start? If we search for the biggest care system worldwide, it's not the hospitals nor the care homes. It's not the health insurance companies nor the pharma companies. It is the informal carers taking care of their partner, parent, relative or friend, day in day out. The impact they have on the lives of these people is huge and yet, the amount of support they receive from governments or healthcare institutions to take on this heavy task, is marginal.

With dementia being the primary cause of death in various countries already, it is not hard to imagine the amount of care this disease requires. After the diagnosis hits, people living with dementia mostly fall back upon the support of the people surrounding them to be able to keep living in the comfort of their home for longer while simultaneously (unconsciously) lightening the stress on professional care institutions. As good as that may sound, this task weighs heavy on the informal carer.

Within the MONUMENT project, we took on the challenge to provide a support system and empower the informal carers of people living with dementia. The last few years, our consortium with 11 international partners has been working and experimenting to see how we can provide an innovative, solid support system, increasing the resilience of the informal carer and making them feel empowered in their role. All of this, based upon the already existing Odensehouse-concept.

Within this report, you will be able to discover what the consortium has worked on. As always when it comes to innovation, we have encountered as many setbacks as victories and each good practice has been preceded by various learned lessons. By sharing what we did and learned – the good and the bad – we hope to inspire you to take action yourself and build upon these foundations we have laid out.

Happy exploring!

Alexandra Winderickx
Project Leader, City of Mechelen

PARTNERS



LEADER
MECHELEN
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 **Norfolk**
County Council
Norfolk County Council
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 **UNIVERSITY**
OF APPLIED SCIENCES
HZ University
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Afeji
Afeji
www.afeji.fr



**Flanders Center
of expertise on Dementia**
www.dementie.be



**National
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The National Trust
for Places of Historic
interest or Natural Beauty
www.nationaltrust.org.uk



WVO Zorg
www.wvozorg.nl



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www.idrops.org



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An abstract graphic on the left side of the page. It features a light pink, semi-transparent shape that resembles a building or a stylized 'M'. Overlaid on and around this shape are several dark purple lines of varying thickness. These lines branch out and terminate in small, solid purple circles, creating a network-like or circuit-like pattern. One line extends vertically from the top center of the page to a circle. Another line branches from the left, with three circles at its ends. A third line branches from the bottom left, with one circle at its end.

CITY OF MECHELEN

OUTPUTS

We built a voluntary network based on the Odense principles. Our volunteers are a mixed group of informal carers, former informal carers and former healthcare professionals. They are the heart of our organisation. They organise and lead our free walk-in moments and in and out of house activities. We also encourage our cohort to propose ideas and activities which our volunteers work out in detail.

We created a cosy place based on a living room concept. This was developed in co-creation with our people living with dementia & informal carers based on the wishes. We enriched our house with assistive technology based on the needs of our informal carer and transformed it into a demonstration house where our visitors can discover technology in a casual way.



TOP TIP 1. Build a strong regional network with other organisations who share your goals so you can share expertise and knowledge. Together you can bring a complementary support programme for informal carers and PLWD.



TOP TIP 2. Involve both informal carers and PLWD when you set up an Odense house. They may have differing priorities, but you can find the commonalities that help make strong foundations.

The City of Mechelen has developed a walk-in centre 't moNument based in Mechelen. It is a place where people with dementia, their informal carers and professional carers can go.

The 't moNument is a central place for information, activities, peer support and a meeting place. It is an anchor point for people living with dementia and their informal carers. In addition to orientation sessions, we also organize training courses for informal carers to give them insight into dementia.

Contact with peers is an important form of support for our informal carers. They can tell their stories in a safe environment. That is why we regularly organize family groups, where experiences and tips can be shared between peers.

Unique to our project is that we also have a family group for people with young dementia. They enjoy being together in a casual atmosphere. As mentioned in our name; moNument, the NU stands for NOW. We value living in the moment, NOW moments for informal carers and people living with dementia to cherish together. This pilot works to offer something special and different to the typical care relationship.

GROWTH

The Odense House will remain the anchor point for our informal carers and PLWD locally. It will continue to provide support as we do now, with the focus on low threshold access. We will expand our voluntary network to guarantee support, activities, and free walk-in moments continue. We are an example in Flanders for informal carers support. In the future we hope to inspire other cities to open an Odense house as well. Going forward there will be a network of Odense Houses in the whole region.



BUILDING BLOCK POLICY LEVEL

The Story of City of Mechelen

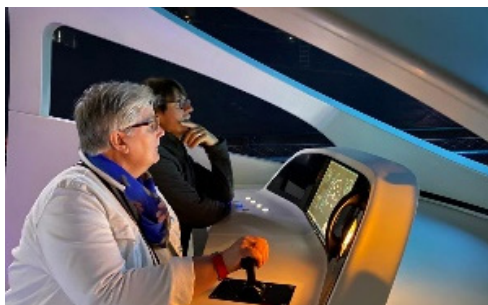
With various activities, we ensure carers and people with dementia can experience beautiful moments :



Like our music moments for people living with dementia and their carers. Singing together connects and makes people with dementia more active. It appeals to their abilities in a positive way.



For our 5th anniversary, we made an artwork. During the Wax & Bronze workshop, our carers and people with dementia worked together with wax. We asked them to create moments that they enjoy. All these small scenes were immortalized in a bronze artwork.



Our visitors are very involved and suggested lots of outdoor activities. Together with their informal carers, we went to the botanical gardens of Meise, Trainworld, and an art exhibition Kunstuur in Mechelen.



Contact with peers is a major form of support for both our informal carers and people living with dementia. They can tell their stories in a safe environment. That is why we regularly organize Family Groups, where experiences and tips can be shared between peers. Unique to our project is that we also have a family group for people with young dementia. They enjoy being together in a casual atmosphere.

The Conversation Pub is a meeting place for informal carers and family members, where, through a variety of topics, you can learn to understand what dementia is and what it means for the person living with dementia. It is a moment where information about dementia is shared with others.



[Click here for the full report, or scan the QR code at the end of the publication.](#)

INFRASTRUCTURE WORKS

A service center adapted to the needs of people living with dementia and their informal carers

The city of Mechelen set up a collaboration with the PhD students Interior Design from Thomas More in order to fully adapt the Odense house to the needs of the people living with dementia and their informal carers. Through various workshops and an iterative process of feedback from the informal carers and the people living with dementia, the PhD students created a design, followed up the tendering of various parties and did the follow up on-site.



One of the main insights was that the space should be as serene as possible, without distractions, patterns and posters as the space is already full of people and activities. These various activities are split up into two zones in the design: an active zone (in white) and a quieter zone (in yellow).



The works carried out are the following:

1. Remove a wall between two smaller rooms
2. Redo the flooring
3. Install a photo wall
4. Install custom furniture in the room
5. Fix lighting, electricity and add a smart TV
6. Install curtains
7. Insert furniture

The part of the process where the people living with dementia and their informal carers have been most involved, is the initiation phase, expressing their needs and thus defining the design. Secondly, they have also been closely involved in the selection of the furniture, giving input on colors, feedback on the designs, and sometimes even testing some of the pieces.

See the original 3D design video : www.youtube.be/lj8bo3Kvonk

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WALK-IN CENTRE 'T MONUMENT**

<https://virtualtours.the360experience.be/Monument/index.html>



FAMILY DAY ORGANIZED BY CITY OF MECHELEN

Say "yes" to new adventures, family trip to Zeeland

Is it still possible for people with dementia and their informal carers to go out and enjoy the holiday?

What started as a joke from our visitors, « *Can we buy a mobile home from the EU project?* », evolved in a well-organized family trip to Zeeland.



In June 2022, we went on a mini-trip to Zeeland (Netherlands) to meet our project partner WVO zorg and visit their facilities: the Odense house of Walcheren and Het tuinhuis. Our participants were welcomed with open arms. They were visibly impressed, and they experienced the Dutch Odense house concept in real life.

During our stay, our volunteers also organised leisure activities on the beach such as a sunset promenade, a laughing session and a KUBB tournament. They were in charge of accompanying the participants and ensured that all participants felt at ease during the entire trip. Our participants really enjoyed it. Not only did they strengthen their bonds, but they also realised that it is possible to go outside, go on a trip, and enjoy many wonderful moments.



FAMILY DAY ORGANIZED BY THE CENTRE OF EXPERTISE ON DEMENTIA

In Augustus 2021 and 2022 a Summer Camp with a two-night stay was organized by the Centre of Expertise on Dementia in cooperation with Alzheimer League Flanders. The camp was for children with a parent with dementia and one adult family member. The Summer Camp took place in a farm/horse enclosure De Maalderie in Houthulst (West Flanders).



The purpose of the camp is to meet peers who are in a similar situation. The participants share experiences, acquire new knowledge, and have fun together. The activities are supervised by experienced carers (such as psychologists, physician specialists, ...) During information sessions and conversations, participants can tell their own story and ask questions about dementia, taking care of yourself, the support for children, ...



"It's good to know that you really aren't alone"

Tiana, participant to camp 2021

See the video of the summer camp 2021:
<https://www.youtube.com/watch?v=TCibVoOd148>



NORFOLK COUNTY COUNCIL

OUTPUTS

Thanks to the MONUMENT project a more proactive and meaningful dialogue and cohesion has been forged between Norfolk's Environment Services, Adult Social Care, and Public Health departments. This combined expertise strengthens the ability of all involved to provide holistic and person-centered support for ageing communities in Norfolk, with a greater appreciation of pan-disability delivery approaches.

The Outreach Officers for NCC have set up and supported the reopening of several dementia-friendly peer-support sessions post-Covid. Our commissioning of specialist UK charity Dementia Adventure has enabled over 70 delegates to attend training, as well as the production of bitesize videos which disseminate the training to a wider audience and provide an additional post-project training legacy.

A network of passionate local stakeholders has been created who remain advocates for carer and dementia-friendly facilities across the county. The MONUMENT project has enabled a variety of new technical supports to be trialled to help promote independence and outdoor activity

TOP TIP 1. Find out what the local population wants. Make research to be sure you address the local barriers which affect whether your carers will want to visit your Odense house.



TOP TIP 2. Make sure you have the backing and regular communication with your local policymakers and stakeholders. Engage their specialist knowledge and share your successes. These people's attention and advocacy can help you access future funding.



Norfolk County Council identified that improving access to green spaces for informal carers of people living with dementia improves their health and well-being. Norfolk developed carer focused experiences at many fantastic venues. The strategic focus became Gressenhall Farm & Workhouse, a museum in an expansive rural setting. The site is the key focus of many environmental enhancements, and having recently launched as an Environmental Hub, NCC seized the opportunity to input MONUMENT's ethos and implement the Odense model learnings there. This museum of rural life boasts many attributes that appeal to carers and people living with dementia including gardens, animals, a café, toilets, ample parking, seasonal events, and a strong staff network. However, this extensive 50-acre site is not without its accessibility challenges. Our MONUMENT pilot has shaped planned landscape enhancements to ensure that the accessibility needs of people living with dementia are met in the future. Specific dementia training was offered to relevant staff involved at this venue. Site audits and piloted leisure days were also held. The MONUMENT team was keen that bottom-up learning from stakeholder and carer engagement events helped identify and advise how future infrastructure enhancements could be installed for the benefit of our county's carer cohort.

GROWTH

Norfolk County Council has learnt a great deal from working on the MONUMENT project. The project has evidenced that there is great appetite amongst local stakeholders to upskill and improve accessibility and inclusivity outdoors to bolster carer wellbeing. We hope hybrid events such as our Family Fun Day can continue in the future, promoting resilience, destigmatisation and the promotion of local services. We also look forward to continuing the strong collaboration at Gressenhall Museum between Environmental, Public Health and Norfolk Museum Services.



BUILDING BLOCK POLICY LEVEL

Norfolk County Council

Norfolk County Council's pilot 'lifts the roof' on the Odense House concept and expands its potential into outdoor space. NCC has delivered bespoke training to outdoor professionals through commissioning Dementia Adventure, a specialist non-profit charity, and piloted a range of unique outdoor leisure activities and informal support opportunities for carers through close collaboration with a range of atypical stakeholders.



Informed by Focus Groups, Outreach Officers worked with local support groups such as Norfolk Museum Services' Community Culture Club and Libraries to trial peer support activities and strengthen local networks. They also trialled outdoor leisure activities with carers and people living with dementia with visits to a range of outdoor sites from sailing lakes to woods and fenland. The scoping visits increased local understanding of carer and people living with dementia priorities: from a need for a pan-disability perspective; fears of open water; to the joy of hands-on activities. Prior to the leisure events, site staff attended 'Pathways into Nature' training to aid their preparation and awareness for how to support carers and those living with dementia. The culmination of this learning was showcased with local carers, friends, and stakeholders at a celebratory Family Day in June 2022.

In the latter half of the pilot, NCC worked closely with the University of Stirling's Dementia Services Development Centre (stir.ac.uk) to provide bespoke training on dementia to internal staff to ensure that the legacy of the pilot is incorporated in future works. Learnings from NCC's pilot will be applied into delivering and expanding enhanced accessibility and an enriched experience within the outdoor green spaces at Gressenhall Farm & Workhouse Museum and other outdoor sites across Norfolk.



Gressenhall and its extensive outdoor space holistically developed into the logical focal point for NCC's Odense concept as the pilot progressed – with improvements on outdoor access through the testing and purchase of an assistive technology as well as simple but effective changes. This included environmental improvements alongside improving the knowledge and awareness for staff.

MONUMENT aligns closely with NCC's local policy ambitions. Norfolk County Council's Environment Service is working on an ambitious 10-year plan, the Norfolk Access Improvement Plan (NAIP), which sets out priorities for increasing public use and enjoyment of Norfolk's public rights of way network. Norfolk is also locally implementing the central aims of the UK Government's 25-year Environment Plan. One of the goals of this plan is 'Connecting people with the environment to improve health and wellbeing'. MONUMENT has provided Norfolk with the ideal opportunity to proactively and innovatively pilot how to improve access to nature for carers and people living with dementia, a growing demographic group.

[Click here for the full report, or scan the QR code at the end of the publication.](#)

INFRASTRUCTURE WORKS

Technical workplan for Gressenhall to ensure dementia friendly locations

As the aim to 'lift the roof' on the Odense House pilot progressed in Norfolk, Gressenhall Farm & Workhouse Museum and its extensive outdoor spaces became the local focal point of NCC's pilot. This was enabled through improvements to outdoor access with the testing and purchase of an assistive technology, staff training, and the development and design of a new dementia-friendly immersive nature walking route to the south of the site.

The Assistive Technology which has been tested and purchased for the site included two three-wheeled electric Trampler TWS trikes with the latest manoeuvrability and safety features. Getting around the vast site easily and safely were major concerns for the carer cohort and this model met their specific requirements. The beautiful site at Gressenhall Museum has a working heritage Farm, orchards, fields, and a river walk. These areas of the site are now more easily accessible for carers and people living with dementia who have mobility needs, enabling a shared experience outdoors and reigniting a sense of adventure.



In addition to the Assistive Technology at the site, a technical plan has been drawn up by experts in ecological human-centered design. Digg & Co was commissioned by NCC as part of the MONUMENT pilot to design an innovative new dementia-friendly walking route enabling better connection to nature. This route will be implemented as a legacy of the project and takes a pan-disability approach with dementia design principles at its heart.



The team at Norfolk County Council who commissioned the design have bolstered their knowledge with the expert guidance and training of the Dementia Services Development Centre (DSDC) at the University of Stirling. This expertise alongside the knowledge gained from the earlier carer and stakeholder focus groups has enabled a well-informed walk design creating a truly special experience.

Gressenhall Farm & Workhouse Museum is also the home of Norfolk's new Environment Hub with activities based there ranging from a Community Tree Nursery to innovative nature-based education outreach. The Odensehuis-inspired learnings that MONUMENT has brought to the site will ensure access to nature for carers and people living with dementia remains a core value, long after the pilot comes to an end.

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TO THE 360° VIRTUAL TOUR
OF GRESSENHALL**

<https://virtualtours.the360experience.be/Monument/index.html>



FAMILY DAY ORGANIZED BY NORFOLK COUNTY COUNCIL

«The Family Fun Day»

In June 2022 the NCC team held the biggest carer event in their project calendar. Family Fun Day took place at The Costessey Centre, Norwich, and welcomed people living with dementia and their families, local stakeholders, and community groups. This event offered a great platform to showcase local dementia-friendly organisations and to celebrate the project's work. From libraries to guineapigs, and boccia to boating; a total of 20 stalls were available offering a wide range of activities, conversation, and dementia-specific information. This hybrid event provided an opportunity for families to enjoy quality time together. Carers could meet relevant services and facilities available in Norfolk in a welcoming and relaxed environment. One carer fed back:

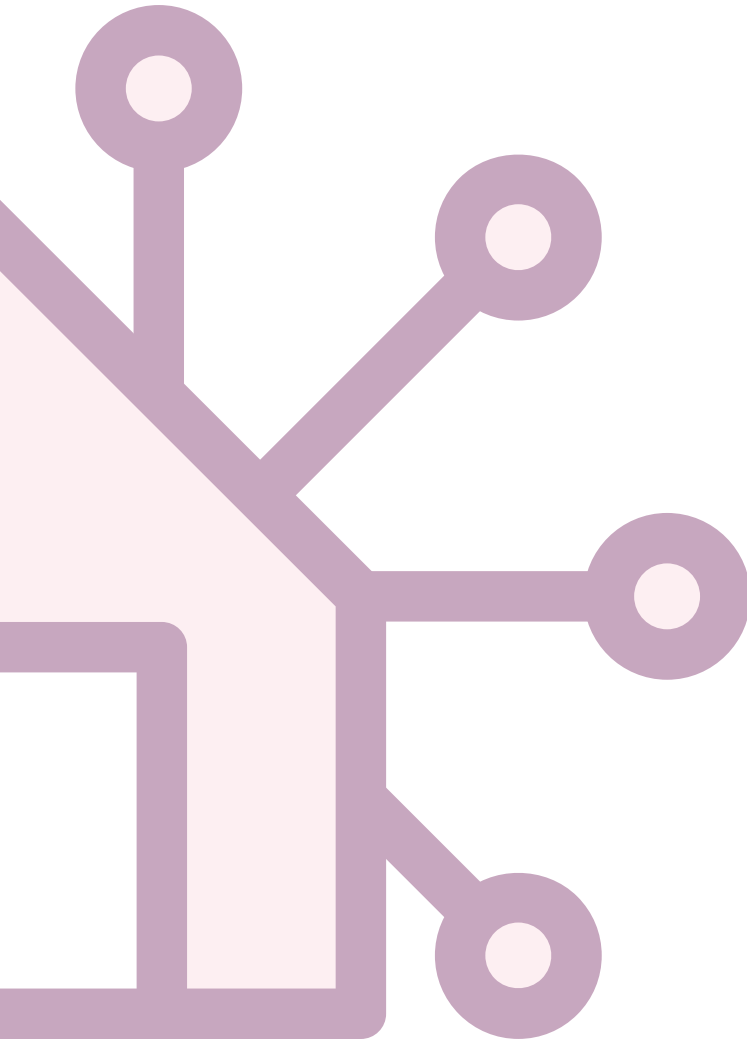
«There was useful information we took away with us, and we were amazed at the free lunch! It was well organised and set out and we stayed much longer than we thought we would.»

The weather stayed bright and over 100 people attended the event and helped to make the Family Fun Day a real success.





AFEJI





AFEJI HAUTS-DE-FRANCE. FR. PROJECT PARTNER 5.

Maison Odense d'Hautmont, Avenue Gambetta,
59330 Hautmont, France

OUTPUTS

The Odense House in Hautmont has developed a network of volunteers with various talents, who support and improve the activities. A fruitful partnership has been forged with the Municipality of Hautmont and a local network has also been established. Opulse training, an online support programme for informal carers has provided new resources and helped give carers confidence to better support their loved one on a daily basis. Activities at Maison Odense d'Hautmont promote informal support: relaxation and well-being activities.

A number of local events have taken place at the Odense House which include project-partnership meetings, Open House Day and Family Day. Effective communication has been an invaluable part of increasing awareness. The Maison Odense d'Hautmont has also been featured in local magazines, newspapers and on local radio. Thanks to MONUMENT 18 informal caregivers have been reached so far to the Odense House activities.

TOP TIP 1. Involve your target group when developing your Odense House. This assures it will satisfy them and match with their needs.

TOP TIP 2. Learn from the experiences of others (stakeholders, facilities, public). Collaboration is a great way to share information, training and best practices.



WELCOMING

SOCIAL

INNOVATIVE

The Odense House from AFEJI Hauts-de-France is part of the set of Afeji establishments and services dedicated to elderly people, including persons with dementia and related diseases and their caregivers. It is specifically linked to the nursing home Les Tilleuls located in Maubeuge. The Odense House in Hautmont is run by a coordinator with a network of active volunteers and the associated project team.

The venue welcomes informal carers, and their family members, friends, and the local community. It offers a safe friendly space to chat over coffee, share advice and discuss about dementia, caring and everyday life. The aim is to offer an informal environment that does not stigmatise. The structure is open to everyone three afternoons a week from 13h30 to 17h30. At the Odense House in Hautmont one can; participate in diverse activities such as topical discussions, carer training, a therapeutic hypnosis programme. Professional support and guidance for informal carers and training for volunteers is also available. Other activities such as board games, convivial meals, trialling assistive technology, well-being workshops are also organised there. Moreover, the venue promotes local human connections and genuine intergenerational contacts.

GROWTH

In order to promote and sustain the Odense House after the MONUMENT project ends, the AFEJI team are keen to capitalise on utilising their financial, material and social resources to good effect. AFEJI Hauts-de-France is active in applying for regional and national proposals for social innovation linked to elderly people and plans to participate in future Interreg projects. As part of the set of Afeji establishments, the Odense House will continue to be used for various activities within the local community.

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www.afeji.org



BUILDING BLOCK POLICY LEVEL

AFEJI summary

The Odense House of Hautmont is located on a major avenue, directly next to a bus stop. This allows passers-by to stop and eventually pass the door.

It is composed of a large living room with welcoming furniture and a kitchen, useful during collective workshops. As the place is relatively new, we first decided to co-create the layout of the space with the help of health care professionals. We then organized workshops with the informal carers and volunteers to define together the needs of the place in terms of decoration and activities proposed.



In order to guarantee the good development of the place, we are working to create solid links with local actors: social organizations, health establishments and local institutions. The objective is to highlight the complementarity of the place with the pre-existing solutions for the target groups.

From these connections, we create a monthly schedule of various activities:

- Informal sharing moments: every Thursday, a meeting over coffee is organized with a psychologist with focused discussions to allow carers to get to know each other and to create new links.
- Training and workshops related to relaxation: 1 well-being session, therapeutical hypnosis sessions
- Artistic and cultural activities: creation of paintings, floral art.
- Ludic activities: board games, karaoke, reading...
- Festive events: an open day of the house and our first Family Day (organized on the theme of a fair).

Finally, to guarantee the quality of the place, we take care to train the public who make up the Maison Odense of Hautmont:

- For volunteers: training on the posture of a volunteer, on the creation and facilitation of group activities with the target public.
- For informal carers, we have organized 4 training sessions on Alzheimer's disease and the posture of the carer, and we plan to involve professionals from the territory to present the different possible accompaniment solutions.
- For professionals, we encourage updating knowledge about Alzheimer's disease, meetings with medical and social professionals as well as about animation and communication in the professional environment via online resources too. We will also be organizing training sessions on the topic of seniors and their inclusion in local life.

[Click here for the full report, or scan the QR code at the end of the publication.](#)

FAMILY DAY ORGANIZED BY AFEJI

On the theme of the fair

The Family day took place on the 23rd of November 2022 at the Odense House in Hautmont. The event was a festive afternoon with traditional games, fairground activities, and a snack. It was a convivial moment between informal carers and their relatives, volunteers, and family members.



The goal of the afternoon was to strengthen the bounds and interactions between the participants around leisure moments. The idea was also to highlight the volunteer's involvement and the carers within the Odense House. Indeed, all the participants were part of the organisation of the event.

The Odense House in Hautmont continues to make itself better known in the area and within the local community.

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TO THE 360° VIRTUAL TOUR OF
THE ODENSE HOUSE OF HAUMONT**

<https://virtualtours.the360experience.be/Monument/index.html>





THE NATIONAL TRUST



THE NATIONAL TRUST. GB. PROJECT PARTNER 11.

**Damsons at the Reed Barn, Peckover House,
Wisbech, Cambridgeshire**

OUTPUTS

So far the main success of the National Trust Odense House has been the considerable membership growth witnessed. With new enquiries every week the need for the facility in the local area is proven. Word of mouth and advertising has been vital to increase the awareness and positive reputation of the Damsons as a safe and welcoming place for carers and people living with dementia within Wisbech. The service has received positive feedback from service users who have commented on the relaxed and friendly atmosphere and fabulous staff team. The National Trust pilot has had a high retention rate at their Odense House with a core group of regular carers attending the same day every week. Some feedback gathered by the team included carers and people living with dementia saying that within the venue they 'feel safe' and have 'made new friends'.



TOP TIP 1. It is invaluable to put the time in and do your research first. Get to know your location, find your network and local advocates as early as possible. It is so much harder to start without this human capital in place.

TOP TIP 2. Always allow your people living with dementia and informal carers to guide you and help make decisions that impact the venue. As a coordinator you can always make suggestions but it is their space, and as such they should feel ownership to lead as they wish.

RELAXED

FUN

SOCIAL

The Damsons at the Reed Barn Odense House is a community space for people living with dementia and their carers designed to fit within a National Trust visitor offer. The traditional Odense House model of volunteer run and community driven activities is enhanced by the National Trust's priorities of giving access to heritage and nature to everyone. The barn is well situated within the grounds of Peckover House and provides fabulous access to the renowned walled garden which visitors to the Odense House have access to enjoy. The team of staff and volunteers who run the service are on hand with refreshments and activities that empower people living with dementia and their carers to promote positive care experience. There has been a particular focus on empowering informal carers by providing a safe space for them to relax and converse free from their caring responsibilities. This provision has also been enhanced by the availability of technology designed to help around the home. A Magic Table 360 from Social Ability has also provided another activity in the Odense House with access for everyone to enjoy and interact with.

GROWTH

The Odense House is looking to become fully self-sustaining from March 2024. Funding has been agreed on for March 2023 until March 2024. In the mid-term, the Odense House wants to increase the number and complexity of volunteering so that more carers and people living with dementia can join. Damsons wants to welcome outside activity providers who can provide expertise not currently at the Odense House.



BUILDING BLOCK POLICY LEVEL

A site adapted to improve the use by people living with dementia and their informal carers, including improvements to signage

The National Trust has transformed the Reed Barn at Peckover House and Gardens in Wisbech into a safe place where people living with dementia, their families, and carers, can share experiences, gain new skills, and take a break from caring responsibilities. This new service called Damsons after the fruit grown in the garden at Peckover for years, which provides a sense of belonging and place.

New furniture has been installed in the Reed Barn to create a more comfortable, homely feel, to help people relax and feel able to participate in any activities on offer.

Lighting has been re-designed to create a space with as much natural light as possible and limited shadow and glare which can be confusing for people living with dementia

The National Trust has also been working with Social-Ability and has incorporated their Magic Table 360 into the Odense House.



The process

The Reed Barn is a Grade II listed building dating to the 17th century and has had many uses over the three centuries. In October 2021 planning started to make adaptations to the Reed Barn for the MONUMENT project. An accessibility audit was conducted using guidance from the Alzheimer's Society, and an informal checklist amalgamated from several key dementia inclusive publications.

Over the course of 2022 until July, work took place to adapt the site to ensure it was dementia inclusive and incorporated the five values of an Odense House.

The largest expense was the change to the lighting completed by RedRoc equipping the barn with sophisticated natural and dimmable lightbulbs. Focus Groups conducted in January and September were used to develop the activities and continue the updates of the Reed Barn to ensure that it is service user led.

[Click here for the full report, or scan the QR code at the end of the publication.](#)

INFRASTRUCTURE WORKS

In the Reed Barn

The National Trust has made significant changes to its grade two listed Reed Barn at Peckover House and Gardens. The process started in October 2021 with an audit and walkthrough of the site following a visitor's journey from the moment they enter into the territory to the moment they leave. Several changes were highlighted including changes to the access to the site and to make the indoor space more dementia friendly and fit for purpose. A total list was put together with estimated costs and timelines associated with each. These were evaluated based on the budget and level of importance and an adaptation tracker was created with a separate workstream devoted to it.



The essential changes made are highlighted in the pictures with a new lighting rig which are dimmable and designed to provide the most natural light to the space. We asked our stakeholders and potential service users what they wanted to see from the space. They came up with some key words which included: space, light, comfortable and informal. These are things we have tried to replicate at the Reed Barn Odense House. Several pieces of furniture were purchased and arranged to provide different zones to meet as many needs as possible for the service users.

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OF THE REED BARN**

<https://virtualtours.the360experience.be/Monument/index.html>





WVO ZORG

OUTPUTS

Odensehuis Walcheren are proud of what they have been able to achieve since their opening. The experience and longevity of this venue has allowed it to offer many examples of best practice for the other project partners of MONUMENT.

Thanks to the MONUMENT project, cooperation with regional partners has been strengthened in the locality of Walcheren. There has been the opportunity to run several courses and training sessions for the cohort of informal carers, and this has been beneficial for the carers and for the people living with dementia too. There have been many opportunities within the training and networking to share expertise and resources. The MONUMENT project has helped Odensehuis Walcheren to increase the use of technology on site to support informal carers in caring for a person living with dementia. At the same time, piloting a variety of technologies has taught the team that many informal carers of an older age demographic can be reluctant or intimidated by new assistive technology.

TOP TIP 1. Make use of local partnerships.; exchange expertise and experiences to build a strong network. Seek connection with civil society organisations such as museums, environmental and cultural associations.

TOP TIP 2. Assume the Odensehuis values; the participants are in the lead. Everyone is of value and has talents that can be used for the benefit of the group and to promote self-esteem.



SELF-ESTEEM

COMMUNITY

CONVIVIALITY

Odensehuis Walcheren has been welcoming everyone since 2011. All inhabitants of Veere, Middelburg and Vlissingen with memory problems, their carers and friends are welcome for a chat, a good conversation, a creative activity, a cup of coffee, a game, music-making, cooking together or whatever they feel like doing. Together with the coordinator and volunteers, a warm and friendly atmosphere is created. Here everyone can be themselves. At Odensehuis Walcheren, all visitors can develop their talents and everyone is valued for who they are. In Odensehuis Walcheren, everyone is equal and everyone's talent is recognised and nurtured: for people living with dementia, informal carers, volunteers and citizens. We work according to the Odensehuis principles and the social approach to dementia. The disease is not the main focus, but the person with their talents and interests.

The Odensehuis itself is spacious and light. The large wooden table is at the heart of the space. But there are also seating areas where people can relax quietly or sit at a smaller table for a game or an intimate conversation. There are various technological innovations inhouse, which are available to use or borrow.

GROWTH

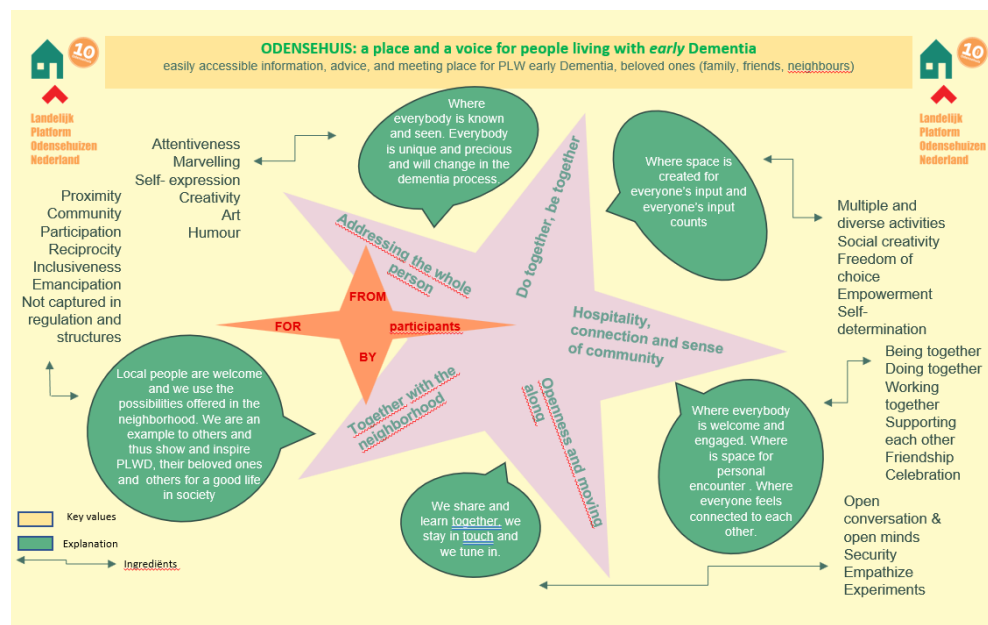
Odensehuis Walcheren is of great social importance within its community; its presence is rooted in Walcheren's society. Visitors say that the Odensehuis is welcoming and helps them to cope with dementia. The building has increased its weekly opening hours and future plans are to expand that further, from two half-days and one full day, to two full days and a morning. The team will work to maintain the cooperative relationships they have built with their regional and project partners. In the future, it is expected that more projects involving technological enhancements will be undertaken. The municipal subsidies may change in the future, but it is the intention of all parties to keep the Odensehuis accessible for the inhabitants of Walcheren.

"Odensehuis Walcheren feels like a second home!" - participant

BUILDING BLOCK POLICY LEVEL

WVO Zorg and Odensehuis Walcheren

Odensehuis Walcheren has more than 10 years of experience in supporting people with (early) memory problems and their informal carers. Anyone living with dementia in Veere, Middelburg or Vlissingen and their partners, family members and friends, are welcome for a chat, a good conversation, a creative activity, a cup of coffee, a game, making music, cooking together or whatever they feel like. Together with the coordinator and volunteers, a warm and cosy atmosphere is created.



For the MONUMENT project, WVO Zorg and Odensehuis Walcheren worked closely together to further strengthen accessible support for people with dementia and their informal carers.

Based on the basic values for Odensehouses, WVO Zorg and Odensehuis Walcheren have been an example for the partners in the MONUMENT project.

The most important values for an Odense house are mutual respect, equality and a positive, social approach to dementia. The disease should not be the focus, it should be the person. WVO Zorg and Odensehuis Walcheren are delighted to have been able to communicate these values to the partners within the MONUMENT project.

For Odensehuis Walcheren and WVO Zorg, the deepened cooperation with partners in the region has proved to be of great added value. This cooperation established thanks to the MONUMENT project improves support for people living with dementia and their informal carers. For example, visitors to Odensehuis Walcheren can easily participate in courses organised especially for informal carers.

Cooperation with dementia case managers has also been strengthened. A dementia case manager is an indispensable pivot for people living with dementia still living at home and their informal carers, as the case manager guides and supports during the entire dementia process.

Odensehuis Walcheren is in an easily accessible location in Vlissingen. It is a spacious and light building, with a large wooden table as the heart of the room. But there are also seating areas where people can relax quietly or sit at a smaller table for a game or an intimate conversation. There are several technological innovations in the house, which can be used or borrowed.

See the original 3D design video : www.youtube.com/watch?v=ExnPmeP5tbE

[Click here for the full report, or scan the QR code at the end of the publication.](#)

Odensehuis Walcheren is a well-known and valued facility in Walcheren society. For more than 10 years it has offered support to people with dementia and their informal carers.

The Odensehuis has extended its opening hours and now opens its doors two full days and one morning a week. On Wednesdays, attendees cook lunch together and once a month a delicious meal is prepared by a former chef.

«Being coordinator of an Odensehuis is the best job in the world - you are always among friends!» – coordinator

The team will work to maintain the collaborative relationships they have established with their regional and project partners. More projects involving technological improvements are expected to be undertaken in the future. Municipal subsidies may change in the future, but through close cooperation with WVO Zorg, all parties will surely succeed in keeping the Odensehuis open for Walcheren residents.

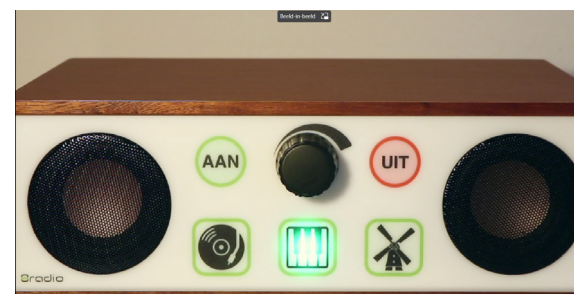
«We do a lot of creative activities. I'm still learning new things here!» - participant



Thanks to the MONUMENT project, cooperation with regional partners has been strengthened. There has been an opportunity to organise various courses and trainings for informal carers, which has benefited not only informal carers but also people living with dementia. Within the training and networking, there have been many opportunities to share expertise and resources.



«I didn't know there was already so much possible, but luckily we don't need it yet» – informal carer



Thanks to the MONUMENT project, Odensehuis Walcheren is making more use of technology to support informal carers when caring for a person with dementia. At the same time, testing a variety of technologies has shown that many informal carers of older age can be reluctant or intimidated by new assistive technology.

«You see people brighten up and you get attached to the people who come here. It feels good that I can contribute to this.» - volunteer

Odensehuis Walcheren has a regular group of loyal volunteers. Together with the participants and the coordinator, they ensure a warm, safe atmosphere and a varied range of activities. Some volunteers have experience with dementia, either as a relative or as a (former) professional. This allows them to support participants with their knowledge and experience.

“Lots of social and community organisations want to help support people living with dementia and their informal carers. Take advantage of that!” – project manager MONUMENT

Odensehuis Walcheren and WVO Zorg like to make use of local partnerships; this way expertise and experiences are exchanged to build a strong network. Connecting with civil society organisations such as museums, environmental and cultural associations yields surprising connections and activities.

“An Odense House is like the taste of oranges. You can't explain it. You have to experience it!” - informal carer

Odensehuis Walcheren works from the basic values and principles of the Odense Houses. This means that the participants are in charge. Everyone is of value and has talents that can be used to benefit the group and promote self-esteem. The result? A tightly-knit group of friends where everyone feels safe and valued!



**SCAN THIS QR CODE TO GO
TO THE 360° VIRTUAL TOUR OF
THE ODENSEHUIS WALCHEREN**

<https://virtualtours.the360experience.be/Monument/index.html>



[Click here for the full report, or scan the QR code at the end of the publication.](#)

FAMILY DAY ORGANIZED BY WVO ZORG

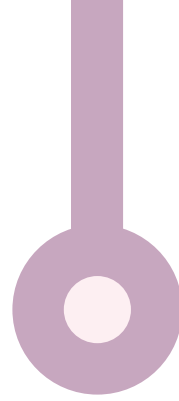
Breinspoken – a Family Camp

The first Dutch summer camp for children and partners of young people with dementia took place from 12 to 15 August 2022. At a great location right by the water, 21 children aged 6 to 18 gathered with 11 parents.

Together they laughed and cried, learned and played, went swimming and lounging. The camp was organised by Alzheimer Centrum Amsterdam (Amsterdam UMC) and made possible with a financial contribution from the MONUMENT project.



The aim of the camp was to support informal carers (children and partners) in their care for a parent and partner with young dementia. The participants found support with each other and look back on a very successful camp. It will be organised again next year.



TECHNOLOGY

MEMO BY MONUMENT

A digital platform to support informal carers

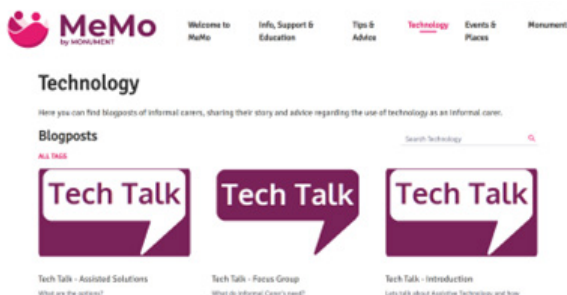
In addition to the support within the (physical) Odense houses, the Monument project extended peer support by developing an online platform, 'MeMo by Monument'. The goal of MeMo by Monument is to empower informal carers and develop a virtual place where tailored information, benefits and experiences of the Monument project could be shared with informal carers. By doing this, the digital platform makes informal carers an empowered community and it offers stakeholders insights into the needs and values of informal carers.

The five main building blocks of the platform aim to:

- Disseminate information and knowledge tailored to informal carers of people living with dementia.



- Allow informal carers to share information
- Communicate on dementia-inclusive places and events.
- Share information on assistive technology for informal carers.



- Provide a place targeted at policymakers and facilitate the transfer of insights gathered within the Monument project.

Via these five building blocks the platform wants to become the digital backbone of the Odense model. The centralisation of information on dementia will give the carers more guidance within the current fractured landscape. By receiving tips and advice from other informal carers and bringing together information on dementia, the platform aims to reduce the burden and improve the resilience and perseverance of informal carers. The content on the platform is user-fed, meaning that it is generated from informal carers input and being published by all project partners.

The online platform has four main target groups:

- Informal carers of people living with dementia: they receive (1) information from professional organisations tailored to their needs; (2) advice from other informal carers via blogposts on general topics and technology and (3) information on dementia-friendly events and places.
- Care providers and stakeholders working on dementia: they will be able to share their services with the informal carers.
- Technology providers: their technology will be shared and evaluated via blog posts.
- Cities, hospitality & leisure sector: Their dementia-friendly activities can be published on the platform.

Next to these target groups, the online platform also delivers added value to people living with dementia, policymakers, stakeholders within the Monument project, volunteers working with people living with dementia, hospitals, doctors, geriatrics, home care institutions, ...

Each region had a separate URL for the MeMo by Monument platform:

- Flanders (Belgium): www.memo-monument.be
- United Kingdom: www.memo-monument.co.uk
- The Netherlands: www.memo-monument.nl
- France : www.memo-monument.fr

To stimulate the exchange of knowledge between the informal carers of different regions, end-users could easily switch between countries on the platform. Apart from the more locally tailored content (eg. Events and places), some content is identical over the different regions such as the Monument page targeted to policymakers to learn about the Odense concept.

[Click here for the full report, or scan the QR code at the end of the publication.](#)

CONNECT WITH THE REMOTE MONITORING PROTOTYPE

Dementia affects the lives of the patient and those surrounding them. To continue living at home, people with dementia rely on family and friends for care and assistance with daily activities. As symptoms and disabilities depend on the stage of dementia and vary over time, carers must constantly adapt. To increase the resilience of informal carers, IMEC developed a modular remote monitoring application that can be customized to the current needs. Providing structural and professional support using digital solutions improves the health and well-being of both the people with dementia and their carers.

Living with dementia

Dementia is a progressive disease compromising the ability to process information in the brain, leading to reduced comprehension, memory, orientation, or language use. Performing daily tasks becomes challenging, making people with dementia reliant on (informal) carers. The world health organisation (WHO) reports that informal carers – mostly friends and family – spent on average 5 hours per day providing care in 2019.



While people with dementia try to maintain their autonomy, informal carers often feel like the provided care is inadequate. The responsibility, lack of professional training, and insufficient support systems cause physical and emotional distress. This affects the health and well-being of the informal carers which negatively influences the perseverance to continue care.

By strengthening the resilience of informal carers, people with dementia can continue to live at home and maintain a sense of independence. This can be achieved with structural support for carers using assistive digital technology. Within the MONUMENT project, IMEC aimed to design a digital solution in dialogue with informal carers – mainly primary informal carers aka life partners – to accommodate their needs.

Mapping a solution to the needs of informal carers

Many assistive technologies exist today but IMEC's state of the art indicates that these technologies are underused due to unawareness or a mismatch with the carer's needs.

Existing technologies mainly target problems related to the following categories:

- Health & wellbeing
- Daily activities
- Safety
- Communication
- Social & leisure activities

Before conceptualizing possible solutions, IMEC asked informal carers to clarify how often a problem occurs and how it impacts their lives. Problems associated with health & well-being, communication, and social & leisure activities appeared most difficult (listed in sequence of importance). Therefore, IMEC worked out conceptual solutions tackling issues within these three categories and discussed the potential added value with informal carers.

The sleep monitoring solution – an example

To prevent night wandering, IMEC designed a sleep monitoring solution (depicted in the illustration below). Several sensors are installed in the bedroom to detect movement. When the patient wakes up during the night, wayfinding lights switch on to guide the patient to the bathroom, a clock lights up to orient the patient in time and an alarm sounds to notify the informal carer.



For this solution, carers rather receive notifications when the patient deviates from the usual route, which is more relevant, and the lights should be adjustable to personal preference.

By involving informal carers in the thought process, the solution could be tailored to their needs with a focus on strengthening resilience. The expert interviews revealed the variability of demands among informal carers. To address diverse needs, IMEC decided to develop a modular application that integrates multiple features in one centralized platform – the MONUMENT remote monitoring prototype.

Designing a remote monitoring prototype

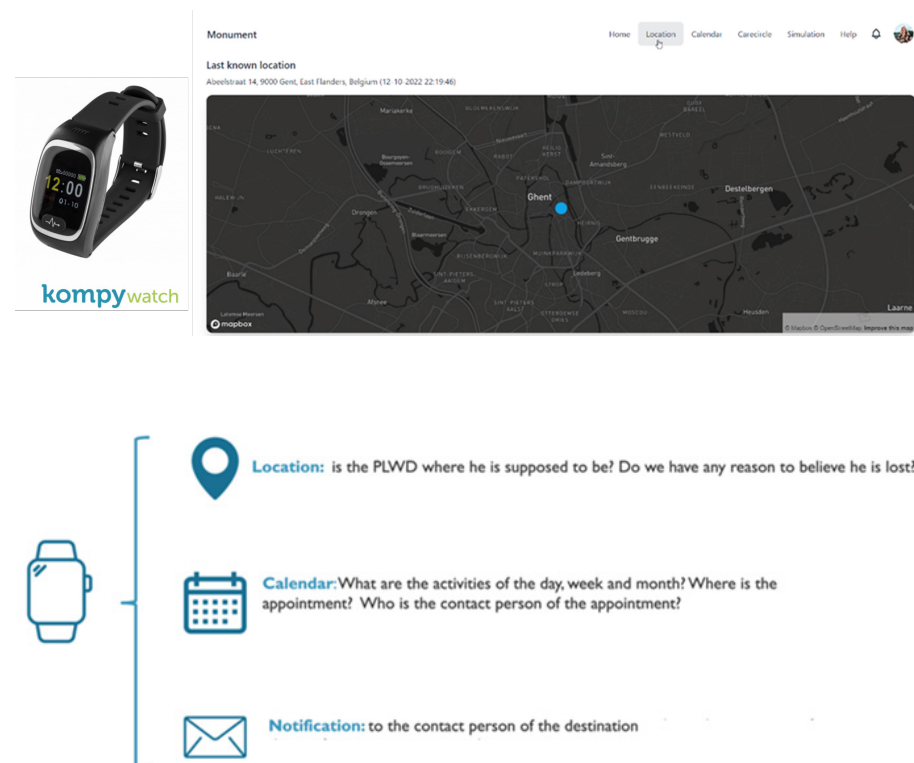
Research shows that exercise prevents cognitive decline and slows the progression of dementia (source: WHO). Therefore, staying active is important, especially for people with young-onset dementia. However, they tend to forget appointments, experience more difficulties in completing simple tasks, and often lose the sense of time and orientation. At this point, technology can help reduce the risk of getting lost while patients remain independent. IMEC decided to design a prototype focusing on this problem, closely involving informal carers to meet their specific needs. Through multiple iterations, IMEC defined the minimal required features for the MONUMENT remote monitoring prototype.



Location tracking using a smart watch

Primary informal carers showed interest in monitoring features like activity, location, and sleep. Tracking these parameters reassures them that the person with young onset dementia is self-reliant when they are home alone, which contributes to the mental health of the carer and the patient.

To safeguard the patient's privacy, IMEC aimed for location tracking using a smart watch. Many smart watches available today have a built-in GPS and SIM card, sufficient to track position and allow communication between the patient and carer.



Calendar feature

To help people with dementia remember events, IMEC included a calendar function in the prototype. The application can send a reminder for scheduled appointments and monitor whether the patient arrives at the destination on time.

Notification system

Linking a calendar function with a location tracker allows to detect unusual behavior: deviating from the normal route or arriving late. When this occurs, a notification is sent to the contact assigned to that calendar event.

The care circle

As more (informal) carers get involved in the later stages of the disease, it becomes increasingly important to connect and share information. The ability to add destination contacts linked to a scheduled event (such as the physiotherapist or Odense House personnel) is critical to timely response when intervention is needed.

Reduce care time and increase quality time with the MONUMENT remote monitoring prototype

SafetyTracer1 offers commercially available devices – Kompy devices – with similar functionalities identified during the prototype iterations. As a starting point for the prototype, IMEC integrated the SafetyTracer location service with an agenda and information-sharing system. The Kompy Watch of a person with dementia is linked to an application (mobile and web) that sends a notification when an unusual pattern occurs. The notification contains a temporary link to the patient's current position so the contact person can take action.

The MONUMENT remote monitoring prototype was demonstrated, tested, and repeatedly optimized throughout the project.

Informal carers are pivotal in the primary care of people with dementia, but support is insufficient and negatively impacts the carer's perseverance. To strengthen their resilience, IMEC developed a simple and user-friendly assistive application, starting from existing technology with minor modification custom to the carer's needs. The modular character permits the incorporation of additional sensory features as the disease progresses.

Overall, the MONUMENT remote monitoring prototype is unique: it saves time when intervention is required, (temporarily) share information with other carers from the care circle, and notifications are sent only when unusual behavior is detected – safeguarding privacy. The prototype gives people with dementia a sense of independence, improving both their well-being.

To allow end users to adapt the prototype to their preferences – using a tracking device of their choice for example – the codebase can be found on the GitHub open resource (<https://github.com/imec-int/monument-plwd>). Visit the MONUMENT remote monitoring web application: <https://monument-activity-web-app.azurewebsites.net/>

Accessible technology for informal carers

Dementia is one of the leading causes for disability among elderly, leaving them dependent on informal carers for a variety of tasks. Although assistive technologies exist, many informal carers are ignorant about these digital innovations. To raise awareness, the MONUMENT pilot partners identified technologies best accommodated to the informal carer's needs using the Innovatrix methodology developed by imec. Making assistive technology more accessible aims to better support informal carers and increase their resilience.



Care for dementia

Over 55 million people around the globe live with dementia. With about 10 million new cases every year, an estimated 78 million people will suffer from dementia by 2030 (Source: World Health Organization). Symptoms and disease progression vary from patient to patient and current anti-dementia therapies often have limited efficacy. Next to medical treatment, the lives of people with dementia can be improved with appropriate care and support to those who provide care.

A range of assistive technologies are available on the market, helping people with dementia to perform their daily tasks, move around or relax. But these technologies are mainly unknown or do not sustain long-term support due to the quickly evolving needs. To change this, the MONUMENT pilot partners investigated and selected existing assistive technologies deemed most useful by and for informal carers. Demonstration sessions towards carers informed them about these technologies and allowed them to test and evaluate the tools before implementation at home.


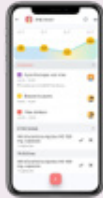








Selecting assistive technology

Improving professional support for the informal carer of people with dementia is key in the MONUMENT project. Therefore, carers were involved in the selection process of assistive technologies that best accommodate their needs. To facilitate this process, the pilot partners applied the Innovatrix methodology, developed by IMEC to fit novel innovations to real-world situations and maximize societal impact.

The Innovatrix approach offers an innovation management framework combined with iterative evaluation involving the end users (1). Including iteration allows to verify, learn, and optimize innovations throughout the process. To introduce the Innovatrix methodology to the pilot partners, IMEC organized a transnational learning session. Each pilot partner received a manual for the Innovatrix digital platform, instructions for conducting interviews with informal carers, and guidelines for drawing conclusions from the received input.

In consultation with the informal carers, each pilot partner selected two technologies. These technologies were then demonstrated to informal carers who provided feedback concerning the usefulness, willingness to adopt and potential improvements of the technology.

OVERVIEW OF THE SELECTED DEMONSTRATORS

	TECHNOLOGY	APPLICATION	PILOT PARTNER		TECHNOLOGY	APPLICATION	PILOT PARTNER
	NOBI	Smart light - Fall prevention and detection	CITY OF MECHELEN (BE)		MANTELZORGER APP	Information sharing platform for a group of caregivers	CITY OF MECHELEN (BE)
	ANYWHERE CARE FOOTPRINT	Location tracker with alarm button	NORFOLK COUNTRY COUNCIL (UK)		BEAMER TRAMPER TWS	All-terrain scooter	NORFOLK COUNCIL (UK)
	THE VIKTOR CUSHION BY FINGERTIPS	Soft digital tablet for leisure and social activities	AFEJI (FR)		THE HYPNOS MASK BY DREAMINZZZ	Self-hypnosis mask-therapy focusing on wellbeing	AFEJI (FR)
	MAGIC TABLE	Interactive projector for social activities	THE NATIONAL TRUST FOR PLACES OF HISTORIC INTEREST OR NATURAL BEAUTY (UK)		PIVOTELL PILL DISPENSER	Safe self-medication	THE NATIONAL TRUST FOR PLACES OF HISTORIC INTEREST OR NATURAL BEAUTY (UK)
	ORADIO	Digital device with pre-programmed music	WVO ZORG (NL)		GOOGLE NEST + VOICEZORG APP	Interactive care assistance - daily structure - remote control	WVO ZORG (NL)

EVALUATION OF THE DEMONSTRATED TECHNOLOGIES

To discuss the demonstration sessions, all pilot partners presented their findings at a partner meeting in Norwich (UK). This highlighted several important aspects that should be considered when developing novel assistive technology:

Familiarize with technology

When introducing a novel technology, the user context should be considered:

- Does the technology fit the needs?
- Does the technology require infrastructural adjustments?
- Does it fit daily life?
- Is the informal carer and/or person with dementia digitally literate?

Niche market

Technologies targeting people with dementia and their informal carers have limited scalability due to specific (and diverse) needs. As opposed to a one size fits all solution, a combination of multiple technologies seems a more viable approach to meet the demands.

Involve informal carer

The demonstrations indicated the importance of involving both the patient and the informal carer in testing technology, preferably in familiar context.

Easy-to-use technology

Technology that is user-friendly and easy to use lower the threshold to adoption. A proper introduction to the technology and the availability of a clear manual adds to that.

Cost

As dementia is a progressive disease, a certain technology might be relevant for a limited time, and thus the return on investment can be low and/or unpredictable. Cost poses a huge barrier and might prevent widespread use. Thus, to maximize inclusivity, providers must consider costs.

Ethical implications

Implementation of technology can have ethical consequences such as tracking the location of a person with dementia. To safeguard these ethical aspects, additional guidelines are required.

- How invasive is the technology in the personal life of the patient?
- Does the technology benefit the informal carer?
- How to ensure privacy?

Technology in a domestic setting

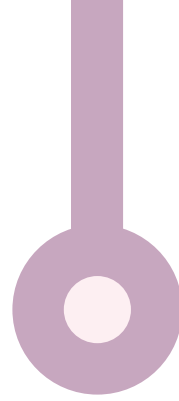
Assistive technologies exist with the aim to support people with dementia and their informal carers at home, but the demand seems low. User research performed during the MONUMENT project indicates that informal carers are often unaware of the technology and their application.



Presenting the technology as demonstrators in an Odense House for example, contributes to increased knowledge and allows the end user to test and evaluate the technology in a domestic setting before the purchase. Moreover, Odense Houses might play a vital role as a trusted place to sell, rent or lend out technologies.

In summary, the project pinpoints the importance of involving the end users in the selection and evaluation of existing assistive technologies before offering them to a wider audience. As such, developers focus on the most valuable solutions that contribute to a dementia-friendly society.

[Click here for the full report, or scan the QR code at the end of the publication.](#)



RESULTS

ONGOING REVIEW OF 5 PILOT SITES

The MONUMENT-project. A cross-border project that created, consolidated and formed 5 greatly different Odense houses.

The MONUMENT-project was active in 4 different countries: Belgium, the United Kingdom, the Netherlands and France. In each of these countries, one (or more) organization(s) were appointed to create an strengthen the Odense model in their region: AFEJI (France), Norfolk City Council (UK), The National Trust for Places of Historic Interest of Natural Beauty (UK), WVO Zorg with Odensehuis Walcheren (Netherlands) and Stad Mechelen (Belgium). Each organization functions within its own, unique context. The difference in context (cultural, organizational, regional, etc.) resulted in 5 Odense houses. Each one more different than the next.

Depending on the context the organizations situate themselves in, there are clear differences in their general strategies and aims for the project. This causes the projects to look differently in each pilot site: other strengths, other focusses, other difficulties, other take away messages, etc. The biggest differences can be found in the pilots' cultural context, as well as their approaches to partnership, communication, and technology.

Cultural context

The cultural context in France (i.e. taboo towards dementia, volunteering is a lesser widespread practice, etc.) caused a lot of issues for AFEJI throughout the project. Whereas, the care-system in Mechelen, for example, aims at an open communication surrounding dementia, which really helped Stad Mechelen in the development of their Odense house.

Partnership

Some organisations have strong connections with external partners. For example, WVO Zorg has a strong partnership with an observer partner for their activities, as well as with Odensehuis Walcheren for their expertise, network, etc.

Communication strategy

What seemed to be very helpful for some of the pilot sites (i.e. National Trust, Stad Mechelen, WVO Zorg) was the presence of a larger network/ infrastructure to fall back on. The National Trust, Stad Mechelen and Odensehuis Walcheren (partner of WVO Zorg) each have a strong network for communication: connections with radio shows and television for interviews, previous experiences, their own communication channels. These pilots have really oriented towards the outside, larger public via press releases, interviews, etc. Other partners did not have such a strong network to fall back on and had to start from scratch.

Technology

In some pilot sites, like Stad Mechelen, Odensehuis Walcheren or AFEJI, the Odense house serves as a demonstration house, where the visitors can discover technology in a casual way. As a surplus, informal carers can also borrow the technology for a short period of time, to make sure it provides a solution to their specific situation, before purchasing it themselves. For others, the technology is mostly supportive in their Odense house. It adds to the experience. The visitors can test it at the Odense house, but it is not meant to take home or use at home.

Challenges

Along the way, these approaches, as shaped by each pilot's specific context, bring about various challenges.

The way the partners approached the project, showcased their strengths and weaknesses during this project. Organizations like AFEJI struggled to reach the informal carers. They are an organization situated in France and they suffered the consequences of the local cultural context. In France, the topic of dementia is strictly taboo. Therefore, it is hard to raise awareness and attract people to a project like MONUMENT. Though they tried their best, the cultural context of France with regards to dementia (i.e. a taboo on dementia), as well as volunteering (i.e. in France it is not a widespread practice), made it very hard for them to draw the people living with dementia and informal carers to their Odense house.

Therefore, a communication strategy that addressed these difficulties was necessary. Additionally, like many other pilot partners, after reaching the informal carers it wasn't always easy to engage them to take part in the Odense house. Furthermore, for WVO Zorg the context they started in (i.e. close partners with Odensehuis Walcheren) posed some difficulties. Because they already had a strong network with a lot of knowledge on the matter, they found the project to be restrictive and at times even confusing. For them, the very structure of the MONUMENT project (deliverables, WP, etc.) made it hard to remain true to their notion of the Odense house principles. Furthermore, in Norfolk, they experienced that working with informal carers isn't always easy. This wasn't a struggle only Norfolk City Council dealt with, but almost every pilot partner struggled to draw the informal carer to the project. Oftentimes, the cause of this difficulty was the carer's fear of leaving the safety of the home. The partners tried to adjust the site to fit these fears by for example finding skilled volunteers to help in the Odense house. However, Stad Mechelen and the National Trust, among others, explained that the greatest difficulty they encountered was finding volunteers for their Odense house.

Thus, every context brought about its difficulties. Therefore, the MONUMENT project, as perfectly described by the National Trust, should be approached as: "a huge learning experience" (The National Trust).

Learnings and insights

Since we should see the MONUMENT project as a learning opportunity, there are certain insights that the pilot sites have acquired throughout this project:

1) Communication is key. That means:

- When working with people in a vulnerable situation one should always communicate consistently. There should be consistency in the message, consistency in the medium, consistency along the entire project.
- When wanting to reach the target group one should always communicate clearly. As mentioned above that means consistently, but also persistently. Reaching the target group takes time, but you should keep trying. If you try hard and long enough, people will come. Breaking shame/taboo takes time.

2) Work with the people's interests/lives.

When engaging the informal carers and people living with dementia or trying to draw them to the Odense house you have to be conscientious of their context/their situation.

3) Form a network with strong partners. They can add expertise where it might still be missing.

4) You cannot remove carers from their responsibilities! Instead, offer moral support and help them manage their time.

- Actively engaging the informal carer in the Odense house can be a long stretch. Start by welcoming them and offering support, so they can find some relief. Even for just a moment.

5) Supporting the carer in their care-task makes them feel less isolated.

Try to strengthen the informal carers in their care activities by creating a peer-network, offering training sessions, ...

6) You must do your best given the circumstance. Work with what you have got. If your situation poses difficulties, then work around them. Fit your Odense house to your situation as best as you can, but do not lose sight of your main goal, i.e. creating a supportive structure that meets the needs of the person living with dementia and the informal carer.

7) Replace shame with recognition: by allowing carers to form a network at the Odense house and allowing them to talk freely about their lives as an informal carer, we allow them to break the taboo and replace the shame on this topic with recognition.

With these insights in mind, the MONUMENT-project leaves you to create your own experiences with the Odense model.

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SOCIO-ECONOMIC FEASIBILITY STUDY

The main goal of the project MOre Nurturing and More Empowerment Nested in Technology project (MONUMENT) was to diminish the burden of informal carers of people living with dementia by providing professional and structural support for the informal carers, e.g., tailor-made technological solutions. It aimed to strengthen the resilience and perseverance of the informal carers so that people living with dementia could stay longer at home.

A social and financial feasibility study were used to evaluate the project's aims. The sociological feasibility study was carried out by HZ University of Applied Sciences, research group Healthy Region. The study was conducted based on quantitative and qualitative findings from focus groups and surveys.



The quantitative data was collected via pre- and post-surveys. The surveys measured changes in informal carers' experiences over time. Within the surveys, questions were asked to informal carers regarding increased self-efficacy, increased resilience, decreased isolation, decreased feelings of anxiety, decreased state of depression and reduced burden of care. The qualitative data was collected via focus group discussions among informal carers and

people living with dementia towards the end of the project. The questions in the focus group discussions focused on access to leisure activities, knowledge and transferable skills of informal carers, reciprocity between people living with dementia and their community, and better informed by peers.

Survey responses indicated slight increasement on all topics under investigation.

TOPIC	RESULT
Increased self-efficacy in support	A slight increase in the mean score (+1,98) between the pre and post-test indicates a higher self-efficacy.
Increased resilience	A slight decrease in the mean score (-0,65) between the pre and post-test indicates a slightly higher resilience.
Decreased isolation	A higher mean score (+1,19) in the post-test as compared to the pre-test indicates that informal carers have access to a greater network and resources.
Decreased feelings of anxiety	A higher mean score (+2,99) in the post-test than in the pre-test indicates informal carers feel less anxious.
Decreased states of depression	A slight decrease in the mean score (-0,24) between the pre and post-test indicates a slight decrease in depression.
Reduced burden of care	The mean score of the post-test showed a minor positive difference between the pre and post-test findings (+0,31).

Results from the Focus Groups are different per partner which is due to the phase they were in (starter of experienced with running an Odense House)

TOPIC	RESULT
More access to leisure activities	<ul style="list-style-type: none"> ○ No increase in access to leisure activities in Mechelen and Afeji ○ Increased access to leisure activities in National Trust
Increased knowledge and transferable skills informal carer	Increase in knowledge and transferable skills carers in Mechelen, Afeji en National Trust
Increased reciprocity between PLWD and their community	<ul style="list-style-type: none"> ○ No increase in reciprocity in Mechelen, Afeji en National Trust ○ Increased interest and visibility of dementia Trust
Better informed by peers	Informal carers felt better informed by peers in Mechelen, Afeji en National Trust

Probis carried out the financial feasibility study. To understand the financial aspects and the impact of professional (residential) care versus home care was investigated. The incremental cost of residential care versus living at home with supported informal care was mapped, both from the perspective of the care recipient and the government/society in Mechelen, Flanders, resulting in a fillable calculation tool (see: Full report on the Memo platform). Mapping the incremental cost of residential care relative to living at home with supported informal care required nuance. Based on the existing source material, the cost of residential care could be calculated accurately from both society's and the user's points of view.

However, the opportunity cost of living at home was characterized by great diversity depending on the person in question e.g., living situation. Therefore, a few standard scenarios and average amounts were used to identify the opportunity cost and calculate the incremental cost of residential care. For each situation, the cost of residential care was higher than the cost of living at home with supported informal care. The incremental cost of residential care was lowest for a single person living with dementia who relied on home care and used a day-care centre. The highest incremental cost was seen among people living with dementia who lived together and did not use either home care or a day-care centre.

In conclusion, based on the social feasibility study, the findings indicated that informal carers' knowledge regarding dementia-friendly places and possibilities for leisure activities had (slightly) increased. Overall, participants were very positive about the Odense House activities as they added value to their quality of life and that of the persons living with dementia they care for. The experiences of the use of technological possibilities differed per pilot partner. More knowledge and participation in Odense House activities increased the feeling of informal carers' resilience. Lastly, the findings indicated that informal carers felt more supported and gained different options to share their burden of care.

From the financial scope of this study, the Monument concept constituted a valid and considerable alternative to complement professional residential care. All MONUMENT scenarios mapped in this financial study resulted in a 'financial gain' compared to professional residential care.

Both studies provide useful insights for policymakers and initiators.

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IMPLEMENTATION OF THE HYCAL AND OPULSE INTERVENTIONS AT THE ODENSE HOUSE IN MAUBEUGE

As Alzheimer's disease (AD) progresses, people living with dementia present a wide range of symptoms which limit their ability to perform everyday activities, and cause a loss of freedom and autonomy, a decrease in self-esteem, and a loss of social status. People living with dementia receive daily emotional, psychological, physical, or financial support from their spouses. These increased responsibilities and tasks may cause spouse carers to neglect their own health and needs. These changes may have negative effects on the quality of life of both partners and cause significant distress. Moreover, the two partners describe a loss of their mutual understanding, fewer moments of sharing and communication difficulties, which are a source of decreased conjugal relationship quality and satisfaction.

The University of Lille has proposed to pilot an online support intervention for carers (OPULSE) and a hypnosis-based intervention for couples (HYCAL) at the Odense House in Maubeuge. These interventions are based on psychological approaches that have already shown their effectiveness on physical and psychological symptoms and on the quality of the conjugal relationship. Evaluations (questionnaires and interviews) were conducted before and after the interventions to assess satisfaction and preliminary effects.

While waiting for the opening of the Odense House in Maubeuge, the feasibility and handling of these two interventions have been tested with couples and carers from respite care platforms, memory centers, the France Alzheimer association, and the Specialised Alzheimer Home Teams of the Hauts-de-France region. Since its opening in September 2022, these two interventions have been part of the package of activities proposed at Odense House and presentation sessions of the interventions have been made to carers: 2 for HYCAL and 3 for OPULSE. These interventions were also presented at the conference on support for carers in October 2022, organised by AFEJI EHPAD Les Tilleuls, in Maubeuge.

HYCAL

A literature review was first carried out on the use of hypnosis with persons with dementia, thus enabling us to identify the precautions to be taken in the hypnosis protocol to take account of the attentional deficits of the persons with dementia (see publication no. 1). The HYCAL intervention was then developed by our team in collaboration with a psychologist trained in Ericksonian hypnosis. It is a hypnosis intervention in 8 sessions of about 30 minutes for couples facing AD. The 8 scripts have been developed around a theme related to the needs and difficulties identified in the literature (the safe place, the resource pot, living in the present moment, acceptance, see the positive, passing an obstacle, listening to their own needs, supporting themselves and their partner). Each session includes: the induction of the dissociative state, the working phase according to the theme of the session and the return to a state of vigilant consciousness.

A first feasibility phase made it possible to check the acceptability of the intervention by the couples, to identify the necessary readjustments and to highlight interesting preliminary results, in particular a decrease in distress in both partners and an improvement in the quality of the relationship (cf. publication n°2). The updated intervention was then proposed to 32 couples and 16 refused to participate either because the partner did not agree or because of lack of interest. In total, 16 couples started the HYCAL intervention, 2 couples stopped their participation before the end. For the 14 couples who completed the intervention, the majority were already familiar with show of hypnosis and therapeutic hypnosis. They accepted to benefit from this intervention because of its innovative, non-drug, couple-based, free and home-based nature. Their expectations from the hypnosis intervention were to be more accepting of the disease and better able to manage it in their daily lives, to be more relaxed, less stressed about the future and to improve the couple's relationship and communication. The questionnaires showed a significant decrease in distress in both partners, an increase in conjugal satisfaction in the spouse carers.

At the end of the HYCAL intervention, the couples were given a USB key (or other suitable medium) with the audios of the sessions and were trained by the hypnotherapist to continue to do the sessions independently and reinforce the effects. The OPULSE intervention was also proposed to carers.

The perspectives are to obtain funding to continue to propose this intervention free of charge to couples faced with AD and to deploy this intervention by training hypnotherapists working in structures that support carers and persons with dementia (e.g. respite care platforms, memory centers, associations).

Scientific publications related to HYCAL :

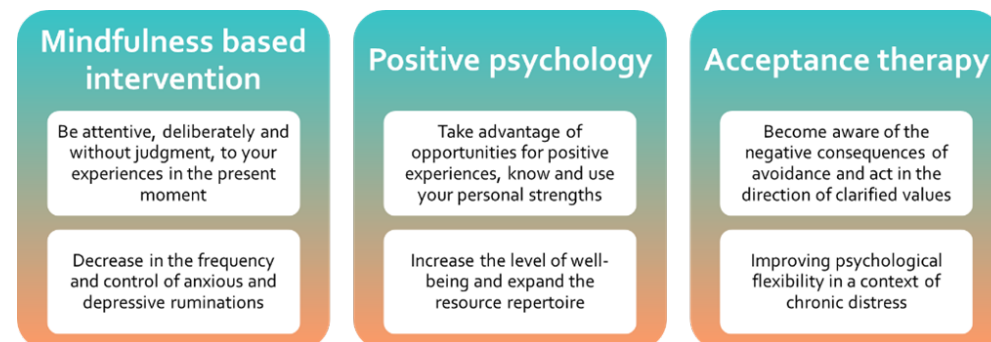
1. Wawrziczny E, Buquet A, Picard S (2021) Use of hypnosis in the field of dementia: A scoping review. Arch Gerontol Geriatr 96, 104453 : This is the first review of the literature on the use of hypnosis with people with dementia.
2. Wawrziczny E, Picard S, Buquet A, Traversac E, Puisieux F, Pasquier F, Huvent-Gruelle D, Doba K (2022) Hypnosis Intervention for Couples Confronted with Alzheimer's Disease: Promising Results of a First Exploratory Study. Alzheimers Dis, (Preprint), 1-16 : This study shows the development of the first hypnosis intervention for couples facing AD based on emerging needs and difficulties in the literature and preliminary results.

OPULSE

Currently being tested, OPULSE is a website available 24 hours a day on computer and smartphone (www.opulse.fr). Aimed at carers of people with dementia, OPULSE proposes four non-drug interventions, each lasting 8 weeks:

- mindfulness practice,
- positive psychology,
- acceptance and commitment approaches
- and information seeking.

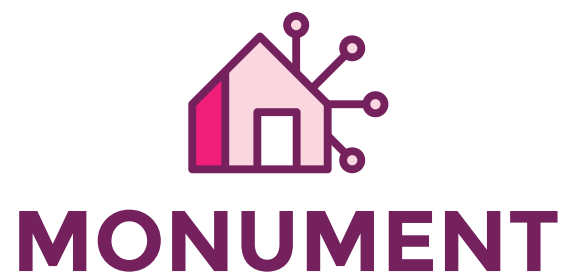
These online interventions consist of 48 activities and are designed to be self-administered, easy to apply and short in duration, less than 20 minutes daily.



A total of 142 carers agreed in principle and were randomly allocated to one of the four interventions, 120 carers started the activities and 91 completed them. Of these, 20 benefited from mindfulness practice, 24 from positive psychology, 18 from acceptance and commitment approaches and 29 from the information seeking. Participants completed an average of 72.93% of the activities.

Across all interventions, after 8 weeks of participation, carers used fewer control behaviours and reported less psychological distress. However, there was no improvement in terms of well-being.

The perspectives are to evaluate this experimentation to identify the activities in each of the 4 types of intervention that most benefited the carers. It will then be a matter of seeking funding to finance the building of a permanent website.



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