

Advance Care Planning for People with Dementia: The Role of General Practitioners

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Abstract

General practitioners (GPs) play a key role in the timely diagnosis of dementia and also in advance care planning (ACP). They often have known patients and their families for decades and are familiar with their values and treatment preferences; they are, therefore, in a position to initiate the ACP process even before the appearance of the first symptoms of dementia and certainly following disclosure of the diagnosis. To do so, they should recognise whether patients are receptive to an ACP consultation or whether they might reject it for personal, social or cultural reasons. Under no circumstances should the patient or their family be coerced into making these provisions. In most countries, the current framework does not provide enough time and money for GPs to carry out actual ACP consultations completely on their own. There is evidence that specially trained health professionals are able to more effectively discuss treatment goals and limits of life-prolonging measures than GPs who are well acquainted with their patients. Consequently, we suggest that it will be the GPs' task to seize the right moment for starting an ACP process, to raise

awareness of patients and their relatives about ACP, to test the patient's decision-making capacity and, finally, to involve appropriately trained healthcare professionals in the actual ACP consultation process. Care should be taken that these professionals delivering time-intensive ACP consultations are not only able to reflect on the patient's values but are also familiar with the course of the disease, the expected complications and the decisions that can be anticipated. The GP will ensure an active exchange with the ACP professional and should have access to the documentation drawn up in the ACP consultation process (treatment plan and advance directive including instructions for medical emergencies) as soon as possible. GPs as coordinators of healthcare provision should document appropriately all specialists involved in the care and ensure that treatment decisions are implemented in accordance with the patient's preferences for future care or the presumed will of the patient.

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Introduction

As the world population is aging, the number of people diagnosed with dementia will increase over the next decades. According to the World Health Organization

Advance Care Planning (ACP) for people with dementia - the role of general practitioners (GPs) - Key messages

1. Look out for warning signs of cognitive decline via subjective cognitive complaints, informant reports or direct observation of GP/health care personnel/practice personnel
2. Discuss subjective/perceived changes with the patient without necessarily naming possible dementia
3. Develop a shared decision about the further workup – respecting the patient's wishes, including a potential refusal of further diagnostic investigations
4. Evaluate the patient's readiness for an ACP process early enough
5. Assess decision-making capacity in a time- and decision-specific way
6. Explore whether the responsibility for the entire ACP process can be assumed alone, depending on own ACP specific skills; otherwise, involve appropriately trained professionals (ACP facilitators) in time.
7. Initiate the ACP process at the earliest possible moment with the objective of preparing individuals for their own decision making and only later for the situation of their potential future decisional incapacity
8. Consider ACP as a continuous process over time
9. Involve early enough trusted persons (surrogates, family, friends)
10. Link discussion of personal values and life goals to specific medical care plans
11. Create the necessary documentation, such as advance directive and Physician Order for Life-Sustaining Treatment (POLST)
12. Make the results of the ACP process and the relevant documents accessible to all those involved in the patient's treatment and care, while ensuring that the usual rules of confidentiality are observed.
13. Assume responsibility for ensuring that wishes, treatment preferences and anticipated decisions are taken into account also if patients change their health care team or are transferred to a different care setting.

Fig. 1. Advance Care Planning (ACP) for people with dementia – the role of general practitioners (GPs) – Key messages. Sources: Pentzek et al. [8] and Sudore et al. [11].

(WHO), a total of 35.6 million people were living with dementia in 2015. We can assume that this figure will double by 2030, and by 2050 it is likely to triple [1]. General practitioners (GPs) have a key role to play in this context, in both stating and communicating a diagnosis [2].

Disclosing the Diagnosis as a Precondition for Advance Care Planning

It is known that GPs often shy away from disclosing a diagnosis of dementia to a patient and are reluctant to talk about the problems associated with dementia with the patient's family [3, 4]. Nevertheless, when talking to patients and their relatives, GPs are ethically and legally well advised to anticipate events that can be expected as the dementia progresses. This concerns particularly experiences of loss, such as the realisation that patients at some point may no longer be able to care for themselves or even follow conversations. In the USA, states of incapability of decision-making are regulated by the Patient Self-Determination Act [5]. In Switzerland, the law on the protection of adults was introduced

in 2013. In line with the beforementioned legal frameworks, the adult protection law is also driven by the intention to strengthen patient autonomy [6]. In addition, we know today that the majority of patients prefer an early communication of a diagnosis of dementia by their GP [7].

Approaches to Improved Early Detection of Dementia

In order for GPs to facilitate the advance care planning (ACP) process, they first of all must recognise symptoms of dementia and be able to talk about them with the patient and their relatives (Fig. 1). Pentzek et al. [8] performed a meta-synthesis of qualitative studies with GPs on barriers to dementia recognition and developed an approach in cases of suspected cognitive decline in a multi-professional team. With respect to recognition of and diagnostic approach to dementia, 3 major barriers were detected:

- GPs often miss the opportunity to involve their patients in diagnostic decisions: i.e., it is left to the GP whether a cognitive testing is made or not.

- GPs often confound diagnostic steps: i.e., GPs equate early recognition of cognitive decline with specialized dementia diagnostics or with the disclosure of probable dementia. Thus, GPs may feel uncomfortable talking about dementia.
- GPs show a poor self-conception of diagnostic specialties and advantages in their GP setting.

Based on these results, the authors developed an intervention model called the CADIF project (Changing Attitudes towards Dementia in Family Practice). The proposed concept for a transfer into practice emphasises:

- an increased awareness for cognitive warning signs (red flags) among practice personnel, initially independently from test diagnostics;
- a geriatric and personal approach to the patient, offering, for example, medication check and home visits; and
- offering follow-up assessments and monitoring, respecting the patient's refusal of further diagnostic procedures or planning a disease-oriented diagnosis [9].

Such and other efforts to sensitise GPs to this problem seem gradually to be successful. We have been able to show in a survey among Swiss GPs that they feel confident about diagnosing patients with dementia (except for patients from a migrant background), that they make these diagnoses at a relatively early stage of the illness, and that – since the efficacy of pharmacological therapy is largely inconclusive – they consider it important not to start drug treatment but provide advice to patients and their families and help them write advance directives at an early stage of the illness [10].

ACP in the Context of Dementia

According to recent consensus definitions [11, 12], ACP is a continuing, dynamic process of reflection and discussion between patients, relatives and healthcare professionals, which allows patients, depending on the stage of their illness, to communicate their values and treatment preferences that are important for their further care and particularly for emergency and end-of-life decisions. Alongside this communication process, documenting the content of the discussions about values and treatment preferences in a standardised and medically meaningful way, especially with regard to the desired approach in situations of emergency, are key elements of ACP. It should also be mentioned at this point that an ACP process has not to be waived when a patient has lost the decision-making capacity. “ACP by proxy” is an ethically justified

concept, in which healthcare professionals and the patient's surrogate establish and document the presumed wishes and treatment preferences of the person for anticipated scenarios [13].

ACP Reduces Burden and Stress on Patients and Caregivers

If ACP is undertaken correctly and by appropriately trained professionals, it can help patients maintain autonomy, dignity and intimacy when their health declines and at the end of their life; it helps relatives to experience the grieving process with less morbidity; and there are also hints that ACP has the potential to reduce inappropriate, unwanted hospital admissions and promote more cost-effective use of healthcare resources [14]. It should be stressed, however, that healthcare workers should sensitively explore whether a patient is receptive to the idea of an ACP consultation or whether they might reject it for personal, social or cultural reasons. Under no circumstances should the patient or their family be coerced into making these provisions.

ACP in the Face of Diminishing Decision-Making Capacity

In general, it is assumed that people with dementia lose their capacity to make informed decisions more or less rapidly [15]. Therefore, a time- and decision-specific cognitive and functional assessment is essential to evaluate the decisional capacity as part of a high-quality, continuous ACP process. For this evaluation, GPs often intuitively rely on the criteria explicitly formulated by Grisso and Appelbaum [16], i.e.:

- ability to understand information in relation to decisions to be made;
- ability to appreciate the situation and the consequences of alternative possibilities;
- ability to weight the information received in a rational way in the context of a coherent value system; and
- ability to communicate the own choice.

GPs are generally not trained to make a more in-depth clinical or neuropsychological assessment. They must ensure that they do not overestimate the decision-making capacity of their patients because of the longstanding and very personal doctor-patient relationship [17]. It is, therefore, essential to have such conversations at comparatively early stages of dementia, so that the patients can make

anticipatory decisions in good time and communicate their values and treatment preferences to both relatives and treating physicians [18]. However, there are several barriers on different levels concerning the implementation of this evaluation process in practical everyday life:

- People have difficulties talking about severe illness, dying and death in comparatively healthy days.
- Surrogates and professionals may feel unsure talking about anticipated decisions that could affect the patient's life expectancy [19].
- Professionals do not consider dementia as a terminal illness [20] with a life expectancy of dementia usually estimated as 3–12 years [21].

Although families and clinicians judge dementia as a progressive and incurable disease, the terminal event – often pneumonia or urinary tract infection – is considered unrelated to dementia and the cause of death.

Precisely because of the above-mentioned barriers, people with dementia are a particularly important target group for ACP. Considering the increasing aging of the population, many families will accompany a member with dementia. Particularly difficult ethical questions may arise due to conflicts between previously expressed preferences of the patient and their current behaviour, especially in cases of personality change.

Who Should Initiate ACP for People with Dementia?

In Central Europe, it is only in the last 10 years that there have been attempts to implement ACP in very different ways and among very different populations, involving different healthcare specialists, while the majority of scientific studies on ACP, including systematic reviews, have been performed in the USA, Canada, the UK, Australia and New Zealand, countries with a tradition of ACP sometimes dating back more than 20 years. Regarding the role distribution, there might, therefore, be differences important for a successful ACP implementation due to different healthcare structures and professional roles. Yet, there is now an international consensus that:

- healthcare professionals should inform patients and their families about the possibility of ACP;
- a trained non-physician facilitator is able to support an individual in the ACP process;
- initiation of ACP can occur within or outside of the healthcare setting; and
- appropriate healthcare providers are needed for clinical elements of ACP, such as discussing diagnosis, prognosis, treatment and care options [12].

ACP Should Be Implemented and Regulated on the Level of Healthcare Systems

Besides necessary skills and structures on the micro-level, recently, the importance of system approaches and regulations on the meso- and macrolevel of institutions, regions and national structures to support ACP is considered as a necessary precondition for high-quality ACP programmes. It is important that consistent regulations should be in place for a whole healthcare system on when ACP should begin, who should be empowered to do so and in what framework ACP should take place.

An expert task force set up by the Swiss Federal Office of Public Health has recommended that people at comparatively healthy stages should be asked, e.g., by their GP, about their values and treatment preferences and that they should be supported to voluntarily initiate an ACP process together with an appropriately trained professional [22]. Depending on the content of the consultation, this professional should have a deep understanding of ACP-relevant concepts. This includes a primary rooting of the whole advance care plan on individualised goals of care – rather than single disease-specific measures – and differentiating therapeutic goals for the relevant situations of incapability of decision-making (i.e., emergency, situations of acute disease with unclear prognosis and chronic states of incapability of decision-making). In addition, more specific medical knowledge to anticipate, in conversation with the patient, certain situations that can be expected in the course of the disease is helpful to specify, for example, an individualised emergency plan with the physician.

The Role of GPs in Facilitating the ACP Process

This raises the question about the role of GPs in facilitating the ACP process, in carrying out time-consuming ACP consultations and in documenting the results of this process. Often, it will be the GPs' task to translate the appropriate values and treatment preferences into concrete medical decisions and measures as the illness progresses. GPs will frequently also be the link to the relatives of the affected person, either informally or in a planned way. Assuming that a caregiver is generally integrated into the ACP process, it is also part of the GP's role, if the patient gives his/her consent to involve the wider family, to create an understanding about the course of the illness and the decisions made by the patient and, finally, to recognise the relatives' needs more generally and respond to them [23].

If a person with dementia is no longer able to communicate verbally, GPs can help understand the emotional expressions of the patient and adapt treatments accordingly. Ideally, the significance of emotional statements in advanced stages of the disease should already be recognised and discussed in the early ACP process. Concretely, the patient may specify whether they would prioritise future behavioural signs of wellbeing (and hence life-prolonging treatment) over advance refusals of care, or the reverse [24]. This could be documented in a dementia-specific advance directive.

Although it is expected in national policies that healthcare professionals and specifically GPs will provide ACP support within their existing roles [25], qualitative studies in countries with an established tradition of ACP have shown that even in these healthcare systems only a minority of physicians actually carry out ACP consultations on a regular basis. The apparent reasons for this are lack of time as well as insufficient knowledge, skills and self-confidence [26]. Healthcare professionals seem to have great concerns implementing ACP in practice for people with dementia, expressing uncertainty over the value of ACP, grounded in an anxiety to deliver patient choice, especially in dementia care [27].

What Is the Ideal Moment to Start an ACP Process?

Patients, their relatives and GPs emphasise that the earlier ACP process starts, the easier it is [28], but apparently, there is nevertheless considerable uncertainty about when ACP should be initiated, not only among GPs but also among patients and their relatives [29, 30]. Triggers for offering an ACP process could be experiences of loss, such as losing the abilities to work, drive a car or care for oneself, as well as transitions like moving to a nursing home or becoming dependent on care [31, 32]. As the disclosure of a dementia diagnosis is a critical, vulnerable moment in the life of the person affected, the ACP process may be more appropriately initiated either before symptoms of dementia are perceptible or once the patient has coped with the new diagnosis and comprehended the course of the illness and the potential decisions that may need to be made in the future. Generally, it is advisable to initiate an ACP process before a deterioration in the health status or an acute life-threatening situation, such as sepsis, pneumonia or femoral neck fracture, occurs.

The wrong assumption that engaging in ACP inevitably means that one loses decision-making capacity soon after initiating the process is undoubtedly an obstacle to

ACP. In the “Consensus Definition from a Multidisciplinary Delphi Panel,” it is clearly stated that ACP corresponds to a continuum over a longer period of time, that it is primarily about preparing individuals for their decision-making for future treatments in cases of incapability of decision-making and later, more specifically, for the situation of a no longer existing decision-making capacity and more specific medical treatment [11].

For patients with mild forms of dementia, certain discussions and making anticipated decisions are possible with limited decision-making capacity. However, it will in many cases be too late to initiate an ACP consultation if this is left until the patient enters a nursing home. In Switzerland, 47% of all residents of nursing homes have a diagnosis of dementia: of these, 40% have severe, 31% moderate and 29% mild dementia [33]. Many people only enter a nursing home when their cognitive abilities no longer allow them to remain in their own domestic environment. It has also been shown that after entering a nursing home the moment for initiating ACP is often missed [34] or the ACP process is inadequately implemented [35], also clearly hinting at the usefulness of an early initiation of the ACP process in healthy days of life.

Conclusions and Recommendations

GPs have undoubtedly an important role in the context of the ACP process for people with dementia. The population has a low threshold in accessing GPs; often, whole families have a relationship of trust with their GP that has developed over many years. In addition, through conversations and experiences around different facets of health and personal life, GPs are often aware of the values and treatment preferences of patients and their relatives. In addition, GPs, as they visit their patients at home, are familiar with their social environment.

In accordance with recently published recommendations [36], it is certainly one of the GPs' core responsibilities to incorporate ACP into primary care before dementia robs patients of their decision-making capacity [37–39]. If dementia has already been diagnosed, GPs should identify the right moments to initiate an ACP process. This includes the period after coping with the diagnosis [12], experiences of loss, any transitions and, of course, any deterioration in health status or a life-threatening situation.

It is not necessary that GPs assume the full responsibility for the actual ACP consultation. Other healthcare professionals, such as advanced practice nurses, social work-

ers or chaplaincy, often have even better conditions to perform this task if trained in ACP-specific skills. What is important is that these healthcare professionals communicate closely with the responsible GP and that patients and their relatives have confidence in their ACP facilitator.

Even if GPs assign the ACP conversation to specially trained professionals, it is of utmost importance that they have access to the documents generated in the ACP process as early as possible. It will generally be the GP's task, as coordinator of the healthcare professionals involved in the treatment, to make the results of the ACP process and the relevant documents accessible to all those involved in the patient's treatment and care, while ensuring that the usual rules of confidentiality are observed [40].

The noblest functions of GPs include implementing the declarations made by the patient, his or her treatment preferences, the wishes set down in the documentation and the order in the medical emergency plans. Since not all imaginable situations in the course of the illness can be anticipated, it will sometimes be unavoidable, despite the exemplary implementation of ACP, to consult with the surrogate appointed by the patient and all the healthcare professionals involved in order to do justice to the "presumed will" of the patient [41]. To minimise the burden on relatives, particularly in countries where legislation transfers a high degree of responsibility to them for decisions made at the end of life, it is important that these decisions are ultimately backed up by the whole team involved in the treatment.

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