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?

general

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

Source: Förderprogramm «Entlastungsangebote für betreuende Angehörige 2017–2020», BAG

Who do they care for?

general

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.)

Source: Förderprogramm «Entlastungsangebote für betreuende Angehörige 2017–2020», BAG

Dementia

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

Source: Alzheimer Schweiz, 2021; BFS, 2015

Dementia

Progression of dementia in **3 stages:**

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

In Anlehnung an die Phasen nach Cora van der Kooij.

Facts

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

Insights

Dementia

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

The caregiving process is not linear!

At home care for the elderly

dementia

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

Ø age of person in need of care: 83 years

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

Mostly: caregiving task unplanned and takes longer than expected

Stress levels increase continuously as the disease progresses

Source: Alzheimer Schweiz, 2021

Scope of care

general

Tasks:

- 38% financial & administrative
- 23% coordinating & planing
- 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

Source: Förderprogramm «Entlastungsangebote für betreuende Angehörige 2017–2020», BAG

Main reasons to seek support

general

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.

Source: Förderprogramm «Entlastungsangebote für betreuende Angehörige 2017–2020», BAG

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

Source: Förderprogramm «Entlastungsangebote für betreuende Angehörige 2017–2020» Programmteil 2: Modelle guter Praxis, BAG

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.»

Source: «Häusliche Betreuung alter Menschen – Eine Informationsbroschüre für betreuende und betreute Personen» Forschungsprojekt, ZHAW Soziale Arbeit, 2012-2014

Facts

Quality of relationship has influence on:

- Motive to care
- Perception of stress
- Risks

Insights

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**

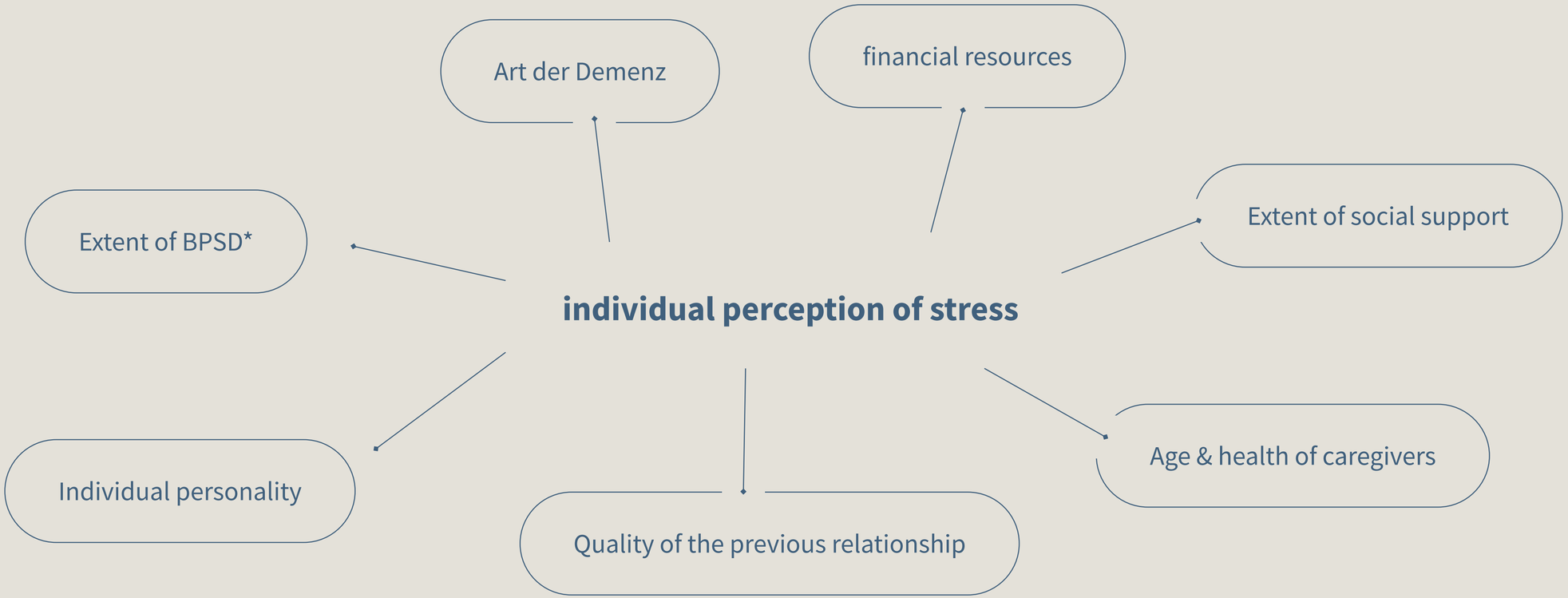
Organization of everyday life is a great burden

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

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

Source: ZHAW, Soziale Arbeit

Perception of stress



Source: ZHAW Soziale Arbeit – Nach Engel, 2007

*Behavioral and Psychological Symptoms of Dementia / Behavioral Disorders / Challenging Behavior.

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.

Source: Förderprogramm «Entlastungsangebote für betreuende Angehörige 2017–2020»
Programmteil 2: Modelle guter Praxis, BAG

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

Source: ZHAW, Soziale Arbeit

Insights

Focus on own resources
Touchpoints must be individually adapted

Needs

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!**

Source: Förderprogramm «Entlastungsangebote für betreuende Angehörige 2017–2020», BAG

Insights

Refer to many existing things and bring structure

Addressing individual needs

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

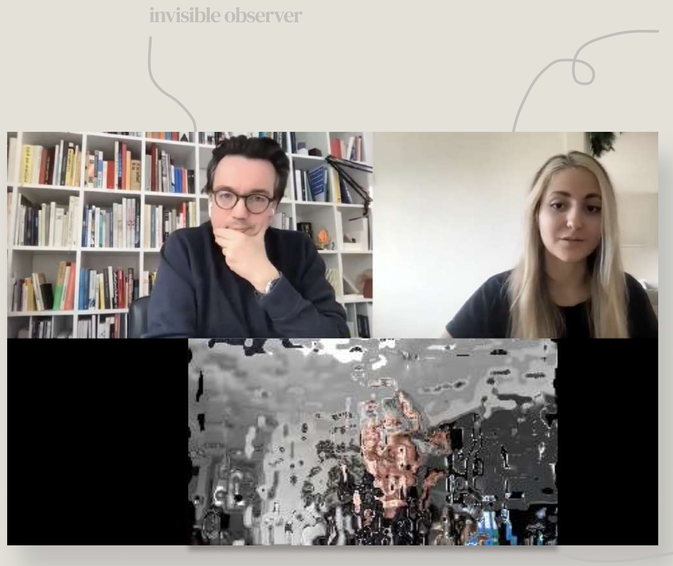
Overview

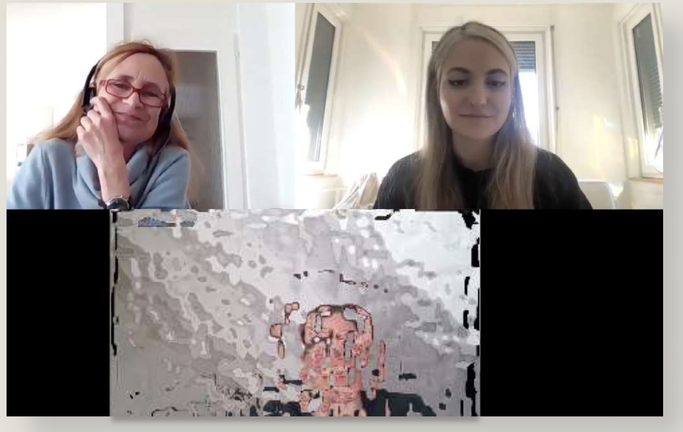
During the time frame 21.01.22 - 11.02.22

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**





Things that stood out

Care of two persons at the same time

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

Different approach to dementia and care

→ **Conflicts with other caregivers**

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

& symptoms get misjudged

→ **Wrong diagnosis “depression”**

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.**

early acceptance of dementia

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

optimize own care system

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

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»
«Einfühlsamkeit»

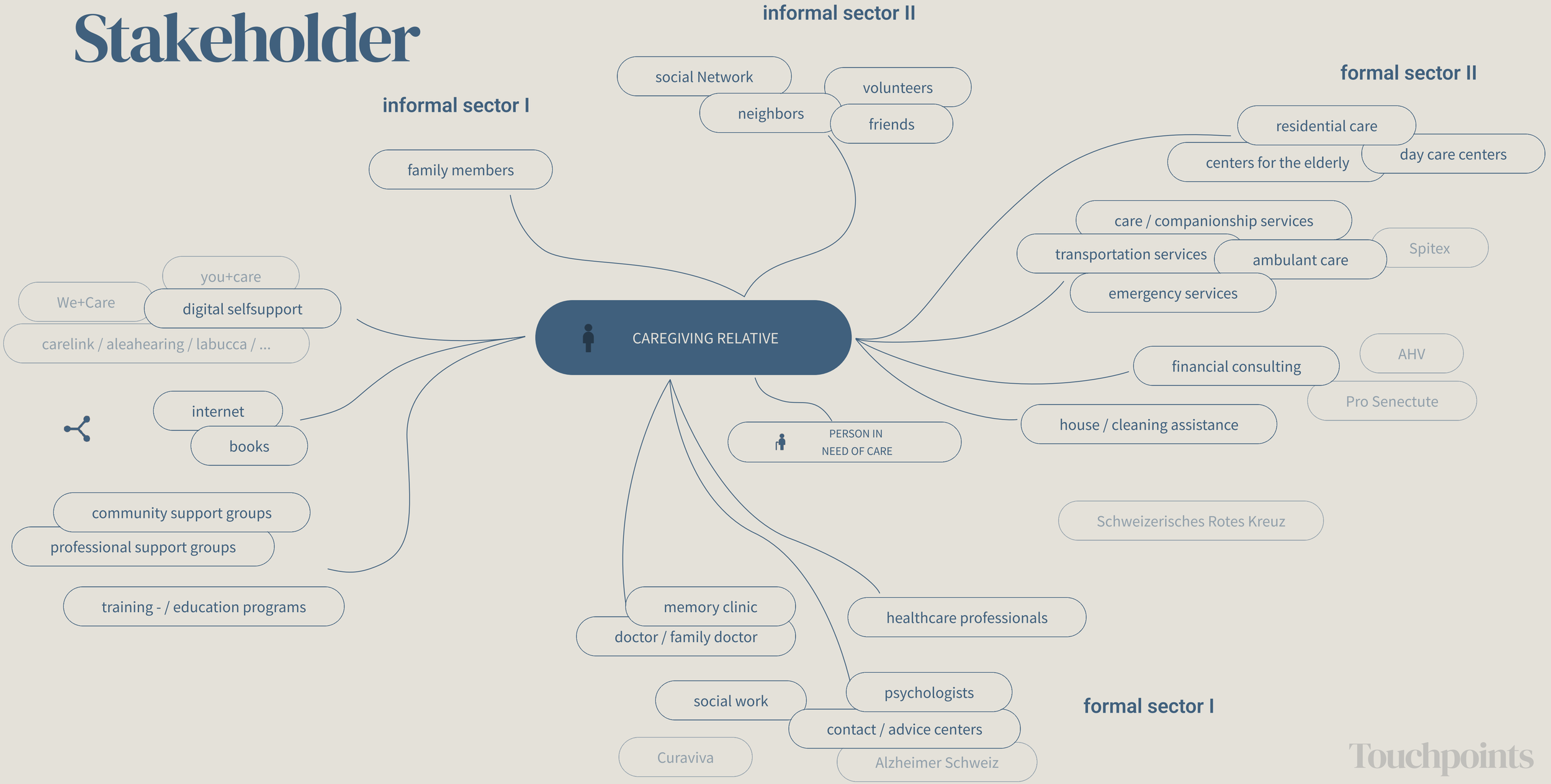
«Obligation»
«Pflicht»

«Unpredictability»
«Unberechenbarkeit»

Touchpoints

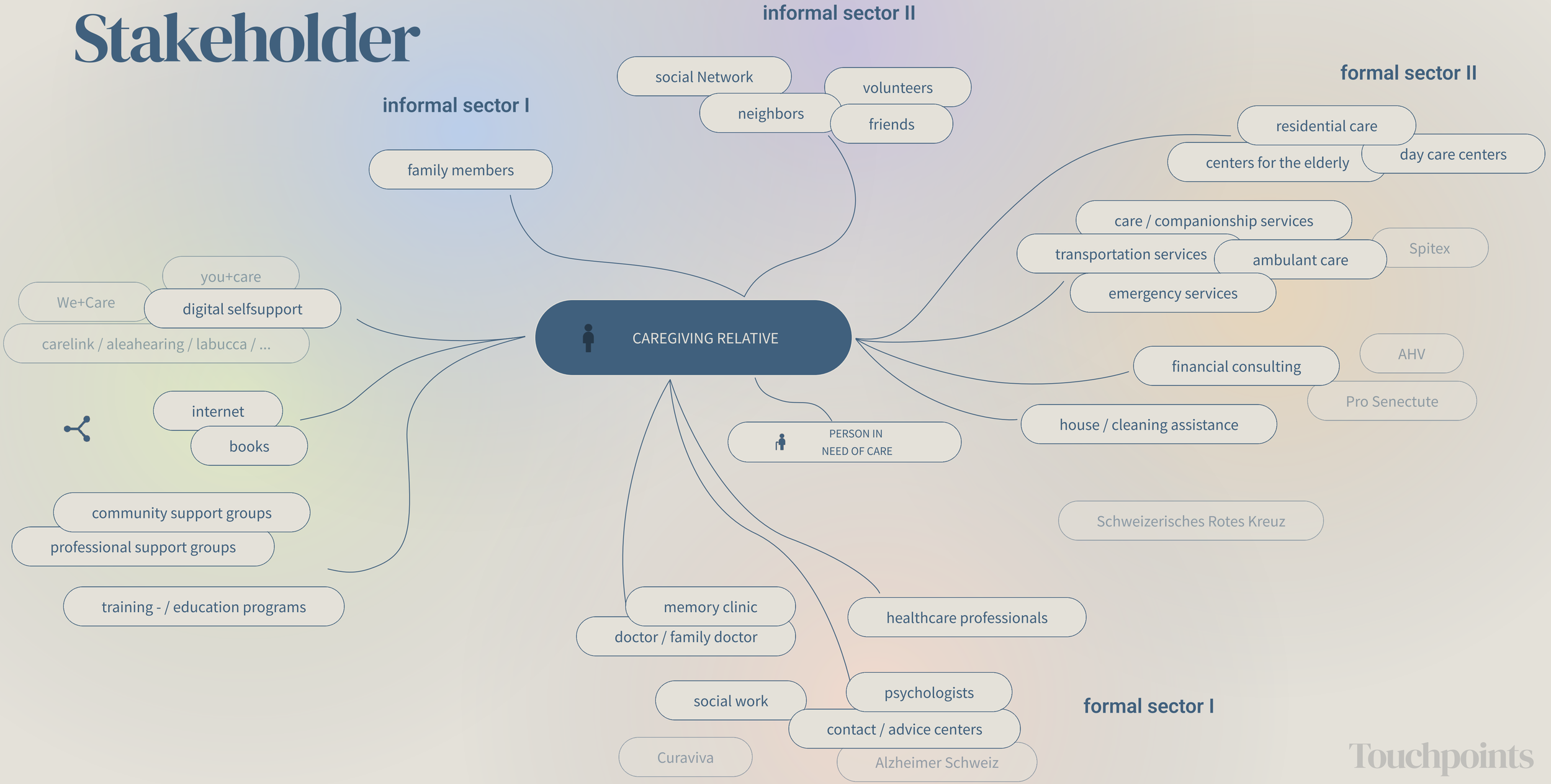
- Stakeholder
- Support system

Stakeholder



Touchpoints

Stakeholder



Touchpoints

Support system

Care must not only be understood as a service provided by one person (family caregiver)

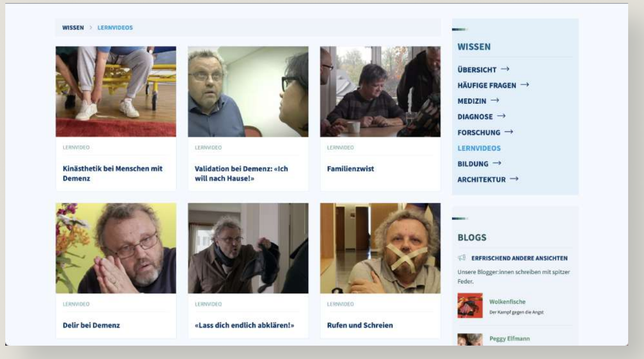
→ **but as a system!**

Fields of potential

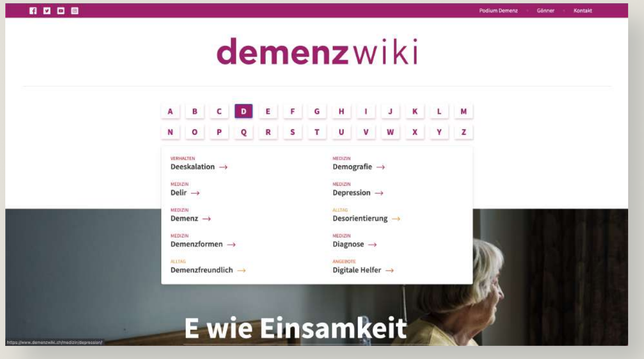
- digital platforms (CH, AT, DE)
- AOK in detail

digital platforms (CH)

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



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

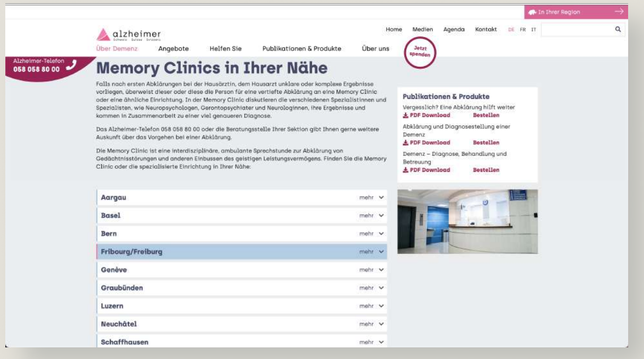


digital platforms (CH)

- 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

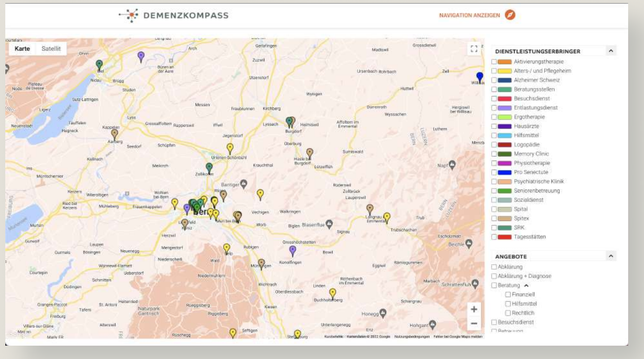
- alzheimer-schweiz.ch
  Blog posts, advice, referrals to support groups and resources, financial counseling, etc.
  Various offers on the website, such as the Alzheimer's telephone for information, advice and help.

  👍 Entry for various target groups

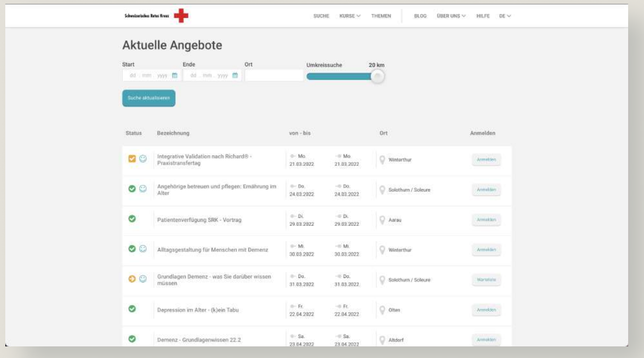


digital platforms (CH)

- demenzkompass.ch
  Link to services
  Map to find helpful services (counseling, nursing homes, day care, etc.)
  Listing of services, however, very incomplete

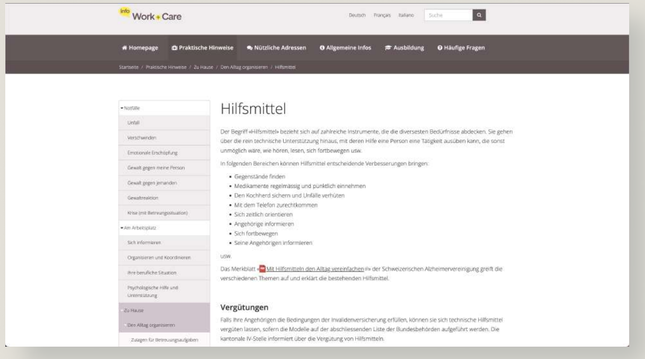


- SRK – Kurse für Angehörige von Menschen mit Demenz
  Courses and easy appointment booking

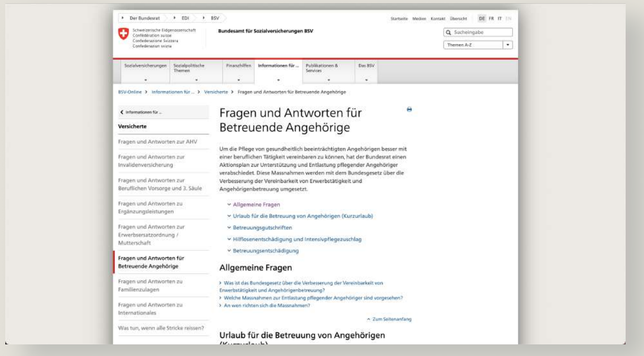


digital platforms (CH)

- info-workcare.ch
  A platform that provides information on how to balance work and care

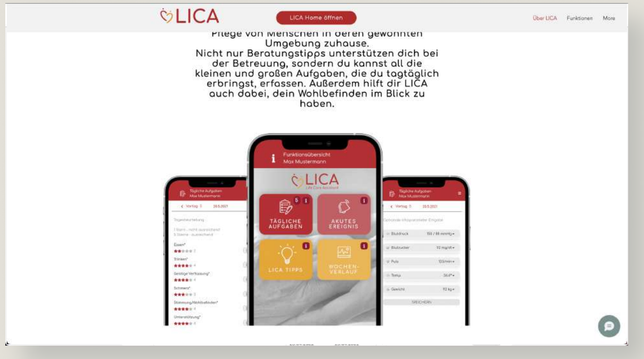


- bsv.admin.ch
  Supporting information from the federal government, but not an app or program



digital platforms (AT, DE)

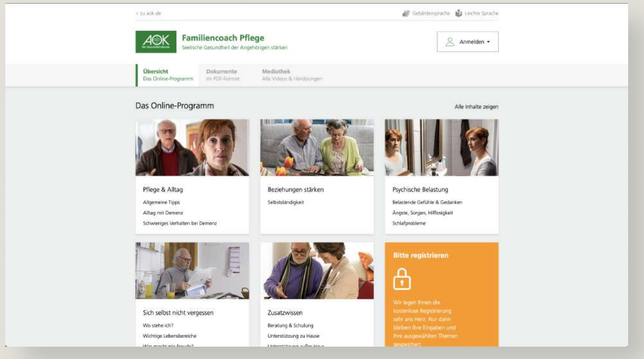
- LICA – Digitale Unterstützung im Pflege- und Betreuungsalltag
  Web app, which provides planning options/support, documentation of vital sign measurements, assistance with special events, tips regarding care and support



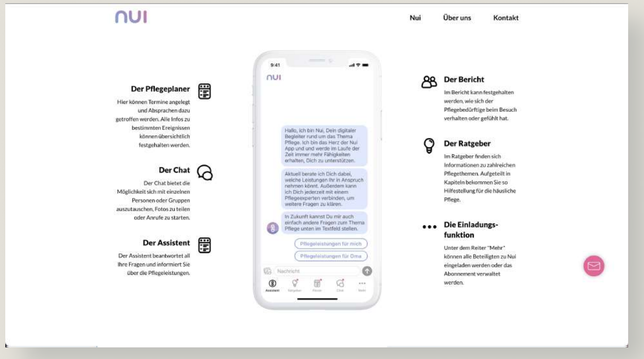
- myo
  An app for professional caregivers that aims to simplify contact with relatives

digital platforms (DE)

- pflege.aok.de – AOK Familiencoach für Pflege 👍
  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
  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

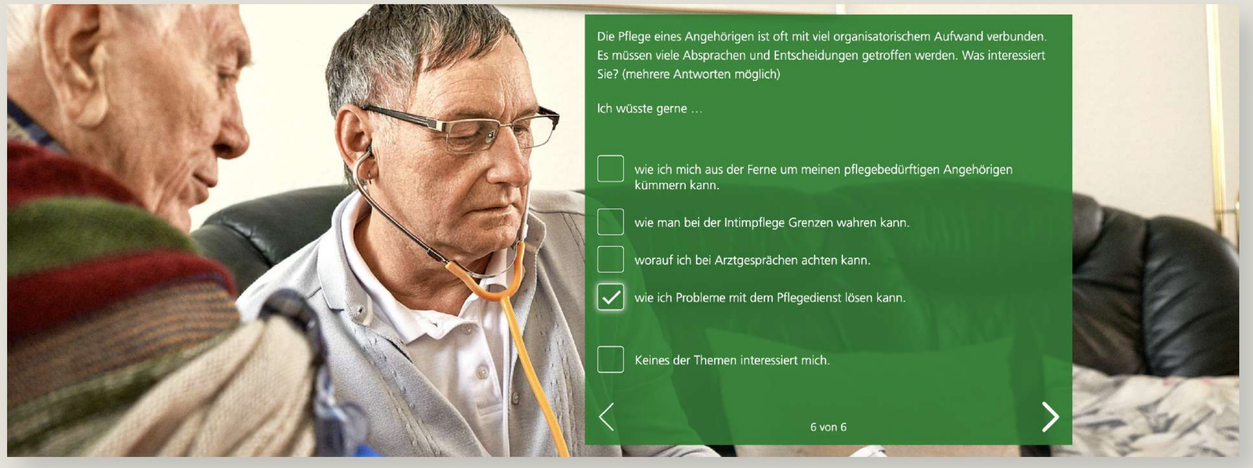


AOK in detail

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

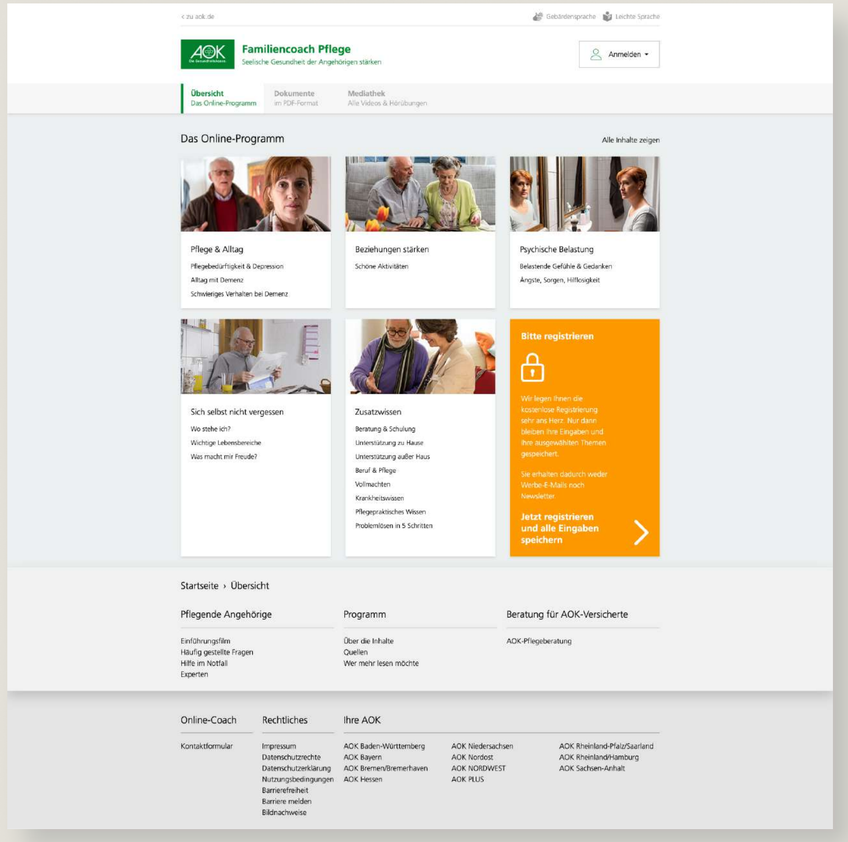


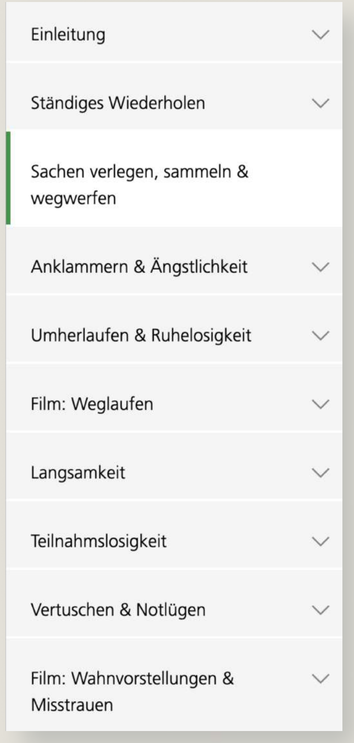
AOK in detail

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.

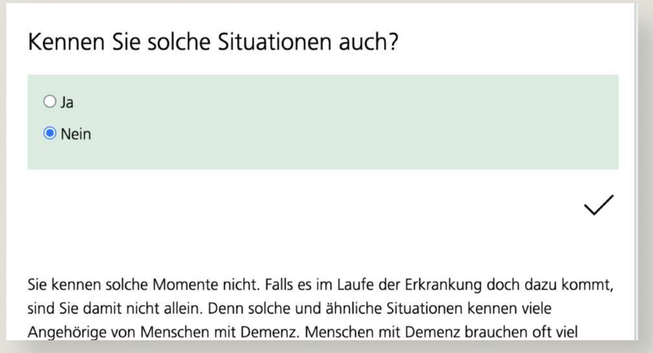




AOK in detail

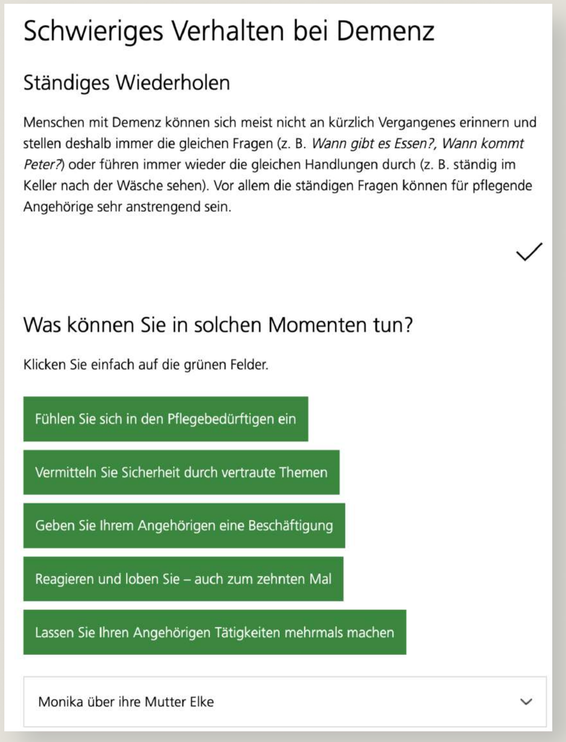
Approach the user in a simple way

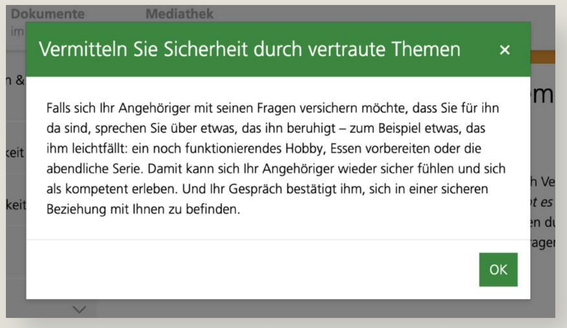
→ Easily customized response with right "tone".



Facts through active clicking and selection

→ Learning effect possibly greater?





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

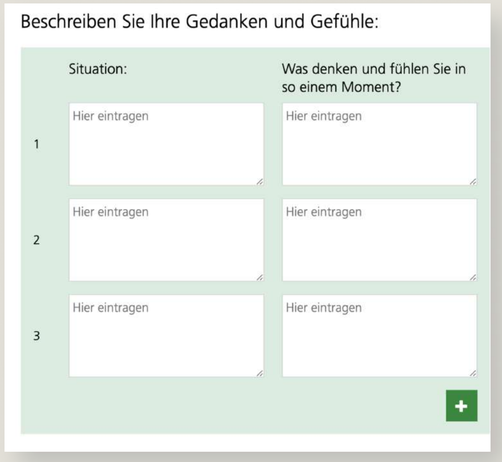
Hermann will Maria von ihrer Idee abbringen – aber so recht will das nicht klappen:

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.

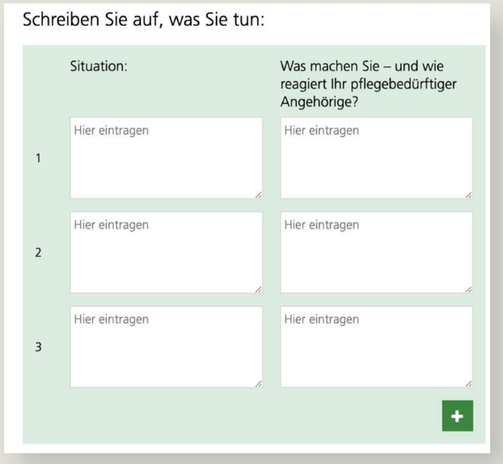
AOK in detail

"Practical exercise"

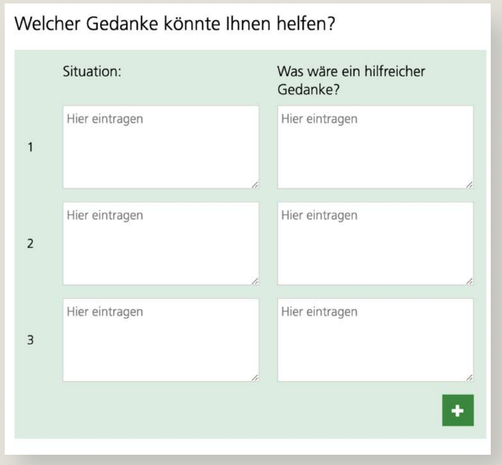
→ How can family caregivers change their perspective?



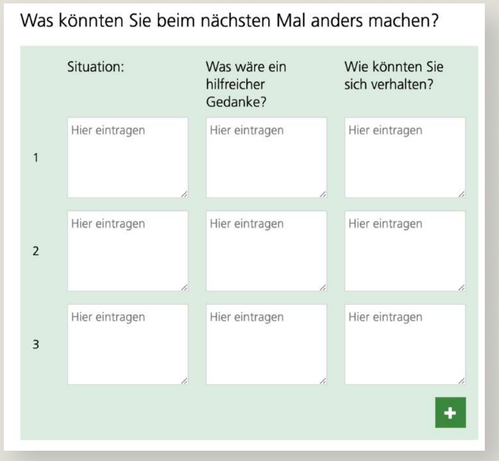
1. DESCRIBE
Express feelings



2. OBSERVE
Reflect behavior and influence on patient



3. REFRAME
Viewing the patient's behavior differently



4. CHANGE
Change handling of situation (behavior)

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?

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...?

How might we...?

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

Thank you!
Questions?