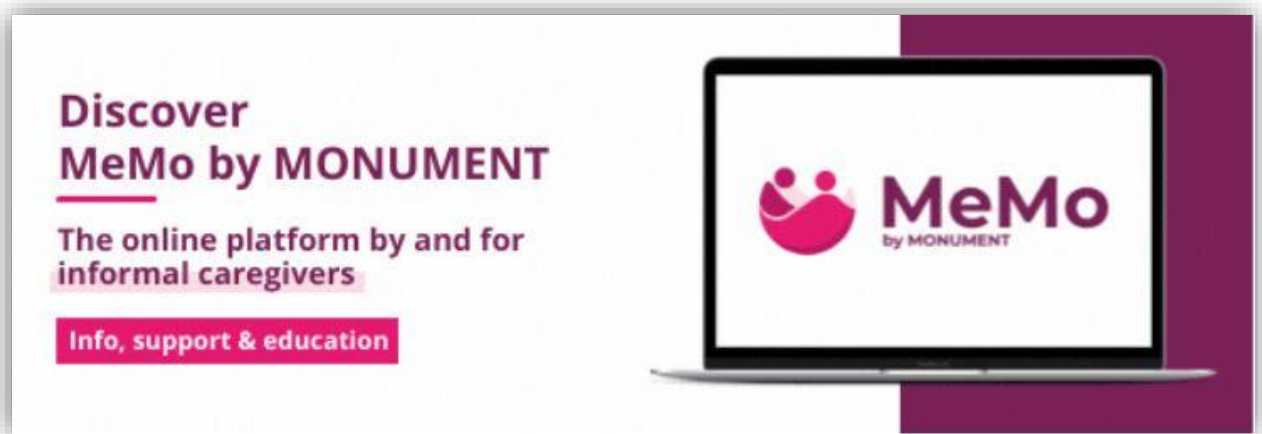




Developing a digital platform

MeMo by Monument



MOre NUrturing and More Empowerment Nested in Technology

With the support of the European Regional Development Fund



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Preface

This document describes how the MeMo by Monument platform was created during the Monument project together with key lessons learned. This document is written for organisations, policy makers and other stakeholders interested in developing a digital platform by and for informal carers of people living with dementia (PLWD).

The purpose of this document is to inform and guide future providers of a similar digital platform so that they can learn from the MeMo by Monument platform. The building blocks, content types and modes of content collection are described in an accessible way with attachments to useful documents and templates.

Goal of the platform

MeMo by Monument was developed within the Monument project, funded by the European Regional Development Fund within the Interreg 2 seas program. This project was carried out to support informal carers of people living with dementia (PLWD). The goal of the project was to increase the resilience of the informal carers of people living with dementia so that people living with dementia could stay at home longer. This was done by initiating Odense pilots where informal carers are supported by each other and professionals.

In addition to the support within the (physical) Odense houses, the Monument project extended this 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 with each other.
- Communicate on dementia-inclusive places and events.
- Share information on assistive technology for informal carers.
- Provide a place targeted at policy makers 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 caregivers more guidance within the current fractured landscape. By receiving tips and advice from other informal caregivers and bringing together information on dementia, the platform aims to reduce the burden and improve the resilience and perseverance of informal caregivers. 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 PLWD: 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 to the informal carers.
- Technology providers: their technology will be shared and evaluated via blogposts.
- 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 PLWD, policy makers, stakeholders within the Monument project, volunteers working with PLWD, hospitals, doctors, geriatrics, home care institutions, ...

General structure and building blocks of the platform

The Monument project is a collaboration of organisations within the Interreg 2 Seas region. Partner organisations from the Netherlands, France, the United Kingdom and Belgium are involved in the project. Because the link with the local community was of utmost importance for the MeMo by Monument platform, an online platform was created for each region.

Language and regions

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

- Flanders (Belgium): <https://www.memo-monument.be/>
- United Kingdom: <https://www.memo-monument.co.uk/>
- The Netherlands: <https://www.memo-monument.nl/>
- France: <https://www.memo-monument.nl/>

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 local tailored content (eg. Events and places) some content is identical over the different regions such as the Monument page targeted to policy makers to learn about the Odense concept.

Roles

Within the consortium imec was responsible for the development and follow-up of the platform. The scoping of the platform was done by all partners. The key element of the online platform is the publishing of relevant content. Therefore, each region had one regional coordinator responsible for the local content on the platform. This group of local coordinators was managed by the Centre of Expertise on Dementia from Flanders, to streamline the published content over the different regions.

A clear division of roles was also needed to supervise the quality of the published content. On the one hand we aimed to have as much user-fed content as possible, but on the other hand we wanted to oversee the quality, trustworthiness and types of content published on MeMo by Monument. The rights to publish content on the platform are therefore divided between project partners and super-users within the partners' organisation. This was done by implementing the Strapi content management system which was used in the back-end. The back-end was organised as follows:

- Every region (Flanders, the United Kingdom, The Netherlands & France) selected one partner with an Admin Strapi account. This Admin Strapi was allowed to add fixed/single type content on the regional platform, eg: About, Contact, Cookie Policy, Feedback, Home, Monument, Privacy, Terms & Agreements.
- Each project partners also had access to their own Strapi back-end to publish content on the platform. To manage the publication of the content, three roles were defined:
 - o **(Super) Administrators:** they can access and manage all features and settings. This role is only for persons within the project consortium. The administrators should guard the overview of the online platform. They can:
 - Invite new users in their Strapi environment
 - Edit content
 - Publish content

- **Editors:** Editors can manage and publish content, including content of other users (eg. create, delete and publish new content on the online platform). They also need to approve the content that was uploaded by the authors.
- **Authors:** They can add and manage content they created to the platform. Authors need approval from the editors before their content get published. This role is particularly interesting for volunteers, informal carers, partner organisations who are interested to add (bottom-up) content on their local MeMo by Monument website.

For each region, the Strapi content from the Partner's back-ends were merged into the local MeMo By Monument website. This resulted in four separate MeMO by Monument websites.

Homepage & advanced search

The homepage of the platform explains what the platform is about. Next to that you can find the latest published and recommended content. General website information is found at the bottom of each platform page (for example About, Feedback, Contact, Terms & Agreements, Privacy, Cookie Policy & Accessibility Statement).

Early in the development it became clear that end-users also needed to easily search for content on the MeMo by Monument platform. An advanced search option was developed. Within the advanced search you could search content via tagwords and content type.

Building block 1: Information, support & education

In the info, support and education section the aim is to bring relevant information on dementia, dementia-related organisations and dementia-related trainings together. Instead of creating new content, this building block centralises the already existing content on other locations. This building block makes the current information accessible in a manageable way for informal caregivers and PLWD. Informal carers can find links to articles, books, organisations, courses, videos, websites and podcasts.

Building block 2: Tips & advice

The tips and advice section is designed to share experiences between peers (PLWD & informal caregivers). To manage the content so it stays reliable and structured, volunteers and employees of the Odense houses wrote blog posts inspired by stories of informal carers or together with informal carers.

Building block 3: Open data on activities and dementia friendly services

In the events and places block informal carers of people living with dementia can find dementia friendly places and events on a map.

Building block 4: policy level

The Monument page was tailored to policy makers and people with an interest in the Monument project. On this page policy makers can find the benefits of the Monument project, as well as links to the local Odense houses.

Building block 5: technologies

In the technologies section blogposts were published regarding the technology demonstrated in WP2 within the Monument project. In these blogposts the (positive and negative) experiences of informal carers regarding the technologies were written down. By having these blogposts we inspired informal carers to experiment with using technology.

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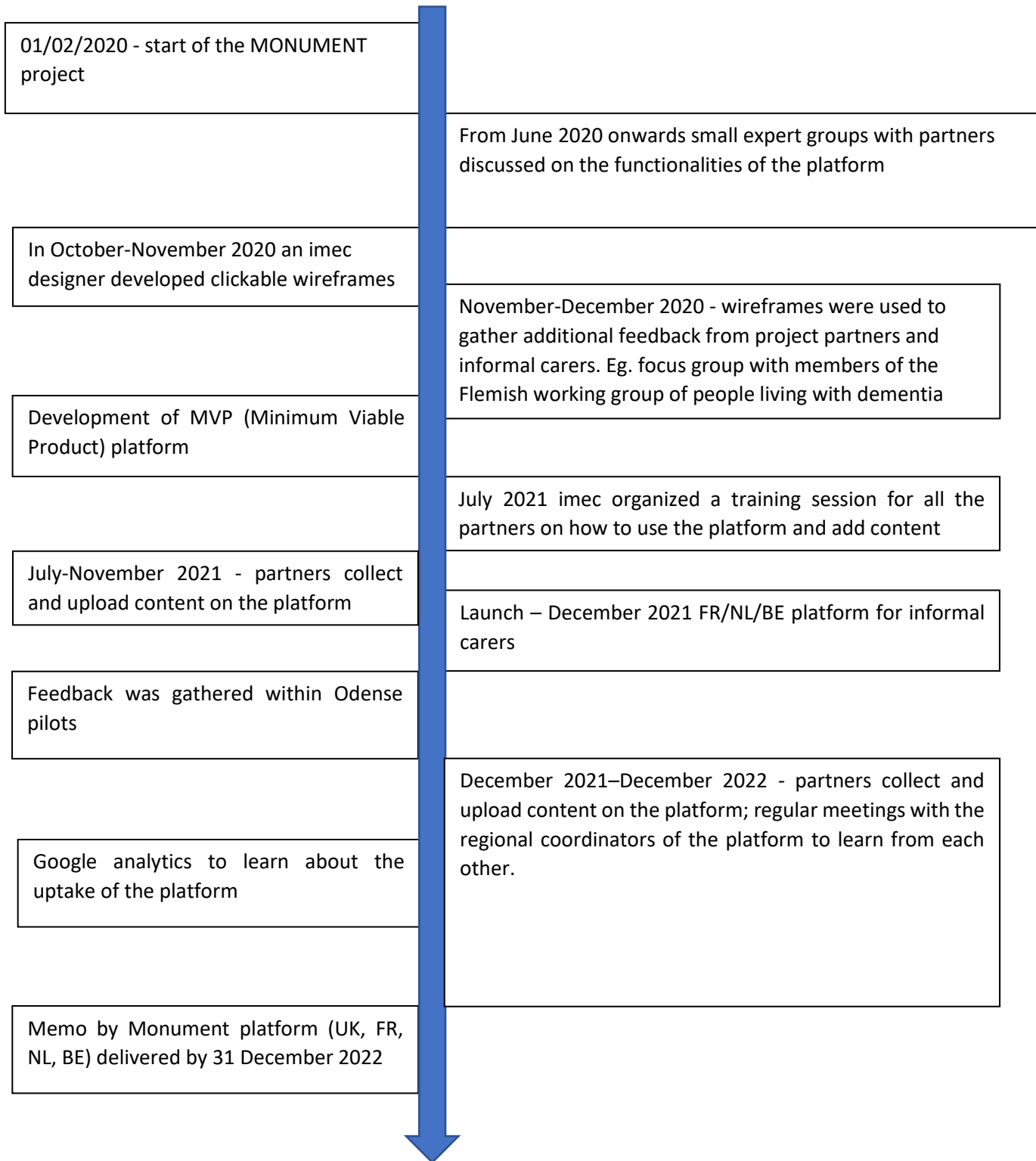


Other functionalities

In the Strapi back-end of the online platform, the authors could add tagwords. These tagwords were then used to search for related content across the whole website.

Process and lessons learned

Process



An iterative process with continuous testing of the platform

The platform was tested during the project in the pilots, namely 't MoNUment (Mechelen – BE), Afeji (Maubeuge – FR), Norfolk and Cambridgeshire (UK), Odense house Walcheren (NL) by project partners, employees and (former) informal carers. Thanks to this iterative process the user friendliness of the platform as well as the usefulness of the content for the end user could be improved. While imec updated the technical aspects of the platform, a working group of regional coordinators of the digital platform, led by the Centre of Expertise on Dementia Flanders, was created to discuss topics as quality insurance of content. This involved visitors of the Odense house creating content for the platform through blogposts, uploading technological solutions for people living with dementia, legal and privacy matters, the launch of the platform, et cetera. The template for asking permission to publish a hyperlink from third parties, template for blogposts and many other instruments and learnings described in this document are the result of the interregional collaboration in this working group.

Based on this experience, it is highly recommended to create a board or working group that meets at least twice a year to monitor the content creation and quality of the platform. Also it is also important to offer permanent feedback opportunities for end users such as the feedback button on the platform.

Roles and responsibilities:

The digital platform is developed by imec. Imec initiated meetings with project partners to first scope the platform and the underlying building blocks. In a next phase Imec made wireframes of the website. These wireframes were used to gather feedback from informal carers and the project partners regarding the online platform. By making the wireframes, the platform became more tangible to iterate upon. When the first scope was approved by all the project partners, Imec applied an existing technology (Strapi) and used this content management system to develop the MeMo by Monument platform.

The first version of the platform was tested by the project partners in Flanders. Via this small scale test some bugs were fixed and functionalities were adapted. In the final stage before launching the platform, a training session for all project partners was organised to onboard them on the platform and give support when uploading the content. Imec also made some instruction videos that could be used by the partners if they had questions regarding the back-end systems. To make sure everyone is onboarded, making enough time for technical support is crucial.

The content of the platform is user-fed and provided by all the project partners. The project consortium chose to keep the control of content under the pilots (Odense houses). In this way, the quality of the content could be monitored. A number of criteria were defined for this purpose (see section 'selection criteria'). It also proved necessary to form a transnational working group with all the pilots with one organisation taking the lead to plan periodic meetings and set the agenda. One purpose of these meetings is to exchange good practices and resources that are transnationally relevant to put on the regional platforms and to learn from each another.

The transnational working group includes the regional coordinators of the regional platforms. They take the regional lead and are responsible for content uploads. This does not mean that they are required upload all the content themselves but that they monitor that the platform is kept up-to-date with new

content and the content is mainly related to the local area. They encourage others from the Odense houses who have an authoring role and seek partners (third parties such as regional stakeholders) to provide and add content.

Content management is key, but not easy

Interaction on the platform

With this online platform, we want to focus on qualitative content. This will help lower the burden on the informal carers and make them more resilient. To guarantee qualitative content and to make content management of this platform feasible for all project partners, all content will be generated and loaded on the platform by the content authors/editors, selected by the Odense pilots. This approach allows Odense pilots to have certainty on the reliability of the content on the platform, and continuous monitoring of content will be limited to the content editors. It is very important that for the creation of this content there is close collaboration with the informal carers so that other informal carers can relate to the stories and experiences that are being shared on the platform.

The approach of allowing informal carer input on the platform via the content authors/editors was not tested during the project time because no volunteers were found to upload content by themselves. The lack of digital skills, a sense of uncertainty and also the COVID-19 pandemic made it even more challenging to engage informal caregivers in actively adding content. To facilitate content collection, we developed templates to stimulate Odense houses to write blogposts in close collaboration with informal carers (see attachment 1 – template blogpost).

If informal carers would wish for more interactivity on the platform, one can experiment with other interactions, for example: allowing comments on some posts; allowing informal carers to like or rate information and/or allowing informal carer to give feedback on events.

Why a blog and not a forum?

During the brainstorming phase, the project consortium aimed to create a place on the platform in which informal carers have enough space to tell their story and get in touch with other caregivers. Although a forum can be a good way to structure questions and answers, we see three main downsides of using a forum: (1) it is dependent on a big community, that is very active online; (2) the format of a forum is rather short, making it harder for informal carers to tell their story and share experiences; (3) currently many alternatives already exist for forums.

Therefore, we introduced the idea of a blogpost, which has three main advantages: (1) There is a direct link with the Odense houses, where the Odense house volunteers or employees can stimulate informal carers to share their story; (2) The goal is to share experiences, resulting in social support. Via a blogpost, we believe this can also be done anonymous (which is harder in a forum); (3) A blogpost gives more space for longer stories;

Content selection criteria

Regarding quality assurance and serving the objectives of the digital platform all content needs to meet following criteria:

- Provides information to informal carers or to people living with dementia
- Does not use stereotypes about dementia, older people or people with disabilities
- Empowers informal carers or people living with dementia
- Accessible (easy to understand) written text or video material
- Link with local Odense house or area around the Odense house
- For Blogposts: contributions must be constructive and positive - no harmful advice

Name of the platform

An important aspect not to forget is to have a suitable name for the platform. Because of the international character of the Monument project, it is important that the name of the online platform works for all three languages of the project. More significantly, an English-sounding name that is easy to pronounce in other project languages. Other criteria for the name were: concise, easy to write and pronounce, recognisable for informal carers, the name must have a meaning for the informal carers, not stigmatising, it should be a non-existing name with an available domain name.

Based on this criteria set-up by Eurasanté, the partners decided in a brainstorm to use the name MeMo by Monument. MeMo refers to memory, but also to a memo-note. Besides this, the platform is also built in a sense that the different information parts on the platform also look like small memos.

The name will go along with a slogan or baseline that would be translated to all languages of the project:

1. **MeMo by MONUMENT** - For caregivers of people living with dementia
2. **MeMo by MONUMENT** - Pour des aidants familiaux des personnes atteintes la maladie d'Alzheimer et maladies apparentées
3. **MeMo by MONUMENT** - Voor mantelzorgers van mensen met dementie

Consents for use

Within the MeMo by Monument platform, information is collected and shared from a wide range of different other sources. Therefore, it is also important to ask permission of organisations for publishing a hyperlink to their website and summarising some of the information they provide. In attachment 2 – consent for use, an example of an email is given which was used for receiving the permission of third parties to share their content. Note that this consent for use form is only an example and will need to be adapted to be used for other projects. Regions and countries can have different legal frameworks. All consents were collected and saved in an MS Teams folder.

Regarding the use of pictures: take into account the copyright of pictures. Use where possible copyright free pictures and double-check to make sure the pictures you use are copyright-free. If not, search and use other pictures. There are online databases with copyright-free pictures such as www.unsplash.com/. Also on the Flemish website www.onthoumens.be/in-beeld about nuanced public perception on dementia has a rich database of pictures, free to use when source is mentioned.

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When no pictures are available to illustrate the upload, free icons which support the different content types are developed in the MONUMENT project (see attachment 3 – Icons Memo by Monument).

Easy navigation on the platform

To make sure informal carers can easily search for specific topics in the platform tagwords were used.

When content was added on the platform via the content management system Strapi, authors could add tagwords to this specific content. The tagwords were implemented for three main reasons:

1. To structure the information on the platform based on topic and make the content searchable
2. To link the content from different building blocks to one another (e.g. You might also like)
3. To link content to specific local Odense pilots

When implementing tagwords it is very important to make general agreements with all authors so tagwords are used in a consequent manner.

WCAG, legal, privacy

User-friendly platform for informal caregivers (and PLWD)

The main target group for the online platform is the informal caregiver. However, we believe the online platform also brings added value to PLWD. Therefore, it is important to give extra attention to the user-friendliness of the website.

In order to increase the accessibility of the MeMo by Monument website, according to the needs of PLWD and their informal caregivers, we took into account some of the best practices and guidelines from other sources:

- WCAG: Web Content Accessibility Guidelines
- Website 'Digitaal Toegankelijk': [Een dementievriendelijke website ontwerpen — Digitaal Toegankelijk](#)
- <https://www.alzheimers.org.uk/blog/how-design-website-someone-affected-dementia>
- <https://rikwilliams.net/ux/accessibility/dementia-digital-design-guidelines/>

Legal and privacy

To comply with legal requirements and to ensure the privacy of users, buttons are linked to different statements: terms & agreements, privacy, cookie policy and accessibility statement. It is key to have such declarations on the website, according to the national context of the project partners, and cover local requirements.

Communication and PR

A communication strategy is needed to raise awareness of the platform and bring it to the end users. The project partners soft launched the platform for the first time in December 2021. The aim was to see how end users use the platform and to collect feedback. Based on this data, the platform could be fine-tuned.

The communication was via the MONUMENT project newsletter and project partner newsletters via social media such as Facebook and LinkedIn.

Google Analytics were used to refine the communication strategy and highlight which communication channels should be addressed more. For example, do an extra social media campaign.

The future of MeMo By Monument

The project consortium is proud of this realisation. The Memo By Monument platform is the result of a transnational partnership and intensive sharing of learnings. This document contains the key lessons learned and aims to inspire, inform and guide future providers of a similar digital platform.

The platform is consultable. Each region had a separate URL for the MeMo by Monument platform, but one can switch regions in the platform. In other words there are four paths to that same platform

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

Contact

If you are interested to get more information about the platform or the development process contact your regional contact point:

Belgium: Centre of Expertise on Dementie Flanders, e-mail info@dementie.be

The Netherlands, email WVO Zorg e.hanse@wvozorg.nl

France: AFEJI, email servicedeveloppement@afeji.org

United Kingdom: Norfolk County Council, email MONUMENT@norfolk.gov.uk

Attachments

Attachment 1: Template blogpost

This template is a tool for writing a blog post.

Blogpost English

Introduction

The MeMo by Monument platform was created for informal carers of people with dementia.

We are looking for informal carers who would like to share their experiences. Specifically, we are looking for general tips and advice for other carers and stories about the use of technology to make care easier.

This document can serve as an aid when writing down your experience. No help needed? Feel free to send your own version to *(insert the e-mail address of the contact person of the Odense house)*

There are a number of key questions to which we expect answers. What is in brackets can be seen as help to get you started on what exactly you can write down.

Afterwards, a writer will work with your words to create your story.

Thank you very much in advance for your contribution!

Your experience or advice

What is the subject of your experience? (Indicate 1 or more)

- Technology
- Daily care
- Administration
- Relaxation
- Other:

Can you tell us a bit more about what you did or what happened?

(Who was involved? When did it take place? How did you get there?)

How did you experience it?

(What feelings did it evoke in you and the person you are caring for? Were there any particular thoughts? How did you react?)

What message or tip would you like to pass on to other informal carers based on this experience?

Is there anything else you would like to say that was not mentioned in the previous questions?

Do you have a suitable image to add to your story? Please send this via email to: *email address of contact person of Odense house*

Can we add your name (without surname) to the blog post?

- Yes, please
- No (a fictitious name will be chosen)

Name:

Email address:

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Telephone number:

Postal code:

Would you like to write another blog post in the future, and may we contact you for this purpose?

- Yes, please
- No, please do not

Blogpost Dutch
als hulpmiddel bij het schrijven van een blogpost

Introductie

Sinds kort werd het MeMo By Monument platform gecreëerd voor mantelzorgers van mensen met dementie.

We zoeken mantelzorgers die hun ervaringen willen delen. Concreet zoeken we algemene [tips en advies](#) voor andere mantelzorgers en verhalen rond het gebruik van [technologie](#) die bijvoorbeeld de zorg verlichte.

Dit document kan als hulpmiddel dienen bij het neerschrijven van jouw ervaring. Geen hulp nodig? Stuur dan gerust je eigen versie door naar [*e-mailadres van de contactpersoon van het inloophuis*](#)

Er zijn een aantal hoofdvragen waarop we een antwoord verwachten. Wat tussen haakjes staat kan gezien worden als hulp om je op weg te helpen bij wat je precies kan neerschrijven.

Achteraf zal een schrijver aan de slag gaan met jouw woorden om een aaneenhangend verhaal te maken.

Alvast hartelijk bedankt voor jouw bijdrage!

Jouw ervaring of advies

Wat is het onderwerp van jouw ervaring? (Duid 1 of meerdere aan)

- Technologie
- Dagelijkse zorg
- Administratie (wilsverklaring, zorgvolmacht,...)
- Ontspanning
- Andere:

Kan je ons wat meer vertellen over wat je hebt gedaan of wat er is gebeurd?

(Wie was er betrokken? Wanneer vond het plaats? Hoe ben je daartoe gekomen?)

Hoe heb je dit beleefd?

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(Welke gevoelens riepen dit bij jou en degene waarvoor je zorgt op? Waren er bepaalde gedachten? Hoe reageerde je?)

Welke boodschap of tip wil je meegeven andere mantelzorgers op basis van deze ervaring?

Wil je nog iets kwijt dat in voorgaande vragen niet aan bod kwam?

Heb je een passend beeld om toe te voegen aan jouw verhaal? Stuur dit gerust via mail door naar: [e-mailadres van contactpersoon inloophuis](mailto:contactpersoon@inloophuis.nl)

Mag je naam (zonder familienaam) bij de blogpost?

- Ja
- Neen (er wordt een fictieve naam gekozen)

Naam:

Emailadres:

Telefoonnummer:

Postcode:

Wil je in de toekomst nog een blogpost schrijven en mogen we je hiervoor contacteren?

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- Ja
- Neen

Blogpost French

Outil pour rédiger un conseil

Introduction

La [plateforme MeMo by Monument](#) a été récemment développée pour les aidants et leurs proches atteints de maladies Alzheimer.

Nous cherchons des aidants qui souhaiteraient faire partager leurs expériences. Plus précisément, nous aimerons ajouter des conseils autour d'[astuces et conseils](#) d'aidants, des témoignages sur l'utilisation de [la technologie](#) et les outils pour faciliter le quotidien des aidants. Ce document peut vous servir de modèle pour écrire votre conseils. Vous n'en avez pas besoin? Alors, n'hésitez pas à nous envoyer votre propre histoire à l'adresse suivante : **(insérer l'adresse e-mail de la personne de contact de la maison d'Odense)**

Il y a plusieurs questions auxquelles nous aimerions avoir vos réponses.

Vous trouverez entre parenthèses en bas un modèle avec des questions pour vous orienter sur ce que vous souhaitez écrire.

Ensuite, nous vous appuierons dans la rédaction pour créer votre histoire.

Merci d'avance pour votre participation !

Votre expérience ou votre conseil

Quel est le sujet de votre histoire ? (Choisissez en un ou plusieurs)

- Technologie
- Soins de la vie quotidienne
- Administration
- Détente, relaxation
- Autre :

Pouvez-vous nous en dire plus sur ce que vous avez fait ou ce qui s'est passé ?

(Qui cela concerne ? Ou est-ce que ça s'est passé ? Comment y êtes-vous arrivé ?)

Comment l'avez-vous vécu ?

(Qu'est-ce que cela évoque pour vous et votre proche aidé ? Est-ce que vous avez eu des souvenirs particuliers ? Comment avez-vous réagi ?

Quel message ou conseil souhaiteriez-vous faire passer pour les autres aidants par rapport à votre expérience ?

Est-ce qu'il y a autre chose que vous souhaiteriez ajouter et qui n'a pas été mentionné dans les questions précédentes ?

Avez-vous une photo à ajouter pour illustrer votre histoire ? Si oui, vous pouvez nous l'envoyer par mail à l'adresse suivante : (insérer l'adresse e-mail de la personne de contact de la maison d'Odense)

Pouvons-nous mentionner votre nom (sans le nom de famille) dans le post du blog ?

- Oui bien sûr
- Non (un nom fictif sera choisi)

Prénom :

Adresse mail :

Numéro de téléphone :

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Code postal :

Souhaitez-vous écrire à nouveau un article dans le futur et être recontacté à ce sujet ?

- Oui, bien sûr
- Non merci

Attachment 2: Consent for use

This is an example of an email, which was used for receiving the permission of third parties to share their content. Note that this consent for use form **is only an example** and will need to be adapted to be used for other projects. Regions and countries can have different legal frameworks.

Dear,

As part of the Interreg 2 Seas MONUMENT project, a digital platform for and by informal carers of people with dementia is being developed. You will soon be able to consult the platform (December) here: www.memo-monument.be. This digital platform meets the need of informal carers to find reliable and up-to-date information about living with dementia in one place, to read tips and advice from other informal carers and to share their own information, to find dementia-friendly activities and locations for leisure time and finally to read about the experiences of other informal carers with technology and tools. We are convinced that a strong network, more knowledge, insight and skills can make the reduce the care burden of family carers.







For the reasons mentioned above, we would like to add a link to your webpage (url of webpage) on the website www.memo-monument.be (to be changed with the url of your country). This link will be permanently visible on the website until we decide to remove it. We hereby ask for your consent that we may establish this hyperlink, including mentioning the title and description of your website as you publish it on your website.




You can give your consent by replying to this e-mail clearly stating that you agree on behalf of your organisation.

** The organisations responsible for managing the website are: City of Mechelen, Expertise Centre Dementia Flanders vzw, IMEC and iDROPS. (Change the responsible organisations into those of your region)*

Thank you in advance for your response.

Attachment 3: Icons Memo By Monument

| | |
|--------------|--|
| Activity |  |
| Article |  |
| Book |  |
| Course |  |
| Location |  |
| Organisation |  |

| | |
|---------|--|
| Podcast |  |
| Video |  |
| Website |  |