

DESIGNING FOR DEMENTIA

PERSONA TOOLKIT



designing for people with dementia
mindful self-empowerment & social engagement

Design can empower people
living with dementia in
everyday social situations.

The aim of this toolkit is to help designers to gain a better understanding of, and to empathize with people living with dementia ^{1,2}.

The toolkit supports you with developing personas as an aid for designing for people living with dementia. It introduces you to the trajectory of dementia and people's correlating needs. It then offers you a set of tools to develop a persona to help you understand them and see them as a holistic person.

What is dementia?

Dementia is an umbrella term for brain diseases that cause progressive decrease of intellectual capacity, associated with loss of nerve cells and shrinkage of the brain tissue. ^{3,4,5,6}



Changes in the brain affected by dementia

Symptoms

Symptoms can be cognitive, psychological, social and behavioural. These symptoms vary between patients, between different types of dementia and change or increase during disease progression. ⁵

Cognitive impairment

Decreased attention, memory loss, difficulties with time and space orientation, difficulties with finding words, performing tasks or identifying objects



Social withdrawal

Fear of social contact, difficulties to communicate, changes in behaviour



Psychological symptoms

Anxiety, depression, apathy, agitation



What are the stages?

Dementia comprises 5 stages:^{7,8,9}

- No visible cognitive decline
- Very mild cognitive decline
- Mild cognitive decline
- Moderate cognitive decline
- Moderate to severe cognitive decline.

No cognitive decline	Very mild cognitive decline	Mild cognitive decline	Moderate cognitive decline	Moderate severe cognitive decline
In this stage dementia is not noticeable yet.	This stage is marked by subtle changes, such as normal forgetfulness. Relatives do not notice the changes.	This stage is associated with increased forgetfulness, difficulties with concentration, remembering new things, planning and organisation.	Difficulties concentrating, remembering recent activities and new locations mark this stage. Help is now often needed with complicated tasks (e.g. handling finances)	In this stage a person has to deal with long term memory problems, forgetting addresses and needs help with daily tasks (e.g. preparing meals, dressing).

Needs of people living with dementia

Research revealed 9 distinct needs of people living with dementia

	No cognitive decline	Very mild cognitive decline	Mild cognitive decline	Moderate cognitive decline	Moderate severe cognitive decline
Internal World, thoughts, feelings, emotions, beliefs, dreams, etc.	1. Coping with the situation: Diagnosis: What now?				
	2. Self value : Insecurity and lack of confidence				
			3. Experiences , identity and the fear of losing that		
Relationships, multiple complex interfaces with people and things	4. Needing to be needed, helping others				
	5. Keeping relationships going				
			6. Understanding and negotiating between carer and patient		
Activities, actions and attributes	7. Deciding what to do and planning new things				
			8. Letting go responsibilities - which are losses		
	9. Activities that have a purpose (and meaning versus keeping you occupied)				

There is no such thing as a stereotypical person living with dementia

The needs of people living with dementia are not only affected by the stage of dementia, but also by their **personality**, **biography**, **health** and **social environment**.^{5,10}

Biography

A person's life story reveals his/her values, interests and habits. To empathise with a person living with dementia, it helps to know their daily activities, hobbies etc.

Health

People living with dementia are often living with additional health issues that cause new problems and care needs. These can be all sorts of conditions, such as diabetes, stroke, urinary infection, hip fracture or visual impairment .

Personality

The way a person lives with dementia is strongly influenced by personality traits. A person's extroversion, adaptability, feelings... can affect the importance of certain needs. But keep in mind that certain types of dementia may affect the personality of a patient as well!

Social Environment

The social network of a person with dementia and the response of this network has a major impact on how a person experiences the disease and his/her relating needs.

3 step process... to creating a persona

This page gives you an overview of the different steps of the process of creating a persona, before steps 1, 2 and 3 are explained in more detail in the following pages.

Three considerations before you start



Work based evidence

Base your persona on interviews with people living with dementia, or even better: co-create them together. See also Toolbox B: co-designing with people living with dementia.



What is the purpose?

Define your area of interest:

what will you use the personas for?

A clear description of its purpose will help to select which (and how many) personas you will need to create and what details they need to incorporate. It will also help others review your personas before you start using them in your design project.



How many?

Try to create a few personas that are representatives of a large portion of your target group and one or two 'outsiders'



Step 1: Give me a profile

Give each persona a name along with age, place of living, home situation and profession



Step 2: Bring me to Life

Tell the story of the person through the **Biography**, **Health**, **Personality**, **Social Environment** cards.



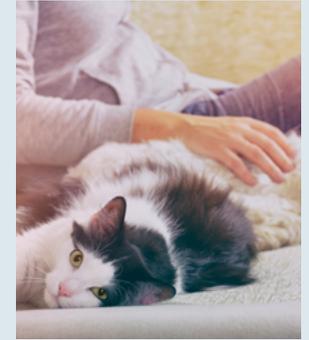
Step 3: Let me say something about my needs and wants

Select needs from the quotes of people with dementia.



Step 1: Give me a profile

Giving your persona a name and profile allows you to characterise them before adding information relating to their experiences and lived-in worlds to create an imaginable person.



Persona development template – Section 1 example.

Step 1: Give me a profile



Name:

Age:

Place of Living:

Home Situation:

Profession:

Diagnosis:

Place of living

Does the person live in the countryside, in a rural area or suburb? Or in a city or in close proximity to a town centre?

Home situation

Is the person living alone? With a partner?
With family close by? In a care-home?

Profession

What is (or was) their profession or other duties?
Does the person still work? Have lots of responsibility?
Rely on their profession for financial security?

Diagnosis

Has the person been recently diagnosed?
Have any other underlying health problem?

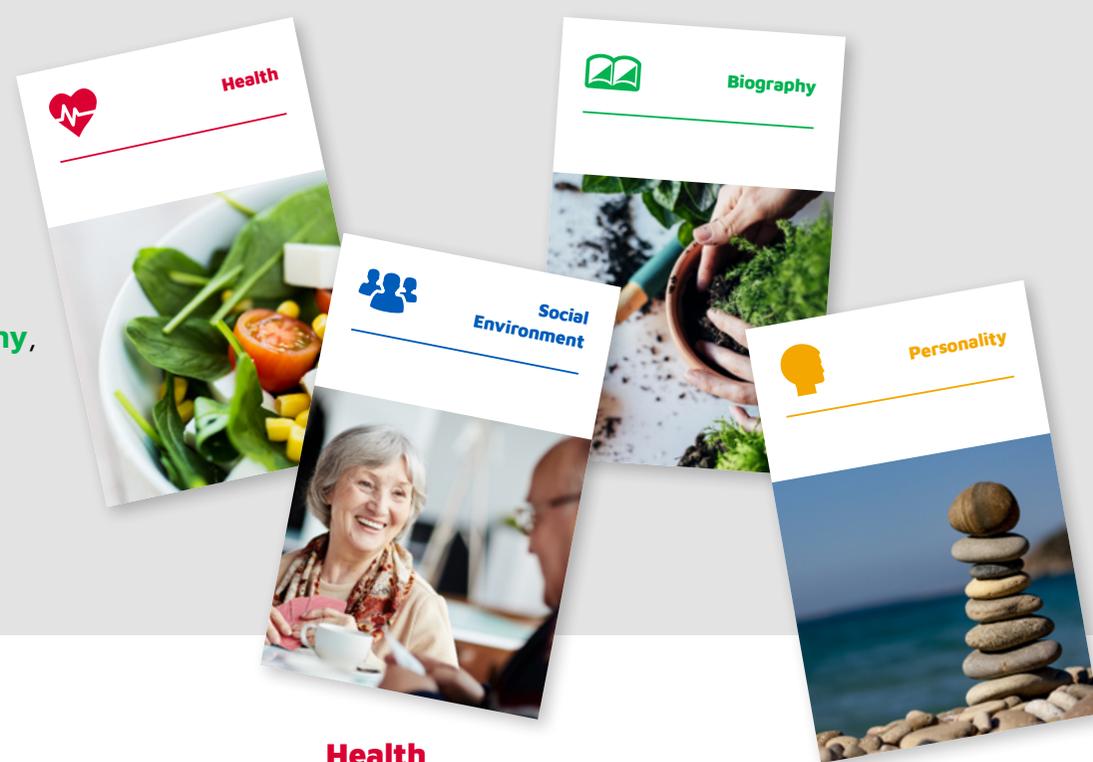


Step 2: Bring me to life

Tell the story of the person through selecting image cards for each of the categories identified as **Biography**, **Health**, **Personality** and **Social Environment**.

There are lots of cards for each need, examples can be found to the right.

Tip: Use the pictures of the image sets or your own to make this persona come to life.



Biography

Describe the life story of this persona.

You may add images from the '**Biography cards**' set or search for images that better match this persona's biography.



Personality

Imagine the character traits of this persona and how that effects living with dementia.

You may add images from the '**Personality cards**' set or search for images that better match this perona's personality.



Health

In what stage of dementia is this persona? Describe also other health issues that this persona might encounter.

You may add images from the '**Health cards**' set or search for images that better match this persona's health.



Social Environment

Picture the relatives of this persona: who are they and how do they interact with the persona?

You may add images from the '**Social cards**' set or search for images that better match this social environment biography.



Step 3: Let me say something about my needs and wants

Use the 'quote-cards' to find a statement that characterizes this persona based on one of the following 9 needs. There are lots of cards for each need, examples can be found to the right.

The 9 card categories that represent each need are broken down as 1. Coping, 2. Self Value, 3. Experiences, 4. Helping, 5. Relationships, 6. Negotiating, 7. Planning, 8. Responsibilities, 9. Activities.



"Everything I am doing is to delay the progress of the problems I have and, as long as I am aware of this and looking for solutions... I can go on with my life."

1. Coping with the situation: Diagnosis: What now?

The moment of diagnosis is difficult to deal with and may lead to depression. Information given during or after the diagnosis is often very general. People feel that it does not apply to them personally.

3. Experiences, identity and the fear of losing that

People with dementia notice that they forget things and that their experiences are changing, this may cause fear of losing identity. The feeling that other people think that they can't be taken seriously may also contribute to a feeling of losing identity.

"I managed people for so many years and now I get nervous when my colleagues do not obey me"

2. Self value: Insecurity and lack of confidence

Noticeable changes can lead to feelings of insecurity about the future and about personal abilities. Starting to lose things or disorientation can lead to lack of confidence to do things autonomously. Eventually, self-value can be affected.

"I am not spontaneous anymore! I am not an interesting person anymore..."

"It is important to me to help others... dependent on my health"

4. Needing to be needed, helping others

There is a continuous need to feel needed and useful by helping others. People with dementia have many skills and can be useful to others in many ways. This is not always recognized.

5. Keeping relationships going

It can be hard for people with dementia to keep relationships going, friends and family may not always understand them that well and participating in group activities may become more difficult. It is, however, very important to continue having social interactions..

"We have one person responsible for putting everyone in contact in our group and helping to set up our meetings."

"I leave most of the decisions to my husband because I no longer have memory for this."

8. Letting go responsibilities - which are losses

As abilities change, people with dementia may have to give over certain responsibilities. Work may be lost, no more driving and dealing with finances can be difficult. Letting go can feel unpleasant, but for some responsibilities, handing over may actually not feel like a loss.

"I am living with my sister and I respect her. Normally, we discuss things and we usually agree in the end."

6. Understanding and negotiating between carer and patient

Carers sometimes worry when a person with dementia wants to do certain activities. A person with dementia needs autonomy and may feel very capable. This requires mutual understanding and sometimes negotiation.

9. Activities that have a purpose (and meaning versus keeping you occupied)

Encouraging someone with dementia to do something creative, some gentle exercise, or take part in an activity helps them to realise their potential, which improves their self-esteem and reduces loneliness.

"Gardening relaxes me because I love my house and the ground I prepared."

7. Deciding what to do and planning new things

Insecurity about what the future will bring may pose a barrier to planning new things. Changes in abilities may result in changes in decision making and in what people can do. People with dementia can find joy in doing things they were not used to doing. Decision making may become more shared between carer and PwD.

"I don't have that many other expectations for the future any more."

...Now you are ready to create your persona!



Follow the individual steps to construct your own persona or personas. Often it is helpful to have several personas with different character traits and situations to be better able to explore different situations and scenarios.

Persona development

By following the 3 step process and filling in the persona template (below), you should be able to develop a persona. The template is split up in to the 3 relevant steps.

Example completed persona development template

PERSONA DEVELOPMENT TEMPLATE

Fill in the 3 step process below to bring your persona to life. Use the relevant cards to assist in completing step 2 and step 3. Personas are a thinking tool for designers to develop empathy in the design process with the persons with and for whom they design.^{12, 13}

Step 1: Give me a profile



Name:

Age:

Place of Living:

Home Situation:

Profession:

Diagnosis:



Give each persona a profile along – age, place of living, home situation and profession

Step 2: Bring me to life



Biography

Health

Personality

Social Environment



Tell the story of the person through the **Biography**, **Health**, **Personality**, **Social Environment** cards.

Step 3: Let me say something about my needs and wants



Characterisation– Summarise your individual needs



Select needs from the quotes of people with dementia.

PERSONA DEVELOPMENT TEMPLATE

Fill in the 3 step process below to bring your persona to life. Use the relevant cards to assist in completing step 2 and step 3. Personas are a thinking tool for designers to develop empathy in the design process with the persons with and for whom they design.^{12, 13}

Step 1: Give me a profile

Name: *Ursula Schmidt*

Age: *82*

Place of Living: *Liepzig, Germany*

Home Situation: *widow, lives alone in an apartment with other tenants.*

Profession: *Shop Assistant*

Diagnosis: *Alzheimer's disease*

Step 2: Bring me to life

Biography *Is proud to have raised two children with good values. She has a special room with everything in it: boxes with Easter and Christmas decorations, suitcase/travel/work bags. Is independent and tidy – washes up, vacuums and cleans. She likes to watch tv and relies on visits from her son and daughter.*

Health *Accepts the diagnosis and tries to be happy. Hopes things will get better with taking medication. Struggles to sleep. She is teetotal.*

Personality *Joyfulness is important – not taking things too seriously so it is not a crisis when things don't go her way. Sometimes she feels emotionally weak/vulnerable (especially when facing uncomfortable neighbours). Having a safe home gives her calmness and a positive outlook.*

Social Environment *She knows other tenants in the apartment but some she likes and some she would like to see less often. She doesn't go out alone anymore, but if she did, she would take her key wallet (with all her keys), sun glasses and woolly hat (because of the cold). She has a cosy living room chair with a TV. One of the tenants has a small quiet dog which she likes.*

Step 3: Let me say something about my needs and wants

Characterisation– Summarise your individual needs

Responsibility / Activities – She's glad not to have to take any responsibility at the moment (it would not be possible!). Would like to do less cleaning (doesn't feel that is necessary daily). When the children come to visit, she often goes out with them in.

Tools and information

Over the next few pages you can find materials to help you fill in the personal including a persona template, Biography, Health, Personality and Social Environment Image cards and Quote cards.

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MinD & project partners. Available from:

<https://designingfordementia.eu/resources/publications>

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Universities



Dementia care & policy



Design



Disclaimer

This tool was created as a part of the MinD project. To learn more visit the webpage <https://designingfordementia.eu/>.

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PERSONA DEVELOPMENT TEMPLATE

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Step 1: Give me a profile



Name:

Age:

Place of Living:

Home Situation:

Profession:

Diagnosis:

Step 2: Bring me to life



Biography

Health

Personality

Social Environment

Step 3: Let me say something about my needs and wants



Characterisation – Summarise your individual needs



Biography image cards



Biography



Biography



Biography



Biography



Biography



Biography



Biography



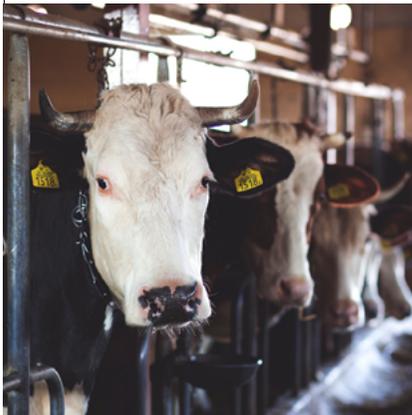
Biography



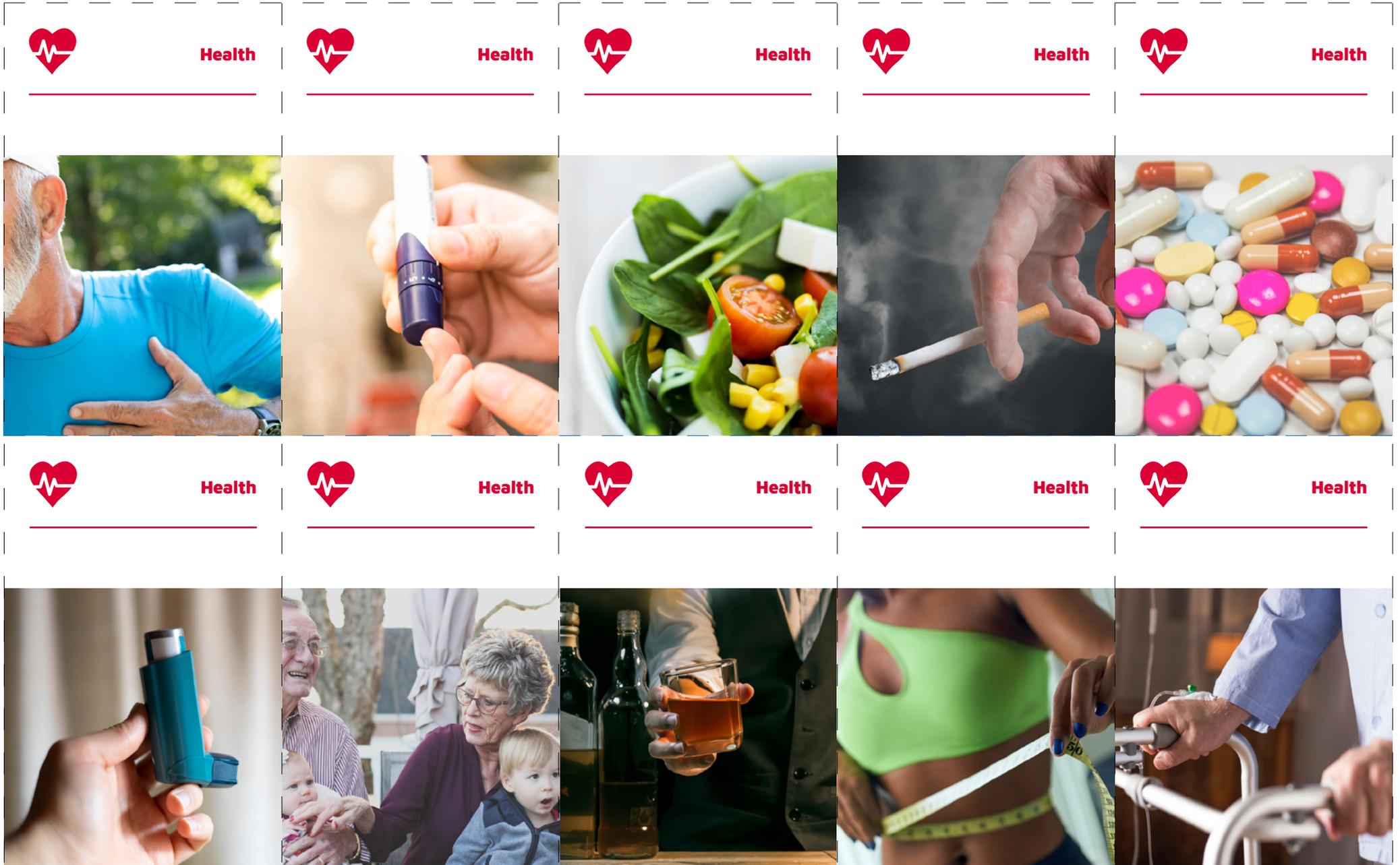
Biography



Biography



Health image cards



Personality image cards



Personality



Personality



Personality



Personality



Personality



Personality



Personality



Personality



Personality



Personality





Social Environment image cards



Social Environment



Social Environment



Social Environment



Social Environment



Social Environment



Social Environment



Social Environment



Social Environment



Social Environment



Social Environment





Quote cards



1. Coping

"Everything I am doing is to delay the progress of the problems I have and, as long as I am aware of this and looking for solutions... I can go on with my life."

1. Coping

"I like to have a peaceful life, tranquility, and now... my life is a tremendous uncertainty."

1. Coping

"Dementia is the scourge of getting older. You are in a phase of your life that allows you to live happy and nice. We do not have to work and we receive a pension... then this happens."

1. Coping

"I am glad not to have to take any responsibility. At the moment it would not be possible! The dementia does not allow it at the moment. But I hope it will get better again."

1. Coping

"I work my memory to live the best way possible, to continue to have an independent life and maintain my autonomy."

1. Coping

"I am not sure yet what I want to do... The dementia diagnosis is still fresh."

1. Coping

"Back then when he had cancer, we just saw what happened... but we did not let this drive us crazy. And now, we also will not let dementia drive us crazy."

2. Self Value

"I have never let myself be dominated."

2. Self Value

"I am too slow to follow discussions in the family."

2. Self Value

"Feeling no pride in my skills; I wouldn't know what to feel pride for."

2. Self Value

"I am not spontaneous anymore! I am not an interesting person anymore..."

2. Self Value

"But hey, you see me so useless? I accept it, because I'm done. It makes me feel clumsy... I think I cannot do it anymore."

2. Self Value

"Making a grocery shopping list together makes me feel secure."

2. Self Value

"I feel emotionally strong when others respect me."



Quote cards



3. Experiences

"I feel nervous the moment I have to do something... and I distract myself and do not remember... and then I get even more nervous and it worries me."

3. Experiences

"I managed people for so many years and now I get nervous when my colleagues do not obey me."

3. Experiences

"I don't like to be picked up (by car)."

3. Experiences

"Friends are fundamental. We are like brothers, if there is something you don't like you just say it."

3. Experiences

"If there is noise around where we are, I feel more vulnerable because there are moments that I do not hear what is said."

3. Experiences

"I wear sunglasses both in summer and in winter. I am very upset by the sun; I almost have to close my eyes if I do not use them."

3. Experiences

"I tend to be very attentive when there is one thing that interests me."

4. Helping

"It is important to me to help others... dependent on my health."

4. Helping

"I loved to take care of the grandchildren when the school called."

4. Helping

"I love to cook but nobody comes to eat with me."

4. Helping

"I love needlework but nobody needs what I produce."

4. Helping

"It motivates me to help others that are more physically or mentally impaired than I am."

4. Helping

"It gives me great satisfaction to be able to help, even if it is indicating to a person a direction that seeks."

4. Helping

"I like to do favours and I am grateful."



Quote cards



5. Relationships

"We have one person responsible for putting everyone in contact in our group and helping to set up our meetings."

5. Relationships

"This group is very accessible, everything is so simple with them that I like to be part of the group."

5. Relationships

"My life is simple but I enjoy it because I can participate, we go to the cinema together."

5. Relationships

"I have friends who make me feel valued and loved."

5. Relationships

"Enjoy with friends: talking, walking, dancing and going to the cinema."

5. Relationships

"I feel happy when I go to see my grandchildren."

5. Relationships

"Not recognizing people concretely (...) Imagine! That would be an isolation."

6. Negotiating

"I am living with my sister and I respect her. Normally, we discuss things and we usually agree in the end."

6. Negotiating

"When I talk to my daughter and she does not reason and wants to impose her judgement."

6. Negotiating

"I want my children to be happy seeing that I am still able to take care of myself."

6. Negotiating

"At home we have freedom to say what we think and decide together."

6. Negotiating

"My daughter helps me with the financial management but she doesn't ask me when I spend my money."

6. Negotiating

"I try to be nice, I try to think before I speak but sometimes the problem is the circumstances."

6. Negotiating

"I like to decide because I'm bossy."



Quote cards



7. Planning

"I don't have that many other expectations for the future anymore."

7. Planning

"I learned how to airbrush! There is even special paper to be used."

7. Planning

"I am in charge of my own life. I feel at ease with myself, I go out with my friends. I can go out by myself where I want. I have complete autonomy in certain aspects of my life."

7. Planning

"I would like to go walking in nature."

7. Planning

"I'll never drive my car again, but I would still like to cycle."

7. Planning

"I go out and go on vacation with my sister and I travel with my friends."

7. Planning

"I go to breakfast once a week with friends because we talk about our things."

8. Responsibilities

"I leave most of the decisions to my husband because I no longer have memory for this."

8. Responsibilities

"I do not care that he chooses what to do or where to go, as long as I can say if I want to do that or not."

8. Responsibilities

"I like to consult with my partner, especially about important things."

8. Responsibilities

"I am glad not to have to take any responsibility. At the moment it would not be possible! The dementia does not allow it at the moment."

8. Responsibilities

"I fulfill my religious and friendship obligations."

8. Responsibilities

"Dusting, vacuuming, ironing, cooking - I like these tasks and I do them well and I am entertained and happy to do them."

8. Responsibilities

"I would like to pass on the cleaning. I don't feel that it is necessary daily."



Quote cards



9. Activities

"Gardening relaxes me because I love my house and the ground I prepared."

9. Activities

"Forcing activities that don't make me happy is the last thing that I want to do."

9. Activities

"I buy a magazine of crosswords that amuses me and encourages me."

9. Activities

"Nowadays, I can't go out any more alone."

9. Activities

"Drawing and colouring relaxes me a lot."

9. Activities

"I enjoy preparing food."

9. Activities

"Sewing entertains me a lot and I like it."