Malteser
…weil Nähe zählt.

Contribution to the IE Call for Submissions – HRC Report 2026

The Malteser Perspective in Germany on Dementia, Autonomy, Participation, Human Dignity and Human Rights

ENGLISH VERSION

Foreword

Malteser has been committed for many years to supporting people with dementia and their relatives in Germany. At the heart of our work lies the conviction that people with dementia remain holders of inalienable human rights regardless of the progression of their illness and are entitled to dignity, self-determination, social participation, and social inclusion.

We welcome the initiative of the Independent Expert on the enjoyment of all human rights by older persons, which focuses attention on the autonomy, participation, and human dignity of older people with cognitive impairments. The following observations are based on the experiences of Malteser dementia services as well as on the principles of the German National Dementia Strategy, human rights standards, and person-centred approaches in supporting people with dementia.

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1. About Malteser

Malteser is a Catholic international relief organisation that is active in Germany in the fields of emergency medical services, civil protection, healthcare, and social services. Around 57,700 volunteers are engaged in supporting people in need in Germany, regardless of religion, origin, or political beliefs. With approximately 41,000 employees, Malteser is also one of Germany's major employers in the healthcare and social service sectors. Worldwide, the Order of Malta, founded in the 11th century, carries out projects and activities in more than 120 countries to support people in need and vulnerable populations.

Malteser has extensive experience in the support and care of people with dementia and their relatives through both professional and voluntary services. Through volunteer-based dementia support programmes such as dementia support groups (Café Malta®), visiting and respite services, carers' support groups, counselling and training programmes, as well as initiatives to promote dementia-friendly communities, Malteser dementia services strive to enable people with dementia to live as independently as possible in familiar surroundings while maintaining social participation and quality of life. In doing so, we follow a person-centred understanding of dementia that places the individual, their life story, relationships, and personal wishes at the centre of support.

The Malteser Dementia Competence Centre supports the professional development of these services and promotes exchange between practice, research, and policy. Its objective is to strengthen human rights-based, person-centred, and participation-oriented approaches in dementia care on a sustainable basis. In this context, we also contribute as a member and stakeholder within the German National Dementia Strategy network.

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2. Statement

A. Voice, Recognition and Lived Experience

In what ways are older persons with cognitive impairments not heard, not recognised, or excluded from participation in everyday life?

From the perspective of Malteser dementia services, people with dementia frequently experience situations in which others make decisions on their behalf rather than actively involving them. This is often not driven by ill intent but rather by uncertainty, lack of knowledge about the disease, lack of time, or a desire to avoid burdening the person concerned. People affected report that in family settings, healthcare services, and public spaces, others are more likely to speak with relatives than directly with them. As a result, they gradually lose influence over everyday decisions as well as social roles that previously contributed to their identity (for example, as the "head of the family" or a trusted adviser). In addition, social stigma and fear surrounding dementia frequently lead to social withdrawal. Many people who have received a dementia diagnosis refrain from participating in clubs, cultural activities, or voluntary work because they fear negative reactions or exclusion, or because they have already experienced discrimination. During a carers' training programme, one family member reported that his father was no longer welcome in a local choir after incontinence related to dementia had become apparent. The consequences of such experiences extend beyond loss of participation and also include loss of purpose and social recognition.

How are their wishes, emotions, preferences and values recognised, interpreted and respected when communication is difficult or fluctuating?

Malteser services follow a person-centred approach. Wishes and needs are not identified exclusively through verbal communication. Staff members and volunteers consciously

pay attention to non-verbal signals such as facial expressions, gestures, body language, emotional states, and familiar routines.

Particularly important is the involvement of relatives and other trusted persons who can contribute biographical knowledge and information about individual preferences and dislikes. At the same time, the person affected always remains at the centre of attention. Even when verbal abilities decline, people with dementia can often continue to express feelings, preferences, agreement, or rejection clearly. The task of professional and voluntary supporters is to recognise and take these forms of expression seriously. This requires both a person-centred attitude and sufficient knowledge about dementia to interpret behaviour appropriately and respond accordingly.

B. Autonomy and Participation

In which situations do care, protection, or "professional" interventions unintentionally lead to decisions being taken over or opportunities for participation being restricted?

Well-intentioned care and protective measures can unintentionally restrict autonomy. In practice, such situations frequently occur in everyday life. Decisions regarding daily routines, leisure activities, nutrition, clothing, or social contacts are sometimes made on behalf of individuals in order to simplify processes or minimise risks. Such protective measures may reduce opportunities for people with dementia to make their own decisions and experience self-efficacy.

Autonomy is not only an ethical concept but also a legal one. Self-determination, supported decision-making, and orientation towards the will and preferences of the person concerned are fundamental principles of the UN Convention on the Rights of Persons with Disabilities and German guardianship law.

In institutional settings, standardised routines may unintentionally override individual wishes. Particularly concerning is the use of restrictive measures resulting from time pressure and staff shortages, such as sedating medication or physical restraints. Furthermore, most hospitals are insufficiently prepared to meet the needs of older patients who, in addition to their primary condition, also experience cognitive impairments or dementia. There is often a lack of staff resources and adequate training. Despite numerous studies and projects addressing this issue, the situation in Germany

has remained largely unchanged for years and is becoming increasingly critical due to demographic change.

How can autonomy be supported when cognitive abilities fluctuate or change over time?

The experience of Malteser shows that autonomy should not be understood as either present or absent. Rather, autonomy changes throughout the course of dementia and can be maintained through appropriate support.

Helpful measures include:

- Allowing sufficient time for decisions and conversations
- Providing accessible and simplified information
- Offering choices rather than directives
- Involving trusted persons
- Providing biography-based support
- Using flexible and situation-specific decision-making processes

In group programmes such as Café Malta®, participation is not defined by performance but by involvement. Even people with advanced dementia can make decisions, build relationships, and express their personality when their environment supports them in doing so.

C. Personhood, Relationships and Belonging

How do cognitive impairments affect the roles, identity, relationships and sense of belonging of older persons?

Dementia often changes social roles within families and communities. Individuals who previously carried responsibilities may find that they are no longer able to fulfil these roles or that these responsibilities are taken away from them. This can result in feelings of loss, dependence, reduced belonging, and diminished self-efficacy.

At the same time, the experiences of Malteser dementia services demonstrate that identity extends far beyond cognitive abilities. Memories, habits, personal values, religious beliefs, and social relationships often remain intact for a long time and

continue to shape the individual's lived experience. Participation opportunities, such as accompanied attendance at cultural events for people with and without dementia, help make a person's identity visible and strengthen social belonging. People with dementia particularly benefit from communities in which they continue to be recognised as full members rather than being reduced to their diagnosis.

Which stereotypes, fears, or societal attitudes most frequently lead to loss of dignity, exclusion, or reduced expectations?

Particularly problematic are assumptions that people with dementia are no longer capable of making decisions, learning new things, or contributing meaningfully. Such attitudes often lead to infantilisation, paternalism, and social exclusion. The widespread fear of dementia also contributes to people being avoided or excluded from social activities. This reinforces isolation and may result in a gradual loss of dignity and self-esteem. Malteser's experience shows that awareness-raising, education, encounters, and personal contact help reduce prejudice and strengthen social acceptance of people with dementia.

D. Good Practice and Recommendations

Which laws, policy strategies, institutions, approaches or frameworks help older persons with cognitive impairments remain heard, included, respected and socially connected?

From Malteser's perspective, the following approaches have proven particularly effective in dementia support:

- Person-centred and strengths-based support
- Promotion of dementia-friendly communities and neighbourhoods
- Low-threshold support services such as Café Malta®
- Home-based care and respite services
- Training for family carers, volunteers, and professionals
- Intergenerational programmes
- Inclusive leisure and cultural opportunities
- Consistent orientation towards the wishes of the person concerned

These approaches promote social participation, counteract loneliness, and support the preservation of dignity and self-determination.

Which legal, policy, professional, or community changes are needed to better protect autonomy, participation and dignity?

Malteser recommends:

- Stronger integration of the rights to participation and self-determination of people with dementia into policy strategies and local measures.
- Nationwide access to benefits under the German Federal Participation Act (SGB IX) for people with dementia and recognition of dementia as a disability.
- Expansion of dementia-friendly structures in communities, healthcare systems, and social environments.
- Training in person-centred communication and human rights-based approaches for professionals and volunteers.
- Greater support for programmes promoting social participation and inclusion.
- Measures to combat stigma and discrimination through public awareness campaigns.
- Sustainable integration of scientifically evaluated projects and concepts into regular service provision rather than repeatedly funding short-term projects that cannot continue due to a lack of long-term financing.
- Simplified and harmonised access to counselling and social benefits across all German federal states.
- Systematic involvement of people with dementia and their relatives in the planning, implementation, and evaluation of support services.
- Adequate financial resources to ensure the sustainable implementation of action programmes such as the German National Dementia Strategy.

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3. Conclusion

People with dementia should not primarily be viewed as recipients of care or protection but as citizens with inalienable human rights, their own history, their own voice, and the right to participate in society until the end of life. A person-centred approach and the promotion of opportunities for participation and self-determination are essential prerequisites for achieving this goal.

4. References

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