

Table F U3 The spectrum of disease specific ethical issues (DSEIs) in dementia care (complemented by quotations from the original literature)

1. Diagnosis and medical indication		Ref.	Quotations for illustration
Adequate consideration of complexity of diagnosing dementia	Risk of making a diagnosis too early or too late because of reasons related to differences in age or sex related disease frequencies	[1, 2]	„Not only is psychiatric illness common in old age - so too are physical diseases and social deprivation of all kinds. When a number of such pressures lead to distress in an older person’s life, the diagnostic boundaries of psychiatric illness may be much less clear-cut than in younger people and experienced psychiatrists often set lower threshold for identifying such illness in older people than they do for the young.” [1]
	Risk of making inappropriate diagnoses related to varying definitions of MCI (mild cognitive impairment)	[1, 3-10]	“Early concerns about utility of diagnosing an irreversible, terminal condition such as AD have waned as effective treatments have emerged. [...] The diagnosis of MCI is more nuanced, because no effective therapies are available as yet, and, although MCI is a risk factor for the development of AD, its prognosis is not clear.” [10]
	Underestimation of the relatives’ experiences and assessments of the person with dementia	[7, 9, 11]	„Physicians should be able to explain exactly how patients, for example, are impacted daily by forgetfulness: The statement merely forgetting their name does not provide enough information. The additional information that comes from family members, namely that the patient forgets the names of his children or other pertinent personal information like his age, directs attention to dementia.” [7]
Adequate point of making a diagnosis	Risk of disavowing signs of illness and disregarding advanced planning	[1, 10-12]	„But there is also the opposite risk that out of a laudable wish to preserve a person’s freedom and to avoid giving false label to an existential problem, signs of illness are missed and the ill old person is denied necessary and effective treatment.” [1]
	Respecting psychological burdens in breaking bad news	[7, 8, 11, 13]	“we have to recognize that the process of being assessed and, as it were, having the disease and the status of illness thrust upon you, which is how it might seem to the person concerned, is upsetting.” [8]
	Underestimation of the relatives’ experiences and assessments of the person with dementia	[7, 9, 11]	„We were told of many instances of the concerns of relatives or the person themselves that ‘something was wrong’ being incorrectly dismissed by general practitioners or hospital doctors. This left people with early dementia, and their families, without access to support.” [9]
Reasonableness of treatment indications	Overestimation of the effects of current pharmaceutical treatment options	[4, 14]	“Researchers do not dispute the modest benefits of cholinesterase inhibitors in treating cognitive impairments. There is also wide acknowledgement that many individuals do not respond. Clinicians are faced with a ‘sense of hope’ they gain from prescribing something that might have some minimal effect on some unidentifiable subgroup, and the ‘despair of having no treatment options at all’.” [4]
	Considering challenges in balancing benefits and harms (side effects)	[1, 9, 14-16]	„A risk-benefit assessment further encourages the person carrying it out to consider the risks of not providing or permitting the activity in question: for example the risks of walking outside or alone should be weighed against the risks of prolonged sitting, boredom and frustration.” [9]
	Not considering information from the patient’s relatives	[9, 17-19]	„Where assessment shows that the patient lacks mental capacity, relatives, carers or others close to the person should be consulted to throw light on what the incapacitated person would have wanted.” [19]
Adequate appreciation of the patient	Insufficient consideration of the patient as a person	[1, 3, 7, 9, 11, 20-24]	„The radical differentiation between the formality intact or ‘then’ self and the currently demented or ‘now’ self, as put forward by some commentators, is simply a misrepresentation of the facts. The reality is that until the very advanced and even terminal stage of dementia, the person with dementia will usually have sporadically articulated memories of deeply meaningful events and relationships ensconced in long-term memory. [...] This is why it is essential that professional caregivers be aware of the person’s life story, making up or losses by providing cues toward continuity in self-consciousness. Even in the advanced stage of dementia... one finds varying degrees of emotional and relational expression, remnants of personality, and even meaningful non-verbal communication (as in the reaching out for hug).” [22]
	Insufficient consideration of existing preferences of the patient	[1, 8, 9, 11, 14, 15, 21, 24-34]	„doctors often rate the quality of life of the patient as lower than the patient perceives it, and the life itself of lower value than the patient rates it. The only way to face ethical dilemmas about treatments is to ask the patient about their perception of their quality of life and their treatment preferences.” [29]
	Problems concerning understanding and handling of patient autonomy	[1, 9, 10, 24, 35, 36]	„protecting negative rights is insufficient. People with dementia need positive rights - support from social care (such as help with communication and decision-making) - to enable them to exercise autonomy.” [35] “A second factor to be considered when applying the principle of respect for autonomy is that the locus of decision making must be the patient. There are cases in which what is in the patient’s best interest may be contrary to the wishes of the family. Although it is extremely rare for families not to want what is best for the patient, the family’s understanding may be inaccurate or incomplete.” [24]

2. Assessing patient decision-making competence (PDMC)		Ref.	Quotations for illustration
Ambiguity in understanding competence		[1, 8-10, 20, 21, 36-41]	<p>“In answering the question of whether the person is unable to make the decision, you should seek to understand whether the person: has a general understanding of the decision that they need to make and why they need to make it; has a general understanding of the likely consequences of making or not making this decision; is able to understand, retain and weigh up the information relevant to the decision; can communicate their decision (by talking, using sign language or any other means)” [38]</p> <p>“It is also paradoxical that respect for autonomy might involve respecting the non-autonomous decisions of the person: ‘non-autonomous’ in that they are made - in the case of some - without insight and without the requisite capacity for the person to exercise true autonomy.” [8]</p>
Problematic aspects in PDMC	Inadequate assessment	[1, 6, 9, 21, 41-43]	<p>“Many patients with dementia are ambulatory, respond to stimuli, and are able to communicate, even if in a rudimentary manner.” [42]</p> <p>“The issue of patient decision-making competence was not a topic of debate or discussion at all among the observed health care professionals. Health care professionals never explicitly asked themselves, or discussed with each other, whether or not a patient was able to take a specific decision.” [41]</p>
	Inadequate consideration of setting or decision content	[1, 9, 10, 43, 44]	“Clinicians also should be mindful of the possibility of incapacity in patients in certain settings, namely long-term care facilities, medical-surgical inpatient units, and hospice. The evaluation of a capacity is distinct from the evaluation of the overall competence to manage one’s affairs, in that the latter involves a formal judicial process, including the selection of a guardian.” [10]
	Disregarding the complexity of assessing authenticity	[1, 9, 21, 39, 45, 46]	„In determining the validity of living wills the physician cannot call into question the authenticity of a living will merely with the argument that a decision is “unreasonable”, or by pointing out that “better” medical treatment is possible. Many authentic decisions made by individuals exercising their self-determination may seem to be unreasonable, whereas they do not violate the right of self-determination in a democratic society.” [45]
	Underestimation of the relatives’ experiences and assessments of the patient	[7, 9]	“Already in the early stages of dementia, questioning the patients relatives or trusted acquaintances about the decline of their cognitive abilities or the deterioration of performance can help confirm the diagnosis.” [7]

3. Information and disclosure		Ref.	Quotations for illustration
Respecting patient autonomy in the context of disclosure		[1, 9, 10, 15, 20, 37, 41, 44, 47]	<p>“For example, asking ‘Even if it is bad news, do you want to be told what we have found from our testing? Do you wish to know your diagnosis?’ are questions that give us an indication of the patient’s wishes.” [44]</p> <p>„in many cases, the difference between ‘the truth’ and a ‘white lie’ may not be as clear as first appears.” [9]</p>
Adequate amount and manner of information		[1, 9, 11, 13, 15, 20, 21, 44, 47]	“The information may need to be conveyed slowly and may need to be repeated, but there can be a genuine negotiation or interpretation of meaning and understanding between the professional and the person with dementia.” [21]
Adequate involvement of relatives		[9, 13, 43, 44]	“However, if the patient refuses to allow contact when the clinician believes it would be in the person’s best interest, the clinician should assess the capacity of the person to make such a refusal, and assess the likelihood of a negative outcome and attempt to convince the person if involving family would be in the person’s best interest“ [43]
Consideration of cultural aspects		[9, 43]	„When patients refuse permission to contact others in the non-emergency situation, the clinician must weigh the risks and benefits of acting beneficently, but in cultures in which the principle of autonomy is a central value, the request by an elder that others not be contacted should be respected in the absence of any medical or psychiatric condition that undermines their capacity to make autonomous decisions (Perez-Carceles et al., 2005). In cultures in which such decisions are made by family consensus or a family spokesperson, the clinician should balance legal standards of care, an appreciation of the cultural standard, and whether an emergency situation is present and requires immediate action.” [43]

4. Decision-making & consent		Ref.	Quotations for illustration
Improvement of patient decision making competence (PDMC)	Risk of inadequate involvement of the patient in the decision-making process	[17, 20, 33, 37]	“In the early stages, patients with dementia have the capacity to undertake decisions with regard to their treatment (i.e. they can choose to accept or refuse), and therefore should not be treated any differently from other patients but instead be allowed to exercise that choice. [...] while a person with dementia has capacity, there should be full discussion with him or her and his or her carers on the use of: advance statements on what action should be taken if the person loses the capacity to make decisions; advance decisions to refuse treatment; lasting power of attorney; a preferred place to care” [17]

	Risk of insufficient conditions for fostering decision-making capacity	[1, 9, 10, 48]	“Reduce the emotional pressure associated with the decision. This pressure may be intrinsic to the decision - all possible options may seem equally frightening, for example. Or it may come from external sources, such as conflicting views among different family members.” [1]
	Risk of disregarding the need of continuous relationship-building with the patient as a means to foster patient autonomy	[1, 9, 20, 37]	„the therapeutic relationship should not only respect, but actually promote the autonomy remaining during the different phases of the disease in order to define shared existential, therapeutic and welfare objectives, and avoid ‘automatic’ decisions and practices relating (for example) to institutionalization and life support treatments.” [37]
	Risk of setting the time for decision-making processes too short	[1, 9]	“Perhaps the most important issue is time. People with dementia cannot be rushed into decisions and a structured, clear approach by a person or persons can go a long way towards bringing about a resolution where the affected person is expressing wishes that are not in their family’s best interests.” [9]
	Risk of weakening PDMC by infantilization	[9, 11]	“Interactions with professional caregivers may also silence the person with dementia and sometimes also family members [...]. This is especially true if sufferers perceive that they are not taken seriously or are ignored or treated like children” [11]
Responsible surrogate decision-making	Adequate handling of „best interest“ and „substituted judgments“ decisions	[1, 8-10, 15, 20, 21, 24, 35, 36, 39, 43, 49-56]	“Surrogates face a number of additional challenges. For example, a study of 81 surrogate decision-makers found that only 73% had correctly identified their family members’ resuscitation orders, and only 47% demonstrated good understanding of the clinical situation. [...] Family members of patients who had advanced dementia identified the following barriers to surrogate decision-making: unrealistic expectations of patients, not having had discussions with patients about preferences (or waiting too long to do so), and patients’ denial of dementia.” [10] “Hence the dilemma faced by physicians and proxies: how to balance the actual preferences of the person with dementia against the patient’s earlier opinions laid down in a now forgotten advance directive.” [55]
	Inadequate communication with relatives	[1, 3, 9, 19-21, 23, 57-63]	“is important that the quality of the relationship between the health care provider and the family caregiver can also be crucial to the provision of care for PWDs and has been shown to assume great importance in situations such as the considerations of end-of-life decision making in the long-term care setting.” [3]
	Inadequate handling of information stemming from relatives	[1, 9, 19, 37, 58, 64]	„The central problem in this case was that there were conflicts of opinion within the family and between the family and the physician.“ [64] “While the role of family and carers is often crucial to safe care of such older patients, it is very important that the wishes and views of older people are not bypassed in favour of family members or carers.” [19]
	Need of advanced planning	[1, 9, 10, 17, 20, 32, 43, 60]	“It is a mistake to wait until the patient is too ill to participate in shared decision making, at which time family consensus building and surrogate decision making will be necessary substitutes for personal autonomy. This may create added stress and conflict among family members who have perceived differences as to the wishes of the patient.” [32]
	Risk of disregarding legal clarifications	[1, 9, 20]	“Certain difficult decisions will require a declaration from the court that the treatment is indeed in the patient's best interest.” [1]
Adequate consideration of living wills/advance directives	Challenges in interpreting the living will/advance directive	[1, 20, 25, 37, 45, 51, 55, 65]	„Some people consider life with dementia to be worse than death and they write advance directives to make sure they will not receive any life-prolonging treatment in the event that they become demented. When they indeed do become demented, however, they may appear tranquil and happy, and it may seem absurd to say that their lives are terrible or that it is better for them not to receive life-prolonging treatment anymore.” [65] “Doubts can arise concerning the competence of the subject at the time the document was drawn up or the amount and type of information given to him/her at that time. Furthermore, changes in the therapy (and therefore the prognosis) of the disease between the time the directives were formulated and the time they are applied may be such as to completely overturn the premises underlying the decision.” [37]
	Challenges in deciding to follow or not to follow the content of the living will/advance directive	[9, 15, 21, 37, 43, 51, 52, 55]	“the Best Interest Standard sets rigorous limits to the bindingness of ADs in two substantively different but formally related dementia modalities: (1) An AD requests that no lifesaving measures be used but the patient is pleasurably demented and faces an acute life-threatening disorder that is easily treated through non-burdensome, minimally invasive procedures. (2) An AD requests that all possible lifesaving measures be used but the patient is painfully demented and suffers from a severe disorder that can only be treated, if at all, through very burdensome, highly invasive procedures.” [52] “advance directives represent a solid moral base on which to take medical decisions concerning a patient who has become incompetent, especially when such decisions involve choices between medical possibilities of which none has been demonstrated to be certainly more valid or between different or even conflicting values.” [37]

5. Social and context-dependent aspects	Ref.	Quotations for illustration
Caring for relatives	[1, 7, 9, 11, 18, 20, 21, 43, 61, 62, 66-68]	<p>“Dementia care should clearly further the life of the person with dementia. However, significant others should also be taken into consideration in the goal of care.“ [62]</p> <p>“Family members also must adjust to the cognitive loss of their loved ones. How they cope may either help or hinder the affected person to deal successfully with dementia. The way in which professional deal with people with dementia and their families also can help or hinder efforts to deal with dementia. At present, the importance of this interaction during early stages of the disease has only been superficially touched on.” [11]</p>
Caring for clinical personnel and professional carers	[9, 21, 62, 69-72]	“Flexibility is therefore an important ingredient, not only in the care process of residents, but also in the administration of staff members in nursing homes.” [70]
Assessment of the patient’s potential to (direct or indirect) harm to others	[16, 17, 43, 73]	„The presence of cognitive disorder or severe mental illness, however, raises the possibility that the person engaging in a high risk activity or behaviour does not have the capacity to make decisions related to its riskiness. When questions of safety arise in individuals with cognitive impairment or severe mental illness at any age, the clinician should either perform an assessment of capacity or refer the person for an assessment of their capacity to determine the specific issue at hand.” [43]
Responsible handling of costs and allocation of limited resources	[1, 4, 9, 10, 17, 74]	“neuroimaging is expensive and labor intensive so that it is important to consider whether this allocation of resources is worth the cost with respect to informing clinical decision making at the individual or societal level. There are times where the rights of the individual are weighed more heavily than those of society.” [74]

6. Care process & process evaluation	Ref.	Quotations for illustration	
Continuing assessment of potential benefits and harms	[9, 14-16, 75]	“Most obviously we should try not to do things which cause harm, but we may also be obliged to stop or prevent processes which are causing harm to an individual.” [15]	
Adequate patient empowerment	Patient-oriented setting	[7, 9, 17, 19, 20, 76]	“The patient’s home should be adapted in order to make movement and walking easier and to reduce the risk of falls.” [76]
	Activation of patients	[7, 11, 12, 77]	„Successful proactive care programmes must acknowledge the importance of involving them as active and dignified participants in their own care. In addition, because both dementia sufferers and their families must adjust together to cope, professional caregivers must consider their concerns seriously.” [11]
Self-reflection of carers	Attitudes towards dementia patients	[9, 17, 75]	“It is not uncommon to note that a physician, after having assessed the patient, talks to the carer as if the patient were not in the room, thus ignoring the patient’s feelings. It is important for us as professionals to recognize the loss of cognitive function does not mean total loss of emotions and human values.[...] any discussion that takes place should involve the patient.” [17]
	Reflection on conflicts of interests and values	[9, 17, 37, 43, 78, 79]	“It could be that, in this style of working, there is little room for critical reflection on one’s practice. The fact that value conflicts are not experienced as being problematic does not necessarily imply that they are not problematic.” [79]
	Continuing education/capacity building of the carers	[9, 11, 43, 69, 80, 81]	“Overt acknowledgment of the ethical nature of the difficulties facing carers, a willingness to discuss matters of values as well as matters of fact, some grasp of alternative ethical viewpoints to allow informed discussion - all these might make a positive contribution to the support given to carers.” [80]
Evaluation of abuse and neglect	[9, 10, 43]	“The abuse of people with dementia by people caring for them raises particular ethical issues, because of the complex relationships and dependencies involved. While definitions of abuse differ, it is widely accepted that the concept extends beyond physical or sexual abuse to psychological and emotional harm, financial exploitation and neglect.” [9]	

7. Special situations for decision-making	Ref.	Quotations for illustration
Ability to drive	[10, 17, 20, 43, 73, 82]	“Such borderline cases with mild dementia must be referred to specialized driving centres for comprehensive on-road testing, and it is our society’s obligation to ensure that such testing is available in a timely and affordable manner.” [82]
Sexual relationships	[9, 10]	“Although sexual activity declines with age, a substantial proportion of older adults, including those who have cognitive impairment and those living in long-term care facilities, remain sexually active. The potential for abuse or exploitation exists, but the capacity of the older adult to consent to a sexual act has been poorly studied.” [10]
Indication for genetic testing	[10, 20]	“In dementia care, a number of challenges arise [...], including (1) genetic testing of patients and family members for irreversible, neurodegenerative conditions;” [10]

Usage of GPS and other monitoring techniques	[9, 21, 83-85]	„the major benefits of electronic tracking using GPS systems were related to the peace of mind of the carers themselves. Although there is no basis to suspect that they did not want the best for the demented person, there is no guarantee that the demented persons would make the same choices about their lives as did their family caregivers and their professional care providers.” [83]
Prescription of antibiotics	[16, 53]	“we must ask whether the interests of the patient are being served by using antibiotics. We must further ask whether the use of antibiotics in each specific patient justifies the risk placed on others by their use” [16]
Prescription of antipsychotic drugs	[9, 10]	“Much has recently been written about the way the anti-psychotic drugs, in particular, have been overused in people with dementia, and this is of particular concern given evidence that use of anti-psychotic medicines in people with Alzheimer’s disease and dementia with Lewy bodies is associated with a shortened life expectancy” [9]
Indication for brain imaging	[9, 74]	“Moreover, it is not yet known how well these scans or CSF tests will work in larger older populations, and hence how useful they will be as an accurate diagnostic tool: a major postmortem study has found a high frequency of individuals showing significant signs of amyloid deposits, which would have appeared as ‘positive scans’, regardless of whether the person in fact experienced any signs of dementia during their life-time” [9]
Covert medication	[21, 86, 87]	“What about when the patient is given medication secretly in food or drink? It cannot be said that the person has consented to take this medication. It is not only covert medication, but also coerced medication.” [21]
Restraints	[8, 9, 17, 20, 37, 72, 74, 88, 89]	“When treatment is both life-prolonging and in the patient's best interests, there would need to be strong justification for not using restraints if restraints are essential to treat.” [88]
Tube feeding	[9, 10, 17, 20, 21, 30, 42, 43, 54, 63, 90-92]	“There is no evidence that a PEG generally achieved any of the desired treatment goals. False hopes and expectations for family members and caregivers had to be corrected. [...] The crucial question in the treatment of patients with advanced dementia should not be, PEG or not PEG?”, but: What are the most important preferences of the patient that fit into their concept of life and that they receive an appropriate palliative treatment (adequate space, care, and the proximity of confidants, etc.)?” [63]
End of Life / palliative care	[9, 20]	„there is evidence that people with dementia experience poor care at the end of their lives, with badly controlled pain, little control over the place and manner of their death, and significant stress on their carers. Moreover, recent research in the UK has suggested that amongst older people who die in hospital, those who have dementia are less likely to receive palliative medication, are less likely to have attention paid to their spiritual needs, and are less likely to be referred to palliative care specialists than people who do not have dementia” [9]
Suicidality	[28, 46]	“studies show, that many individuals with dementia enjoy human interaction, physical and mental activity, and other aspects of living even as the disease progresses. Thus, the comment I hear from many cognitively intact adults, ‘I wouldn’t want to live that way,’ does not seem to be true for the majority of people who develop dementia.” [28]

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