

you+care



Facts → Insights → Needs

Interviews



Fields of Potential → *How might we...?*

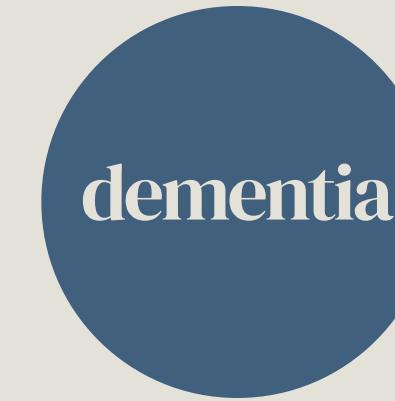
# Facts

- **Who** are family caregivers?
- Who do they care for?
- **Dementia**
- At home care for the elderly
- Scope of care
- Main reasons to seek support
- Self-management
- Relationship patterns

# Disclaimer



Facts about **caring relatives** for different people (general).



Facts about relatives caring for people with **dementia** and dementia patients receiving care.

# Who are family caregivers?

Family caregivers are:  
children, teenagers, adults & retired individuals

49'000 caregivers < 16 years old  
543'000 caregivers > 16 years old

Majority: **54 - 64 years old**  
Ø middle age: 54 years

83% swiss

61% receive from **at least 1 other person** assistance  
with care and nursing

**2/3 employed**  
Part-time, those who care with high intensity

Health: tends to be slightly worse than average  
population

# Who do they care for?

Adults:

- mostly parents & parents in law

Elderly:

- partners

< 16 Jahre:

- 40% grandparent
- 32% parent
- 14% sibling
- 14% outside family

Dementia patients:

- **require long-term care situation**
- 24/7 monitoring when advanced stage
- dementia diagnosis takes a long time
- financially challenging

The dying:

- significant phase of life for relatives
- requires energy and triggers fears
- requires professional support (information about the process, space to say goodbye, administrative, etc.)

# Dementia

approx. 146'500 people with dementia (CH, 2021)  
30'400 people become ill every year

73% women

6% develop disease before the age of 65

- 5% < 65 years old
- 9% > 65 years old
- 40% > 90 years old

Ø Life span: 8 - 10 years

Progression of disease can currently not be stopped /  
disease can not be cured,  
Slowing down of the course possible.

**50% receive no diagnosis**  
25% receive specific medication

2/3 APE residents are affected by dementia  
**60% live at home**

**1-3 relatives are affected per patient**  
Relatives and close associates provide 47% of care and support services

# Dementia

Progression of dementia in **3 stages**:

- mild – threatened self
- medium – confused self
- severe – sunken self

Dementia stage has influence on:

- caregiving tasks
- caregiving scope

The impact on the caregiving phase shows what the central activity and challenge of family caregivers is:

- 1st phase: arrive – enable
- 2nd phase: caregiving – apply
- 3rd phase: hand over – decide

# Dementia

1st phase

**arrive – enable**

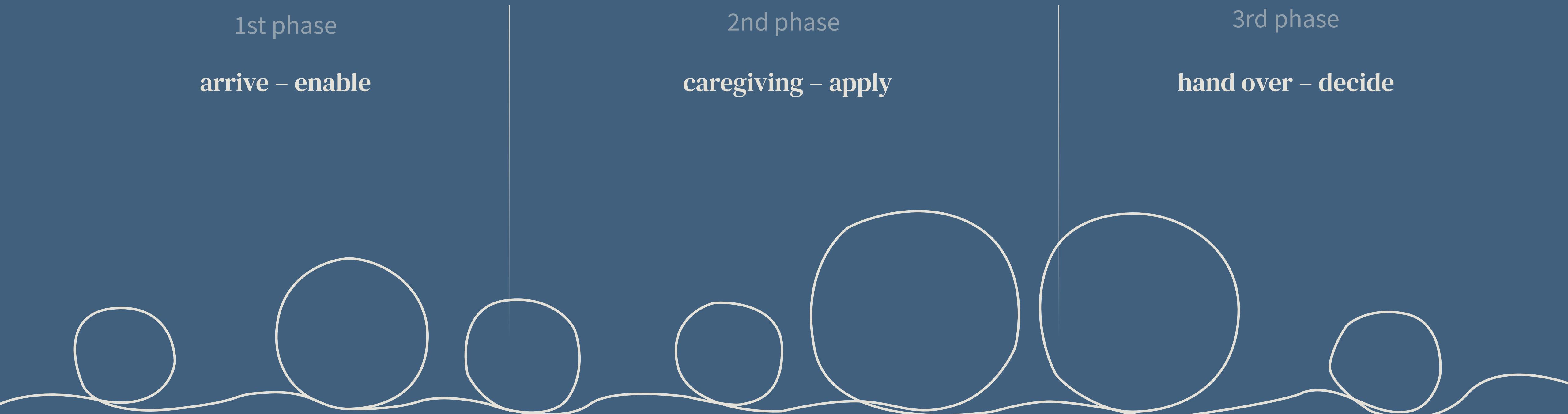
2nd phase

**caregiving – apply**

3rd phase

**hand over – decide**

# Dementia



The caregiving process is not linear!

# At home care for the elderly

50-52% > 65 year olds are cared for **at home** (CH)

Mostly: caregiving task unplanned and takes longer than expected

Ø age of person in need of care: 83 years

**Stress levels increase continuously as the disease progresses**

50% are in **strong need of care**

50% of care is provided by partners

Care from women: Ø 11.4 hours

Care from men: Ø 4.5 hours

# Scope of care

## Tasks:

- 38% financial & administrative
- 23% coordinating & planning
- 23% everyday life & household
- 21% emotional & social

< 16 years: mostly takes over emotional and social care

## Scope:

- 63% < 10h per week
- 19% 10-20h per week
- 6% 21-30h per week
- 4% 31-40h per week
- 8% around the clock

# Main reasons to seek support

5 main concerns for support:

- Emergency assistance
- Conversations with health professionals
- Transportation services for assisted person
- Advice on financial & insurance matters
- Help to recover themselves

These 5 main concerns show that access to professionals & information is difficult.

# Self-management

«Self-management involves what family caregivers do to manage the changes and challenges in their lives that come with their involvement as a family caregiver and to actively find solutions.»

3 building blocks of self-management:

- **Knowledge** about one's own situation forms the basis for dealing with the situation
- Active confrontation with one's **motivation** as a driving force of care
- **Competences** to be able to manage everyday life

# Relationship patterns

4 types of quality of relationship in caregiving

- **appreciative relationship**  
«I received a lot, now I would like to give something back»
- **dutiful relationship**  
«Helping her is something I've always done. So what choice do I have now?»
- **detached relationship**  
«I've hardly gotten any recognition. Why should I sacrifice myself?»
- **mutually needy relationship**  
«I help you and I need your help.»

Quality of relationship has influence on:

- Motive to care
- Perception of stress
- Risks

# Insights

- Perception of stress
- Individual care
- Support services



# Perception of stress

Entry into care:  
**slowly or suddenly**

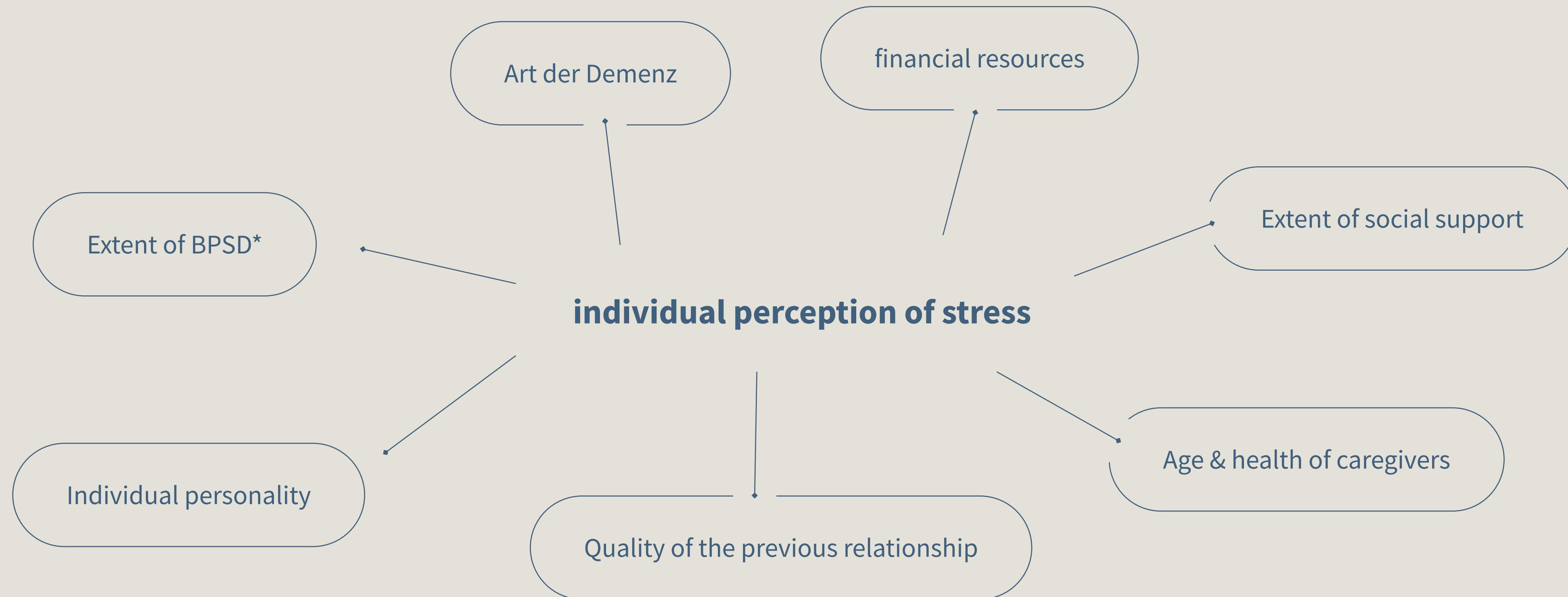
Care & nursing takes time and energy  
→ **Relatives are pushed to their limits**

Organization of everyday life is a great burden

**Subjectively very different** and  
depends on **personal perception**

Care also brings positive experiences  
including skills / competence training, etc.

# Perception of stress



# Perception of stress

**«The stress is individual. And so is the relief!»**  
**«Die Belastung ist individuell. Und die Entlastung ebenso!»**

– **Bettina Ugolini,**  
Head of the Counseling Center *Leben im  
Alter (LiA)* at the University of Zurich.

# Individual care

Relationship between resources and burdens is influential for the perception of stress

Perception of stress depends on life situation:

- Scope of care (duration & intensity)
- situation of relatives (health, job, financial etc.)
- social status

Focus on own resources  
Touchpoints must be individually adapted

# Support services

Services to relieve the burden are already available in numerous formats:

- Offers, support, knowledge about dealing with dementia...etc.

Biggest problem:

→ **Offers and demand do not match!**

Refer to many existing things and bring structure

Addressing individual needs

# Needs

# Needs distributed over phases of the care process

- 1: arrive – enable
  - 2: caregiving – apply
  - 3: hand over – decide



# 1. arrive – enable

→ Find right service

→ Receive correct diagnosis

→ Accepting the role of the caregiver

→ Clarification & patient progressions

→ Good planning

→ What next...?

## 2. caregiving – apply

- Find right service
- Spend more time with cared-for person
- Recognition, appreciation and gratitude
- What next...?

# 3. hand over – decide

→ Find right service

→ Certainty in decision-making

→ Consolation

# Interviews

- Overview
- Things that stood out
- From experience, it has been advised...
- My individual care in one word

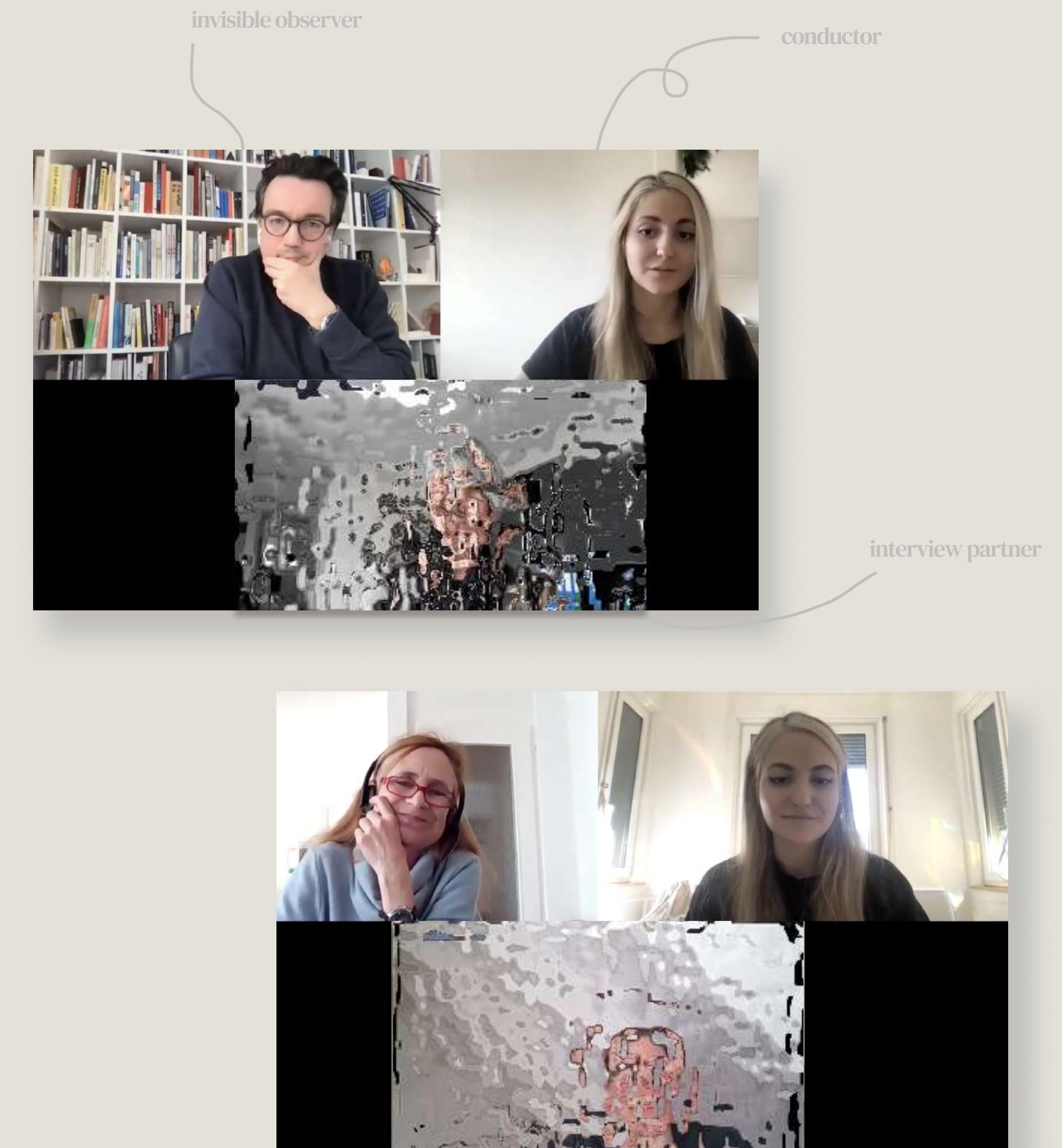
# Overview

During the time frame 21.01.22 - 11.02.22

Interview with **4** family caregivers of people with dementia

The interview was guided by the following topics:

- **Entry into caregiving**  
Getting the Diagnosis  
Environment and support during diagnosis
- **Perception of care**  
Type of relationship with family caregiver and its changes  
Identification with role of caregiver
- **Daily life**  
Education & Offers  
Caregiving tasks  
Support during caregiving
- **Stress management**  
Stressful moments  
Self-care and time-out  
Handover to the nursing home
- **Looking back and wishes**



Interviews

# Things that stood out

Care of two persons at the same time

→ **Care ran differently because relationship to both persons different**

Behavioral changes of the person with dementia lead to conflicts (in private and at work → bullying)  
& symptoms get misjudged

→ **Wrong diagnosis “depression”**

Different approach to dementia and care

→ **Conflicts with other caregivers**

Not identifying with the role of a "caregiver"

# Things that stood out

appreciative relationships

- **have more time for emotional care, which is highly valued**
- **generally more patient and sensitive treatment of the person being cared for.**

optimize own care system

- **recognize patterns in behavior and thus save money**
- **respond to individual need**

early acceptance of dementia

- **understanding way of dealing with problematic behavior in everyday life**

# From experience, it has been advised...

«**Network** immediately! [...] You don't have to be strong, you can say **now I can't take it any longer!**»

«I don't have to think I'm weak when I see he has to go to the **institution**.... I can **already have a look** at what it out there.»

«**Finding your own solutions that fit** and not just accepting everything without questioning what you are advised to do. Being courageous so that you don't just have the option of home or not - this **decision is more complex...**»

«Distance. Always keep distancing, distancing, distancing. **Keep setting boundaries and reflecting.** [...] Because it's absorbing and incisive.»

«"By all means, **don't make a taboo** out of it!"»

«Drawing **attention** to the topic.»

«Being able to **stay together** as long as possible and **accepting additional help** from outside.»

# My individual care in one word

«**educational**»  
«**lehrreich**»

«**Empathy**»  
«**Einfühlksamkeit**»

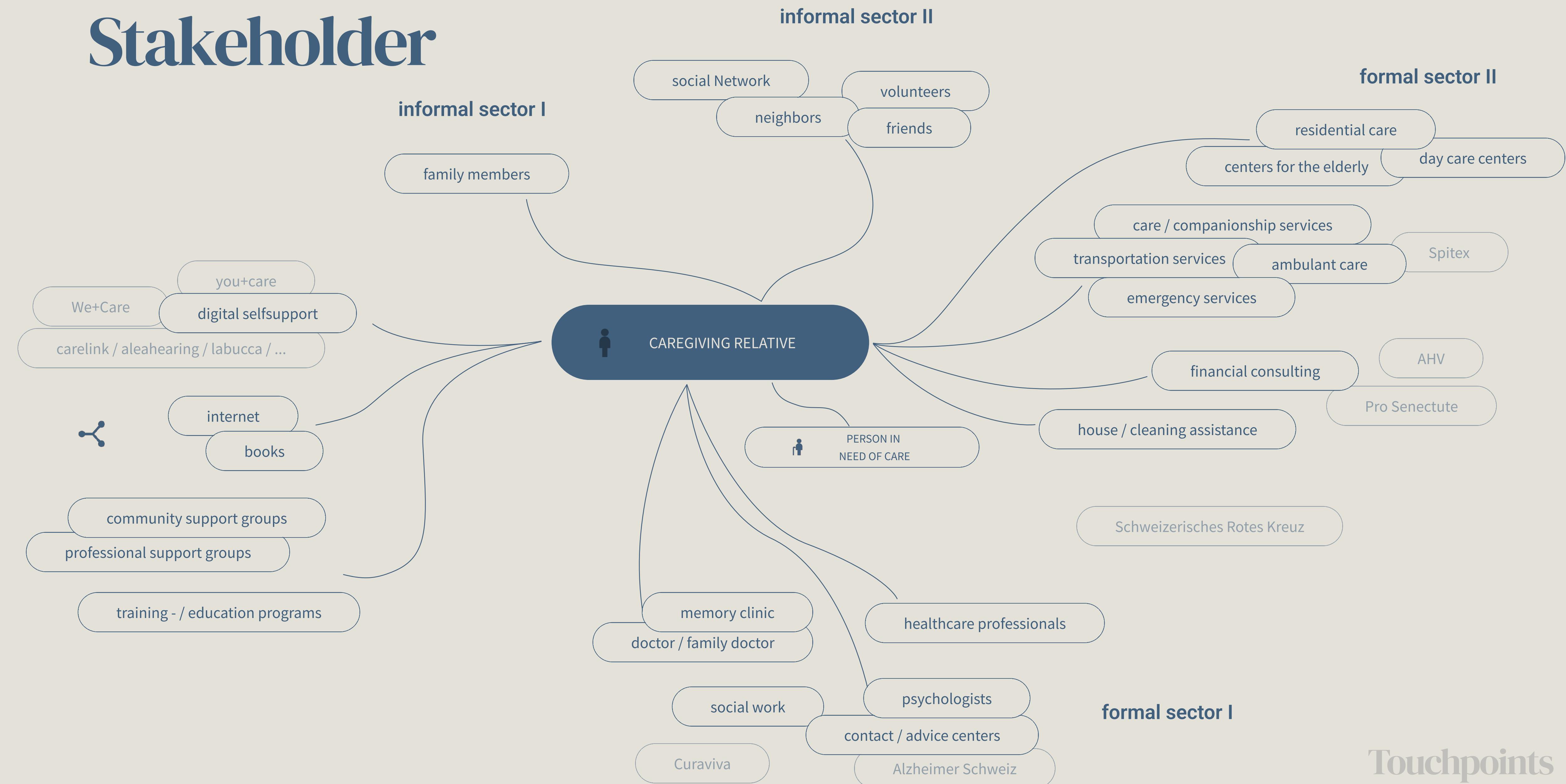
«**Obligation**»  
«**Pflicht**»

«**Unpredictability**»  
«**Unberechenbarkeit**»

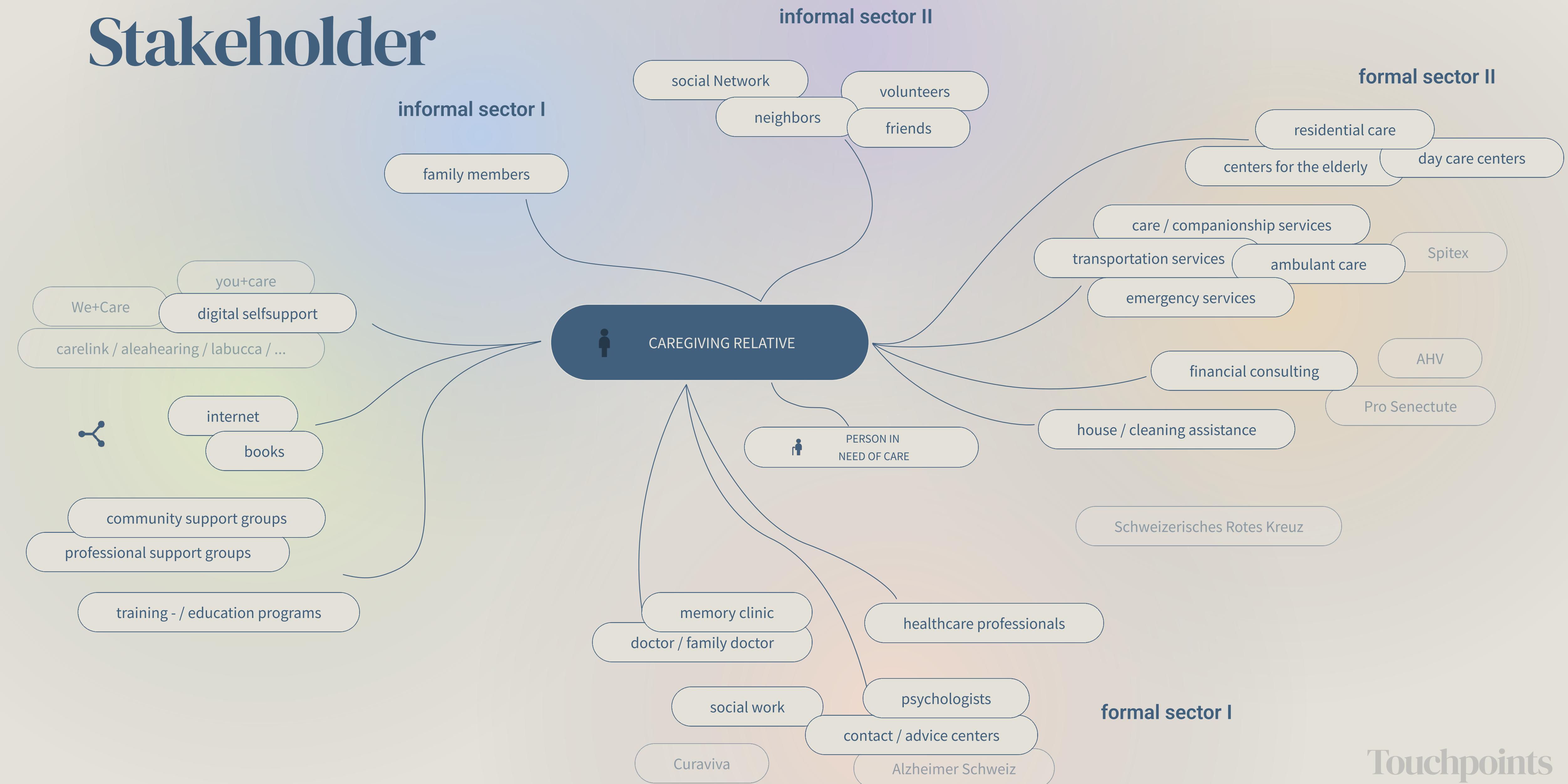
# Touchpoints

- Stakeholder
- Support system

# Stakeholder

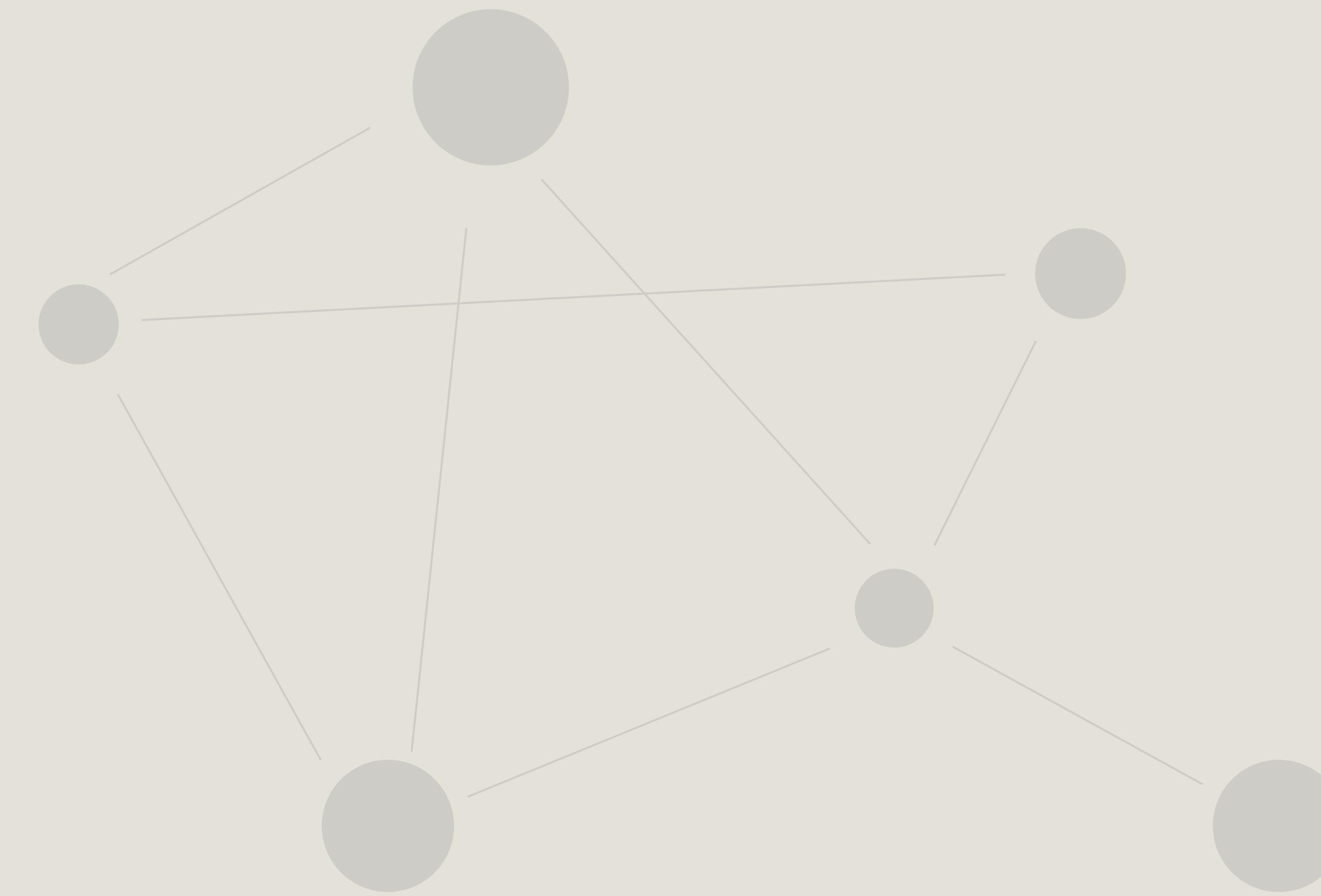


# Stakeholder



# Support system

Care must not only be understood as a service provided by one person (family caregiver)  
→ **but as a system!**



Touchpoints

# Fields of potential

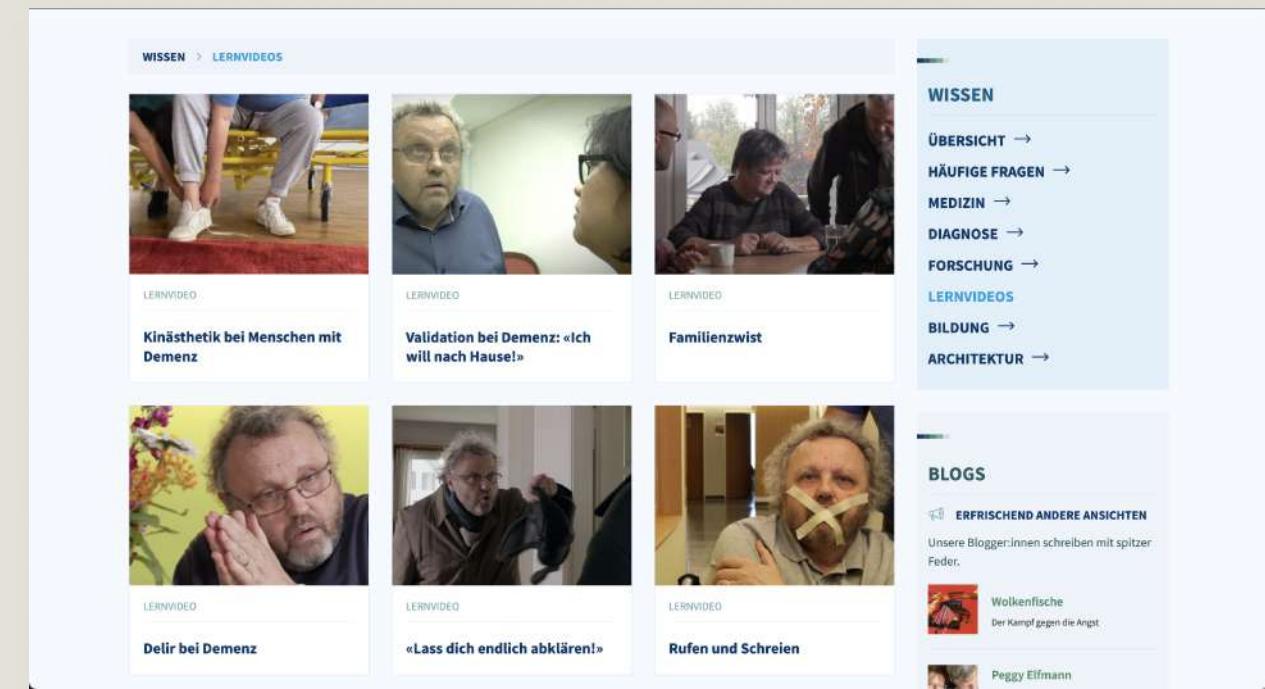
- digital platforms (CH, AT, DE)
- AOK in detail



# digital platforms (CH)

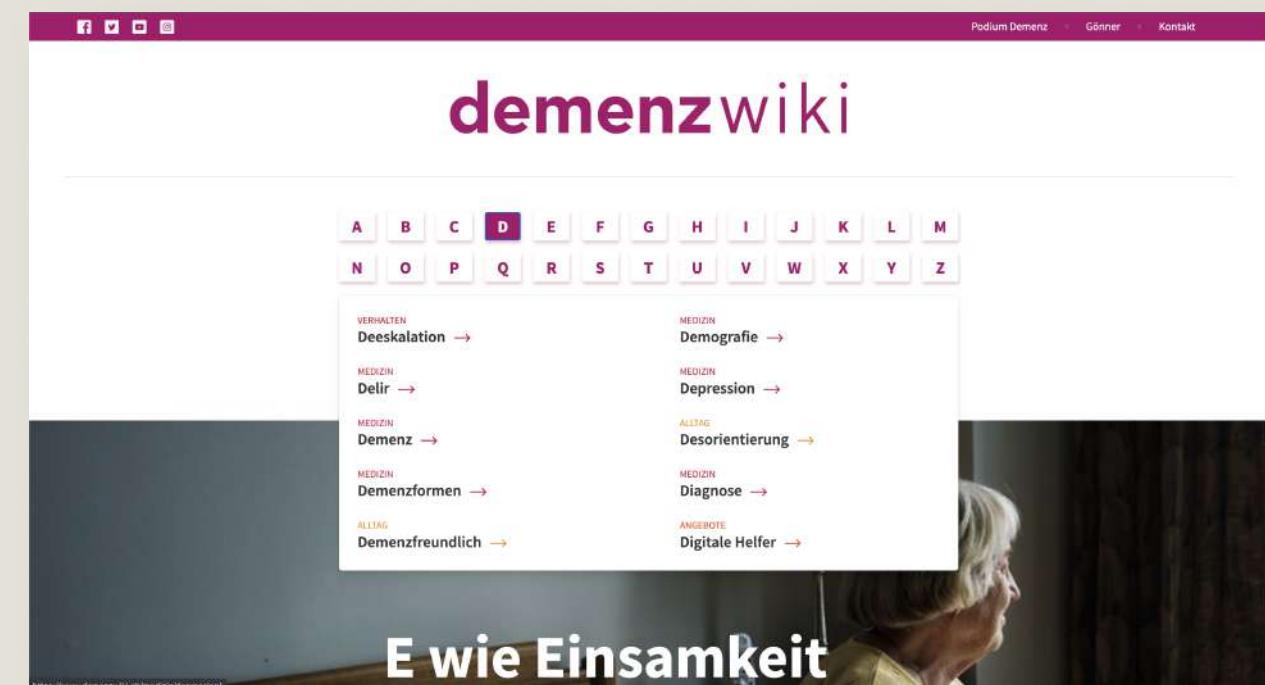
- [alzheimer.ch](http://alzheimer.ch)

Educational videos, reportages, case studies, tipps, blogs and interviews  
& active exchange between affected persons, relatives and professionals on social media



- [demenzwiki.ch](http://demenzwiki.ch)

online dictionary to quickly and easily find information on the most important keywords in the field of dementia



Fields of potential

# digital platforms (CH)

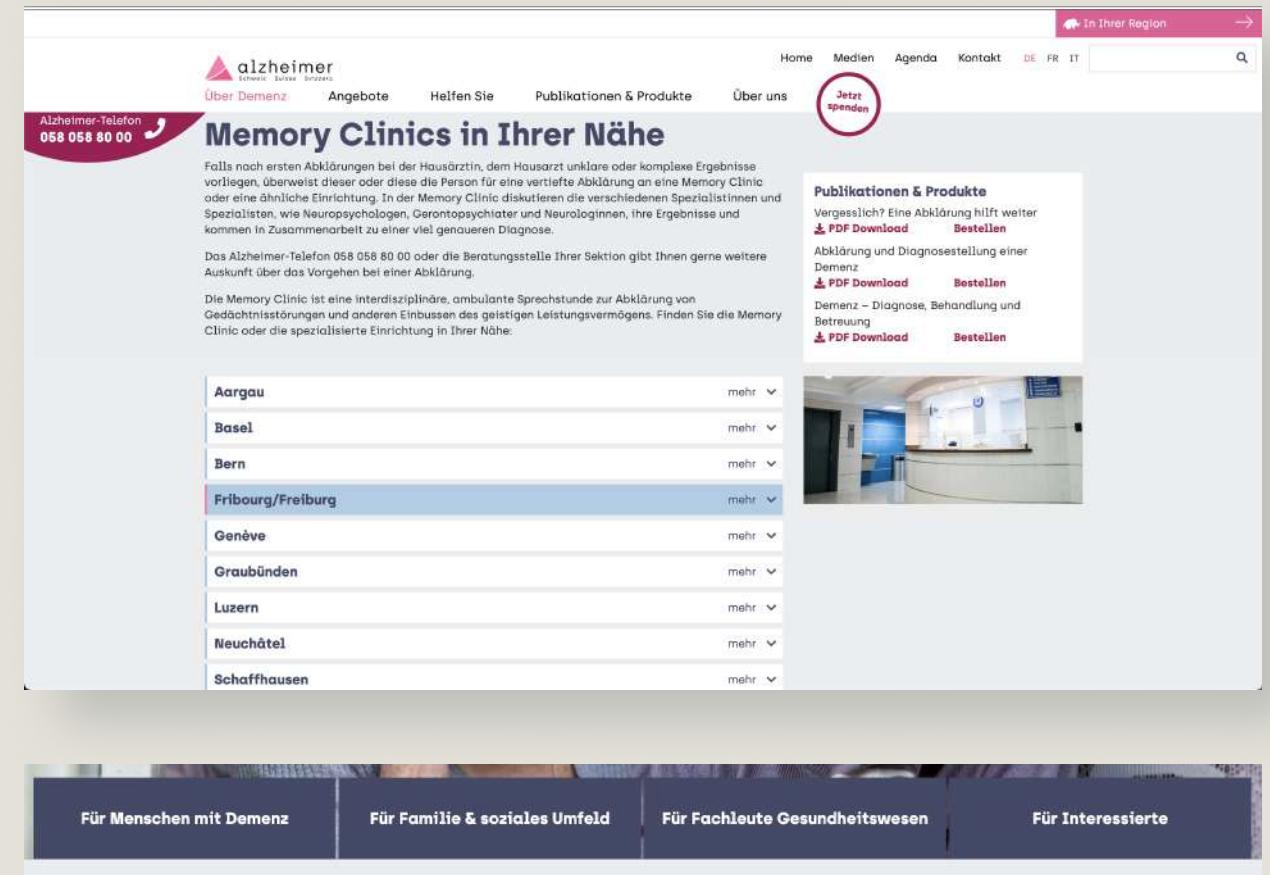
- [memo-info.ch](#)

Raise public awareness of dementia and motivate individuals to get diagnosed early  
Online test to identify possible dementia  
Information on prevention and help



- [alzheimer-schweiz.ch](#)

Blog posts, advice, referrals to support groups and resources, financial counseling, etc.  
Various offers on the website, such as the Alzheimer's telephone for information, advice and help.



👍 Entry for various target groups

Fields of potential

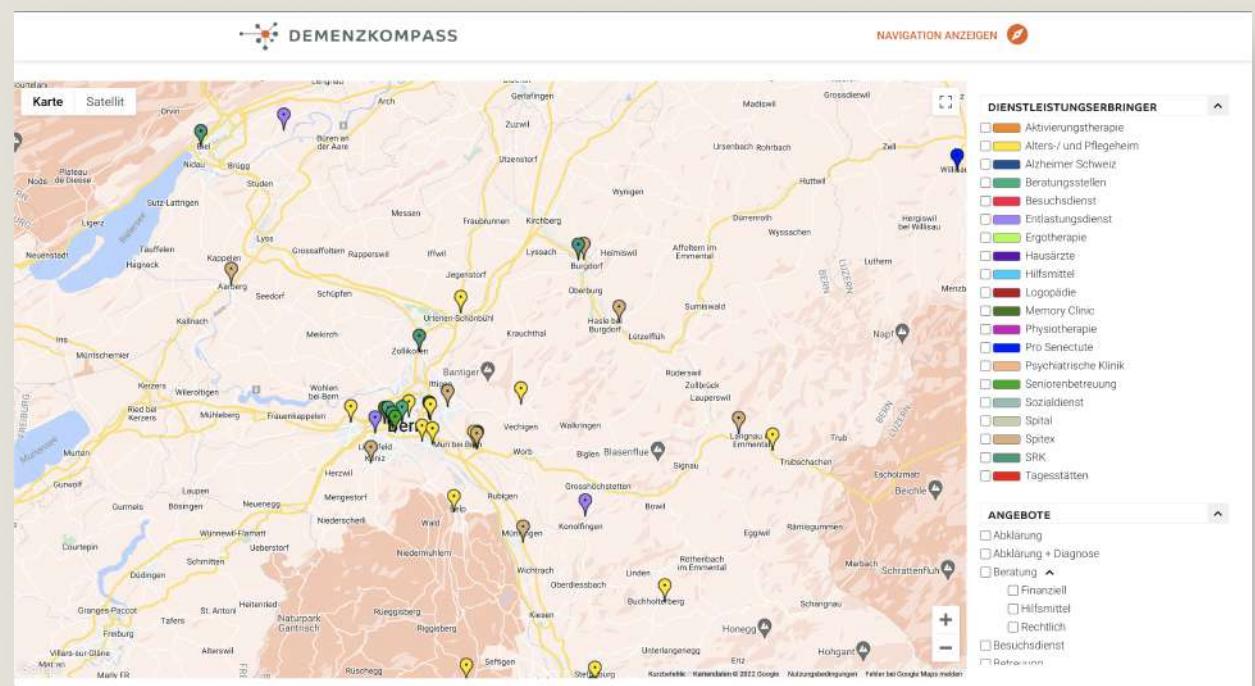
# digital platforms (CH)

- [demenzkompass.ch](https://demenzkompass.ch)

Link to services

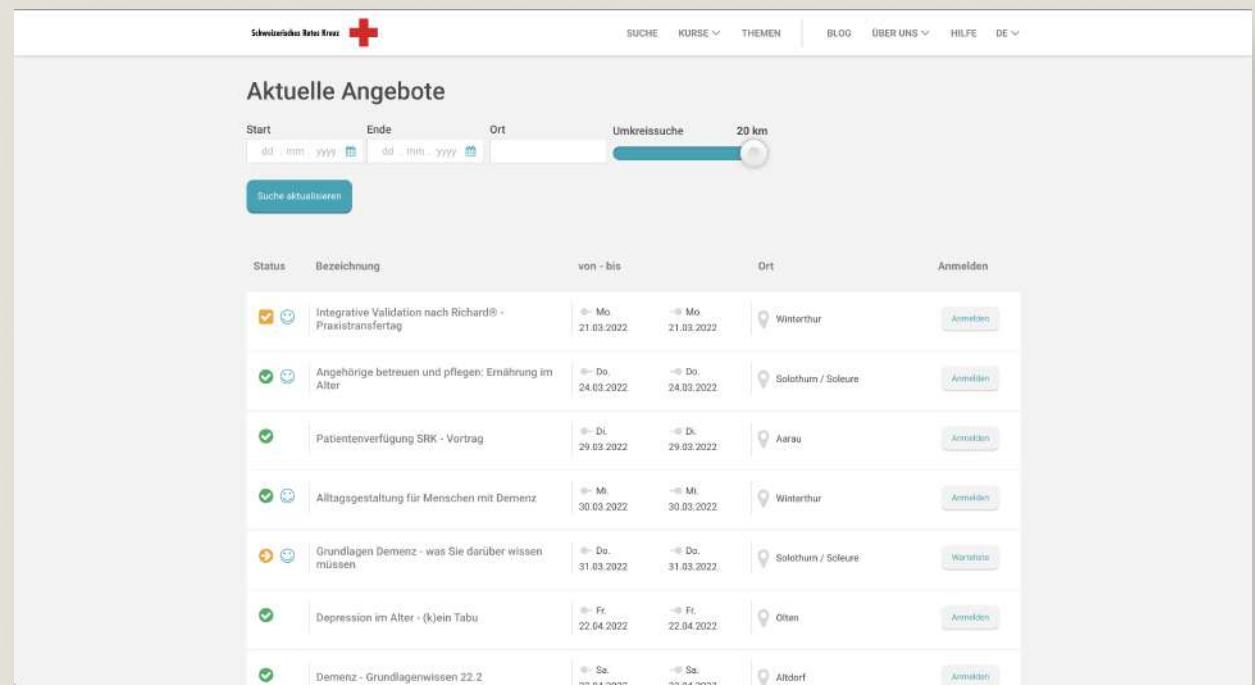
Map to find helpful services (counseling, nursing homes, day care, etc.)

Listing of services, however, very incomplete



- [SRK – Kurse für Angehörige von Menschen mit Demenz](https://www.srk.ch/kurse)

Courses and easy appointment booking



Fields of potential

# digital platforms (CH)

- [info-workcare.ch](http://info-workcare.ch)

A platform that provides information on how to balance work and care

The screenshot shows the homepage of info-workcare.ch. At the top, there's a navigation bar with links for 'Homepage', 'Praktische Hinweise', 'Nützliche Adressen', 'Allgemeine Infos', 'Ausbildung', and 'Häufige Fragen'. Below the navigation, there's a breadcrumb trail: 'Startseite / Praktische Hinweise / Zu Hause / Den Alltag organisieren / Hilfsmittel'. The main content area is titled 'Hilfsmittel' and contains a sidebar with categories like 'Urtal', 'Verschwinden', 'Emotionale Einschränkung', 'Gewalt gegen meine Person', 'Gewalt gegen jemanden', 'Gesamtsituation', 'Krise (mit Bettungssituation)', 'Am Arbeitsplatz', 'Sich informieren', 'Organisieren und Konsolidieren', 'Ihre berufliche Situation', 'Psychologische Hilfe und Unterstützung', 'Zu Hause', and 'Den Alltag organisieren'. The main text discusses what 'Hilfsmittel' are and lists various ways to manage daily life.

- [bsv.admin.ch](http://bsv.admin.ch)

Supporting information from the federal government, but not an app or program

The screenshot shows the BSV (Bundesamt für Sozialversicherungen) website. At the top, there's a header with the BSV logo and links for 'Der Bundesrat', 'EDI', 'BSV', 'Startseite', 'Medien', 'Kontakt', 'Übersicht', and a search bar. The main content area is titled 'Fragen und Antworten für Betreuende Angehörige'. It includes sections for 'Versicherte' (with links to AHV, Invalidenversicherung, Beruflichen Vorsorge und 3. Säule), 'Betreuende Angehörige' (with links to Pflegeleistungen, Erwerbsersatzordnung/Muttersehaft, and Internationales), and 'Allgemeine Fragen' (with links to Urlaub, Unterkunft, and Betreuungsgegutschriften). A sidebar on the right provides links to 'BSV-Online', 'Informationen für...', and 'Themen A-Z'.

# digital platforms (AT, DE)

- LICA – Digitale Unterstützung im Pflege- und Betreuungsalltag

Web app, which provides planning options/support, documentation of vital sign measurements, assistance with special events, tips regarding care and support



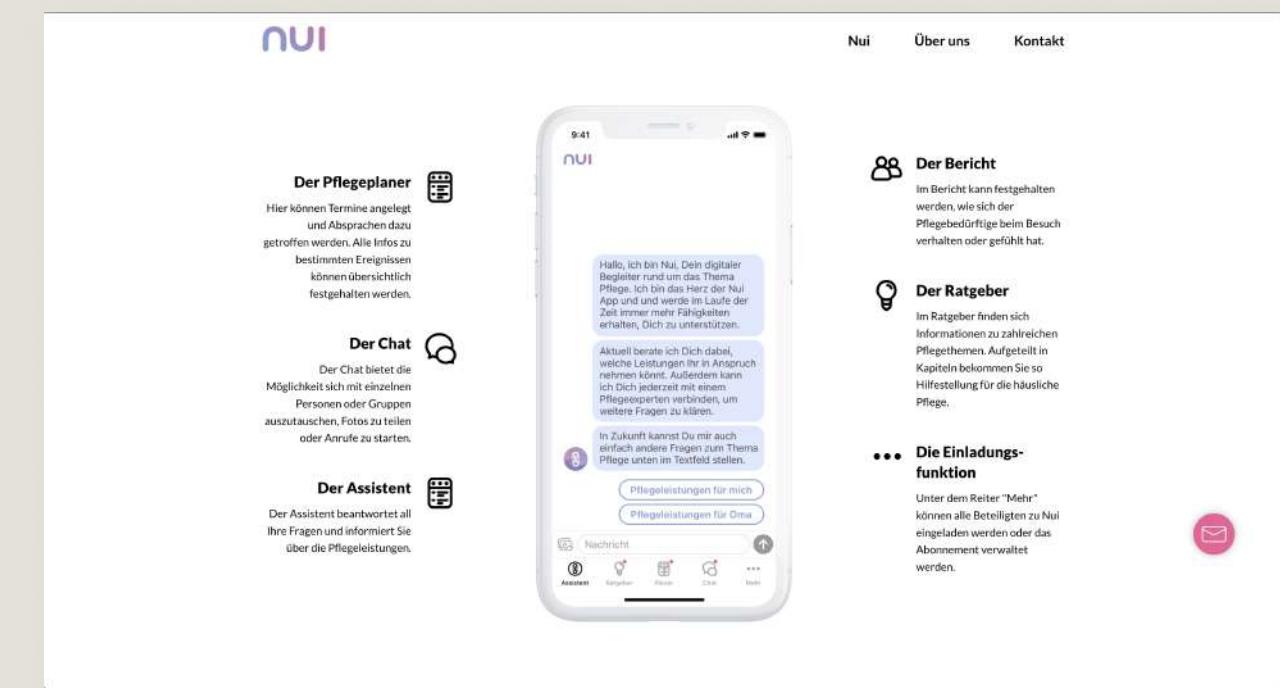
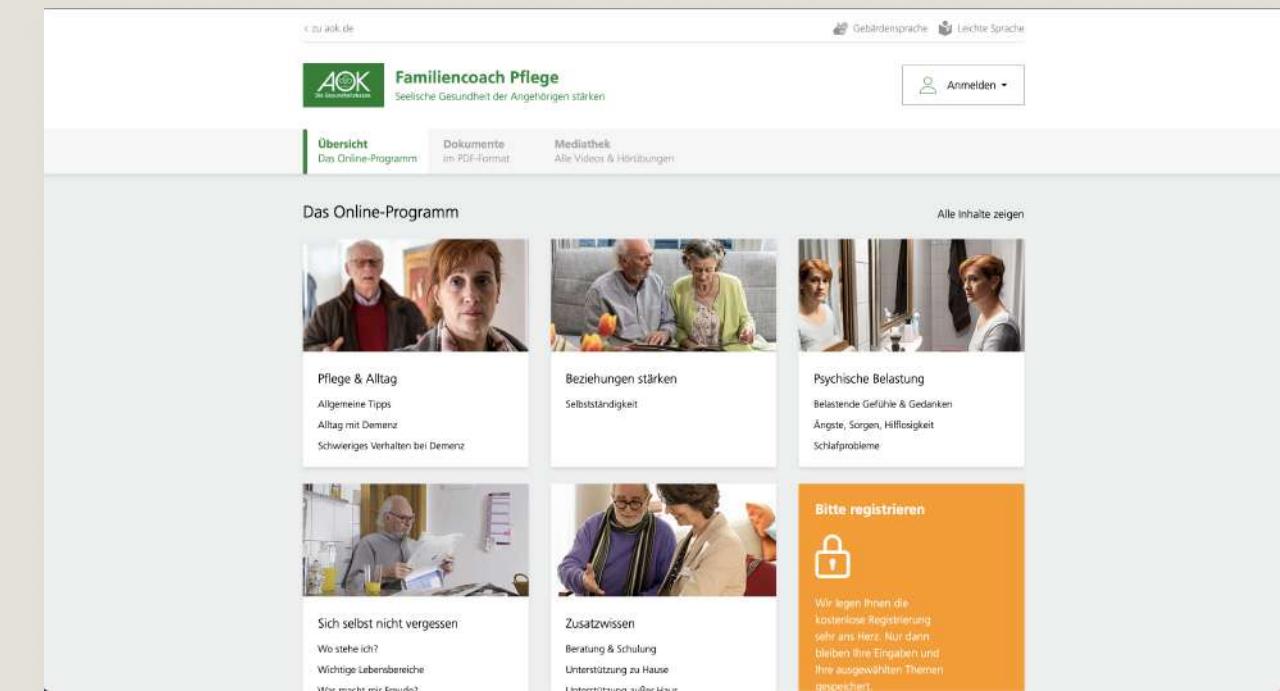
- myo  
An app for professional caregivers that aims to simplify contact with relatives



Fields of potential

# digital platforms (DE)

- [pflege.aok.de – AOK Familiencoach für Pflege](https://pflege.aok.de/) 👍  
Based on a survey on the health status of caregivers. The program is available online, free of charge and anonymous. The website displays appropriate tips (via questionnaire), interactive exercises, videos and audios according to needs
- [nui – Die PflegeleichtAPP](https://nui-app.com/)  
Digital companion  
Nui helps organize appointments and has an answer to almost every question, knows which care services you are entitled to, has sample applications and checklists at the ready, and much more



Fields of potential

# AOK in detail

A **questionnaire** is used to display topics **tailored to personal situations and needs**.

Questions address:

1. emotions and bad sleep
2. relationship with the patient
3. self-care
4. behavioral changes of the patient
5. knowledge about dementia disease
6. specific organizational difficulties



# AOK in detail

An overview of the individually relevant content follows

There is a **topic overview** per topic

Guided Reading: Depending on the topic, there are **interactive exercises** (with data input), self-evaluation, case studies, videos, etc.

The screenshot shows the AOK Familiencoach Pflege website. At the top, there's a navigation bar with links for 'Übersicht' (Overview), 'Dokumente im PDF-Format' (Documents in PDF format), and 'Mediathek' (Media Library). Below this is a section titled 'Das Online-Programm' (The Online Program) with a link 'Alle Inhalte anzeigen' (Show all contents). The main area displays four topic cards:

- Pflege & Alltag**: Includes sub-topics like 'Pflegebedürftigkeit & Depression', 'Alltag mit Demenz', and 'Schwieriges Verhalten bei Demenz'.
- Beziehungen stärken**: Includes sub-topics like 'Schöne Aktivitäten'.
- Psychische Belastung**: Includes sub-topics like 'Belastende Gefühle & Gedanken', 'Angste, Sorgen, Hilflosigkeit'.
- Zusatzwissen**: Includes sub-topics like 'Beratung & Schulung', 'Unterstützung zu Hause', 'Unterstützung außer Haus', 'Beruf & Pflege', 'Vollmachten', 'Krankheitswissen', 'Pflegerätschliches Wissen', and 'Problemlösen in 5 Schritten'.

To the right of these cards is a yellow sidebar with a lock icon and the text: 'Bitte registrieren' (Please register), 'Wir legen Ihnen die kostenlose Registrierung sehr ans Herz. Nur dann bleiben Ihre Eingaben und Ihre ausgewählten Themen gespeichert.', and 'Jetzt registrieren und alle Eingaben speichern' (Register now and save all entries). At the bottom of the page, there's a footer with links for 'Startseite', 'Übersicht', 'Pflegende Angehörige', 'Programm', 'Beratung für AOK-Versicherte', and various legal and contact links.

- Einleitung
- Ständiges Wiederholen
- Sachen verlegen, sammeln & wegwerfen
- Anklammern & Ängstlichkeit
- Umherlaufen & Ruhelosigkeit
- Film: Weglaufen
- Langsamkeit
- Teilnahmslosigkeit
- Vertuschen & Notlügen
- Film: Wahnvorstellungen & Misstrauen

Fields of potential

# AOK in detail

Approach the user in a simple way

→ Easily customized response with right "tone".

Facts through active clicking and selection  
→ Learning effect possibly greater?

Kennen Sie solche Situationen auch?

Ja  
 Nein

Sie kennen solche Momente nicht. Falls es im Laufe der Erkrankung doch dazu kommt, sind Sie damit nicht allein. Denn solche und ähnliche Situationen kennen viele Angehörige von Menschen mit Demenz. Menschen mit Demenz brauchen oft viel

**Schwieriges Verhalten bei Demenz**

**Ständiges Wiederholen**

Menschen mit Demenz können sich meist nicht an kürzlich Vergangenes erinnern und stellen deshalb immer die gleichen Fragen (z. B. *Wann gibt es Essen?*, *Wann kommt Peter?*) oder führen immer wieder die gleichen Handlungen durch (z. B. ständig im Keller nach der Wäsche sehen). Vor allem die ständigen Fragen können für pflegende Angehörige sehr anstrengend sein.

Was können Sie in solchen Momenten tun?

Klicken Sie einfach auf die grünen Felder.

**Fühlen Sie sich in den Pflegebedürftigen ein**

**Vermitteln Sie Sicherheit durch vertraute Themen**

**Geben Sie Ihrem Angehörigen eine Beschäftigung**

**Reagieren und loben Sie – auch zum zehnten Mal**

**Lassen Sie Ihren Angehörigen Tätigkeiten mehrmals machen**

Monika über ihre Mutter Elke

Dokumente Mediathek

**Vermitteln Sie Sicherheit durch vertraute Themen**

Falls sich Ihr Angehöriger mit seinen Fragen versichern möchte, dass Sie für ihn da sind, sprechen Sie über etwas, das ihn beruhigt – zum Beispiel etwas, das ihm leichtfällt: ein noch funktionierendes Hobby, Essen vorbereiten oder die abendliche Serie. Damit kann sich Ihr Angehöriger wieder sicher fühlen und sich als kompetent erleben. Und Ihr Gespräch bestätigt ihm, sich in einer sicheren Beziehung mit Ihnen zu befinden.

OK

Fields of potential

# AOK in detail

Difficult situations and how to react to them in an improved way are demonstrated with staged videos.

Individual key moments of the video are analyzed and interpreted.

→ Storytelling important

Hermann will Maria von ihrer Idee abbringen – aber so recht will das nicht klappen:



Hermann geht nicht auf Marias Wahrnehmung ein, sondern versucht ihr klarzumachen, dass sie bereits zuhause ist – was sie aufgrund der Demenz nicht verstehen kann. Deshalb lässt sein Versuch, sie wieder ins Bett zu schicken, Maria noch unsicherer zurück.



# AOK in detail

"Practical exercise"

→ How can family caregivers change their perspective?

Beschreiben Sie Ihre Gedanken und Gefühle:

| Situation:     | Was denken und fühlen Sie in so einem Moment? |
|----------------|---|
| Hier eintragen | Hier eintragen                                |
| Hier eintragen | Hier eintragen                                |
| Hier eintragen | Hier eintragen                                |

→

Schreiben Sie auf, was Sie tun:

| Situation:     | Was machen Sie – und wie reagiert Ihr pflegebedürftiger Angehörige? |
|----------------|---|
| Hier eintragen | Hier eintragen  |
| Hier eintragen | Hier eintragen  |
| Hier eintragen | Hier eintragen  |

→

Welcher Gedanke könnte Ihnen helfen?

| Situation:     | Was wäre ein hilfreicher Gedanke? |
|----------------|-----------------------------------|
| Hier eintragen | Hier eintragen                    |
| Hier eintragen | Hier eintragen                    |
| Hier eintragen | Hier eintragen                    |

→

Was könnten Sie beim nächsten Mal anders machen?

| Situation:     | Was wäre ein hilfreicher Gedanke? | Wie könnten Sie sich verhalten? |
|----------------|-----------------------------------|---------------------------------|
| Hier eintragen | Hier eintragen                    | Hier eintragen                  |
| Hier eintragen | Hier eintragen                    | Hier eintragen                  |
| Hier eintragen | Hier eintragen                    | Hier eintragen                  |

## 1. DESCRIBE

Express feelings

## 2. OBSERVE

Reflect behavior and influence on patient

## 3. REFRAME

Viewing the patient's behavior differently

## 4. CHANGE

Change handling of situation (behavior)

Fields of potential

# How might we...?

For the next phase, the team formulated four how-might-we-questions as problem hypotheses that help us take action and think about solutions.

The questions are divided into the topics of motivation, knowledge, competence and support - which at the same time reflect the 3 building blocks of self-management for successful and sustainable care and nursing of relatives.

# Motivation

How can we design a **digital coach** for family caregivers  
that is trustworthy and **motivates** them to use it?

How might we...?

# Knowledge

How can we gain insight into the **current/individual care** to give caregivers **needed information at the right time** to help them shape their care process in a sustainable way?

How might we...?

# Competence

How can we provide **practice-oriented** information that supports or relieves the caregivers **in their situation?**

How might we...?

# Support

How can we increase awareness among caregivers so that they **accept help early** enough?

How might we...?

# How might we...?

## Motivation

How can we design a **digital coach** for family caregivers that is trustworthy and **motivates** them to use it?

## Knowledge

How can we gain insight into the **current/individual care** to give caregivers **needed information at the right time** to help them shape their care process in a sustainable way?

## Competence

How can we provide **practice-oriented** information that supports or relieves the caregivers **in their situation**?

## Support

How can we increase awareness among caregivers so that they **accept help early** enough?

How might we...?

Thank you!  
Questions?

