Living with dementia and caring for others

In this article, Lieselotte "Lilo" Klotz, member of the European Working Group of People with Dementia (EWGPWD) writes about her experience of living with a diagnosis of dementia and at the same time being a family carer.

Lieselotte Klotz

Since 2020, I have been working on a voluntary basis at the European level, bringing in my personal experience. Over these years, I have contributed in various European and national networks, organisations, expert groups and events to ensure that the perspective of people with dementia is not only heard but taken seriously and structurally embedded. I live with a diagnosis of dementia and at the same time I am a family carer. But I am not speaking only for myself – I am speaking for many people in Europe who live with a similar double role.

It is important to me to make this clear: my work in Europe is not some abstract "committee work", but an expression of my own life with dementia – and of my commitment to making sure that other people with dementia and their families receive support earlier, have more rights and gain real opportunities to participate.

In the EU today, millions of people live with dementia, and this number will increase significantly over the coming decades; projections suggest that the number of people with dementia in Europe could roughly double by 2050. At the same time, family members in all Member States carry the main burden of care. We know that around 80 % of care in Europe is provided informally – in families, neighbourhoods and circles of friends. For me, one thing is clear: dementia is not only a medical issue but a European test of our commitment to human rights, social justice and solidarity.

Living with dementia and caring for others: in official language, people like me hardly appear at all – people who live with dementia themselves and at the same time care for relatives. I experience every day how much systems, requirements, services, bureaucracy and legislation assume that family carers are always healthy, resilient and fully capable of decision-making. In reality, my own illness amplifies every gap in services, every bureaucratic hurdle and every delay – and makes me particularly vulnerable, socially and financially. I experienced this in a particularly painful way in 2025.

When politicians talk about "strengthening home care", they must also think of people like me: doubly burdened, living with an illness, often women, usually very close to the limits of their strength. I do not need more pilot projects, but a permanently funded, local coordination point, less bureaucracy, low threshold services, real respite options and systematic involvement of people with dementia and family carers in all bodies and areas where "decisions about us" are made.

I want Europe to recognise that family carers need more protection, more respite and better social security – and that in situations of double burden, as in my case, additional, specific support is needed, because the point of self-overload is reached much more quickly. This includes better reconciliation of care and employment, social protection for family carers and targeted services and support for people who are both living with an illness and providing care.

In concrete terms, this means: when European programmes, research projects or guidelines on dementia are developed, the central guiding question should be "What really improves the lives of people with dementia and their family carers?" – and WE must be involved in answering that question.

In my work since 2020, I have seen how much the discussion changes as soon as people with dementia are actually at the table. From Europe, I expect that it understands "dementia" as a mandate to build humane, solidary, inclusive and cross border structures.

For me, this includes:

- A clear European dementia agenda that brings together and strengthens national strategies
- Protection and support for family carers who provide around 80% of all care work
- A consistent human rights and participation perspective in line with the UNCRPD
- Research that is guided by our everyday lives and our quality of life and is not narrowly focused on technology and medications.

Dementia must not be reduced to numbers, policy papers and market forecasts; it has to be translated into concrete rights, reliable support and genuine participation – including for people who live under the "double burden".