

## Planning ahead with dementia: what role can advance care planning play? A review of opportunities and challenges

Bosisio Francesca<sup>ab</sup>, Jox Ralf J<sup>ab</sup>, Jones Laura<sup>ab</sup>, Rubli Truchard Eve<sup>ac</sup>

<sup>a</sup> Chair of geriatric palliative care, Lausanne University Hospital and University of Lausanne, Switzerland

<sup>b</sup> Palliative and supportive care service, Lausanne University Hospital and University of Lausanne, Switzerland

<sup>c</sup> Service of geriatric medicine and geriatric rehabilitation, Lausanne University Hospital and University of Lausanne, Switzerland

<sup>d</sup> Institute of Humanities in Medicine, Lausanne University Hospital and University of Lausanne

### Summary

Advance directives emerged in the 1960s with the goal of empowering people to exert control over their future medical decisions. However, it has become apparent, over recent years, that advance directives do not sufficiently capture the temporal and relational aspects of planning treatment and care.

Advance care planning (ACP) has been suggested as a way to emphasise communication between the patient, their surrogate decision maker and healthcare professional(s) in order to anticipate healthcare decisions in the event that the patient loses decision-making capacity, either temporarily or permanently. In more and more countries, ACP has become common practice in planning the treatment of terminal diseases such as cancer or amyotrophic lateral sclerosis. However, even though neurodegenerative dementia results in the gradual loss of decision-making capacity, ACP is still extremely rare. There are several reasons for this. Firstly, some people have difficulties talking about illness and death, especially when this involves anticipation. Secondly, lay people and professionals alike struggle to consider Alzheimer's disease and similar forms of dementia as terminal diseases. Thirdly, although patient decision-making capacity gradually decreases with the progression of dementia, the patient retains the ability to communicate and interact with surrogates and professionals until the later stages of the disease. Therefore, surrogates and professionals may feel unsure or even ambivalent when enforcing advance directives, in particular when those decisions may shorten a patient's life expectancy. Finally, to be effective, existing ACP interventions should be adapted to patient's cognitive impairments and lay out dementia-specific scenarios.

Current WHO estimates indicate that by 2050 one out of four people will potentially have to take care of a relative with cognitive and communication impairments for several years. In Switzerland, the Federal Office of Public Health and the regional states have established national strategies on dementia and palliative care. These strategies em-

phasise the need for ACP as a means to prepare patients and their relatives for future decisions, as soon as someone is diagnosed with dementia. This moment is thus especially conducive to develop appropriate processes to prompt the elderly and people diagnosed with dementia to engage in ACP. Therefore, the aim of the present paper is to identify the benefits and challenges of ACP in dementia care, outline strategies to design appropriate procedures and tools, and provide professionals, patients and their relatives with opportunities to engage in ACP.

**Keywords:** Advance directives, advance care planning, dementia, care plan, Alzheimer's disease

### From advance directives to advance care planning

Over the last few decades, the use of innovative technologies and strategies in healthcare have increased opportunities for prevention and treatment of life-threatening illnesses. Consequently, people with these diseases are faced with healthcare decisions more frequently and these decisions present more diverse choices than before. One of the first responses to this situation was the development of living wills (advance directives), piloted in the United States in the 1970s in order to enhance patient autonomy in situations where the patient has temporarily or permanently lost decision-making capacity (DMC). However, clinical practice [1–3], as well as empirical studies [4–6], have demonstrated that advance directives do not give sufficient attention to the complex process of planning care and making end-of-life decisions, which is why they are often ineffective. The situation in Switzerland is reflected in estimates that 70% of the population has thought about completing an advance directive, but only 20% have in fact written one [7, 8].

There are several possible reasons for this lack of implementation. Firstly, many, including professionals, are uninformed about advance directives or reluctant to talk about a worsened health state and the end of life [9, 10]. Secondly,

#### Correspondence:

Francesca Bosisio, PhD,  
Centre Hospitalier Univer-  
sitaire Vaudois, Avenue  
Pierre-Decker 5, CH - 1011  
Lausanne, Francesca.Bosi-  
sio[at]chuv.ch

much of the effort to improve advance directive completion has focused on creating the perfect document and has overlooked the psychological process of decision making and people's wishes regarding the type of planning [11]. Thirdly, even when advance directives are documented, it is not always clear where they should be stored and who is responsible for disseminating and updating them. Finally, even though physicians and surrogates are generally relieved to be able to rely on advance directives to guide their decisions, doubts may persist about their authenticity and validity [3]. Moreover, advance directives can be ambiguous or difficult to apply in concrete situations [3, 12].

Advance care planning (ACP) is a concept that emerged in the US in the 1990s [13] and gained momentum over the following two decades [14], with increased international visibility. Advance directives form one part of the comprehensive process of ACP, which is conceived as a more systemic healthcare intervention. Whereas advance directives can be lawfully filled in by one person alone, ACP usually involves one or several face-to-face meetings with a healthcare professional specifically trained to initiate and guide ACP conversations [2, 13, 15, 16]. During these conversations, people are prompted to "identify personal values, reflect on the meanings and consequences of anticipated illness scenarios, define goals and preferences of care for these situations, and issue appropriate documents and legal instruments that will help direct future healthcare decisions" [3] (page 167). It is highly recommended that the ACP process also involve family members or future healthcare surrogates. Indeed, the goal is to orient and empower these persons to implement advance decisions and to make informed surrogate decisions in line with the patient's preferences in the event that the patient cannot make or express their wishes in unanticipated situations [3,

11, 12]. For this reason, ACP promotes a *relational*, rather than *individual* autonomy [3, 17, 18].

Most existing ACP programmes involve professional training, conversation prompts, decision aids, and advance directives to document anticipatory treatment decisions (see table 1 for examples of the most widely known and published ACP interventions and documentation in English and German). Some ACP programmes or modules within programmes are designed to address specific illness scenarios (see table 1 last column). A summary of the general benefits and remaining challenges of ACP are presented in table 2.

## Benefits of advance care planning in dementia

Life expectancy is increasing and the global population is ageing [30]. In the coming years, an exponential increase in the number of people diagnosed with dementia is expected. The World Health Organization (WHO) [19] estimates that the global prevalence of dementia among people over the age of 60 years is currently 6–9%. This rate is predicted to double by 2030 and triple by 2050 as a function of population aging. One consequence of this is that large parts of the population will have to take care of a family member with cognitive, emotional and/or communication impairments [5].

Taking care of someone with dementia poses a significant challenge for both relatives and professionals. Cognitive impairments may fluctuate and be difficult to assess in concrete clinical situations [20]. Even in the early stages of the disease, DMC may be selectively or temporarily impaired due to exacerbations or acute complications, such as infections or trauma [21]. Others may retain DMC with respect to medical treatment, at least during lucid periods, into the

**Table 1:** Examples of the most widely known and published ACP interventions and documentation in English and German.

Programme	Country	Contents				
		Professional training for facilitators	Conversation guides	Decision aids	Physician orders and advance directive forms	Includes additional disease-specific materials
Respecting choices® [14]	USA	Face-to-face	Yes	Written	Yes	Not to be determined
Advance care planning – Zurich University Hospital [16]	CH	Face-to-face	Yes	Written, Videos	Yes	No
Speak up [19]	CA	Webinars	Yes	Written	Yes	Cancer Prostate cancer
Respecting patient choices [20]	AUS	Webinars, seminars, face-to-face	Yes	Written, videos	Yes	No
ACP New Zealand [21]	NZ		Yes	Written, videos	Yes	No
Serious illness conversation [2]	US	Face-to-face	Yes	No	Refer to existing legal tools	No
Goals of care [22]	US	None	Yes	Written, videos	Refer to existing legal tools	Dementia

AUS = Australia; CA = Canada; CH = Switzerland; NZ = New Zealand; USA = United States of America

**Table 2:** Benefits and challenges of advance care planning [4, 13, 23–29].

<b>Benefits</b>	People report gaining clarity about what information and document better translate their values and preferences.
	ACP improves communication and understanding between the (future) patient, her/his relatives, and her/his healthcare providers.
	Proxies and healthcare providers feel more in control after ACP.
	ACP improves patients', relatives' and caregivers' experience of the patient's end of life and facilitate the access to palliative care.
	ACP decreases healthcare costs by preventing unnecessary and/or unwanted procedures [28, 29].
<b>Challenges</b>	Patients, their relatives, and healthcare providers struggle to find the "right" moment to initiate ACP.
	Specific training for ACP facilitators/professionals is still scarce and professionals have a limited readiness to engage in this training.
	It is not clear where documents and medical orders should be stored in order to enable quick and easy access to them when necessary.
	It is difficult for healthcare providers to promote ACP in healthcare systems that do not have conducive funding schemes and incentives for ACP.

later stages of the disease. In the advanced stages of dementia, conflicts between anticipatorily expressed preferences and current behaviour may occur, especially in cases of personality change, thus raising questions about continued personal identity and the priority of critical or experiential interests [22–24].

In Switzerland, the Federal Office of Public Health and the regional states (cantons) have established national strategies on dementia and palliative care [25, 26]. These strategies emphasise the utility of ACP as a means to prepare and empower patients and their relatives for future decisions, particularly when someone is diagnosed with dementia. Indeed, ACP has been shown to be more appropriate than the use of advance directives alone for people diagnosed with dementia [9, 27]. In addition to the benefits listed in table 2, we describe four reasons for the effectiveness of ACP in empowering patients with dementia and their relatives to exert control over future care:

- ACP fosters conversation about dementia-specific illness scenarios;
- ACP can effectively address inconsistencies between advance directives and the patient's observed behaviour;
- ACP emphasises prospective and relational autonomy; and
- ACP may be more adapted to decision making style and needs of elderly people.

#### **ACP fosters conversation about dementia-specific illness scenarios**

The ability to plan ahead requires appropriate information to weigh up the pros and cons of various options [28, 29]. ACP provides patients and their relatives with an opportunity to obtain more information about the disease, its likely course, expected problems and therapeutic options [31, 32]. Currently, the diagnosis and stages of dementia are not always explained in a timely manner nor are they fully understood by the patients and their relatives [33, 34]. In addition, dementia is not always acknowledged as a terminal disease even though it often limits the life span [35, 36]. Furthermore, although the person with dementia may have already experienced some cognitive impairment before diagnosis, the point of diagnosis is often the moment at which the families take a more active role in shared decision making [28]. In dementia, decisions may vary in complexity and importance, ranging from decisions on daily life matters to decisions about life or death [37]. Important differences in expectations may exist between people with dementia and their families. Many people with dementia believe that their family would be sufficiently confident and knowledgeable to act on their behalf if they lose DMC, whilst the carers feel poorly prepared to fulfil this role [37, 38]. The person with dementia may also strongly refuse to plan ahead and there may be differences of opinions about whether and how to do it [28]. Within this context, misconceptions about the course of the illness add confusion to the questions about who should make care decisions, when and about what [5, 12, 39]. Gessert et al [12] have highlighted several concerns of families in these situations: “Which changes in patients' conditions are likely or even inevitable? Can impairments in ambulation and

in cognitive capacities be due to the natural course of the disease or to inadequacies in personal or professional attention to the patient? When a feeding tube is forgone, is the family ‘causing’ the death, ‘allowing’ the death or ‘witnessing’ the death?” [12]. Addressing these questions is essential since it allows caregivers to understand their roles and incorporate patients' wishes into care plans [40]. Passively offering written information may not be sufficient to enable families to prepare and make treatment decisions for advanced stages of dementia [28]. ACP may provide people with dementia and their relatives with opportunities to gain further information, increase their general and disease-specific understanding, and discuss end-of-life topics. By providing a structured communication process facilitated by a professional, ACP supports both the patient and the proxies in anticipating decisions under concrete circumstances.

#### **ACP addresses inconsistencies between advance directives and patient's observed behaviour**

Since people with dementia are mostly alert and able to interact with their environment even when they lack DMC, patients could react in ways that are perceived as contradicting the advance care plan they themselves had established at a time of full DMC [41]. Similarly, nonverbal communication – expressions, gestures – could be interpreted as a desire to continue or stop medical treatment, which may conflict with an advance directive [5]. In this context, it is central to assess the patient's DMC. Indeed, as long as the patient retains it, it is possible for them to change their written instructions at any time. However even when DMC is impaired, surrogates and professionals may want to take current non-verbal communication and patient behaviours into consideration when implementing previously documented decisions. Thus, dementia-specific ACP should include strategies designed to help the patient, their family and professionals to address those scenarios and prepare them for the personal and ethical dilemmas associated with these situations [5, 42].

#### **ACP emphasises prospective and relational autonomy**

ACP values shared decision making with professionals and relatives. In the event of a loss of DMC, the patient's autonomy is supported not only by documents, but more specifically by the surrogates and healthcare providers who have been involved in the discussions and hence have a sound knowledge of the patient's preferences [3]. This feature of ACP is critical in dementia care. Indeed, advance directives do not preclude the need for ongoing planning with the healthcare surrogate in order to adapt advance decisions under changing circumstances [12]. When deciding on behalf of someone else, the surrogate and relatives in general have a strong desire to do the right thing even if they are not clear about what “the right thing” would be in concrete terms [12]. Some feel apprehensive in becoming the main decision maker [28]. The burdensome effects of dementia – such as the feeling of guilt, a sense of failure when the person with dementia is placed in a long-term care facility and the lack of information on the disease trajectory and its prognosis – leave many family members unprepared to make effective decisions about end-of-life care on the behalf of their relative [43, 44]. In this context, feelings of guilt may increase surrogates' tendencies to opt for

life-sustaining therapies [44]. On the other hand, negative assumptions about the quality of life of the relative with dementia may not reflect the actual experience of that person but may lead surrogates to opt for palliative measures [44]. For all of these reasons and many others, surrogates' predictions of patient wishes are often not accurate, particularly during acute episodes [45, 46] and when scenarios progressively focus on future severe illnesses [37]. In this sense, an essential feature of ACP is to increase the understanding between patients and their surrogates in order to make the latter feel more confident and be more accurate when deciding under concrete circumstances and when facing unanticipated decisions [3, 11].

#### **ACP may be more adapted to decision making styles and needs of older people**

Due to the focus on communication and the early involvement of the patients' surrogates, ACP may be a more appropriate framework to elicit and transmit the decisions of people over the age of 65 in whom dementia is more prevalent.

Firstly, older people tend to focus on the post-death period, such as funeral plans, rather than on the nature of their care prior to death [38]. Moreover, older people fear damaging relationships or appearing insistent when bringing up discussions about the end of life with their relatives and healthcare providers [47, 48]. In a group of elderly patients – possibly with multiple morbidities – discussion about ACP may be addressed as a part of conversations on care planning [49] or post-death arrangements [38], in particular when one of the patient's diagnoses entails the prospect of the loss of DMC. In patients with dementia, an adapted communication process seems more effective than general written aids to provide them with important information about their healthcare [38, 50–53].

Secondly, older people consistently appear to place high priority on communicating their preferences orally, whereas the law generally regards written advance directives as the gold standard [4, 11]. In addition, people seem more interested in conveying their personal values and goals of care than specifying concrete treatment interventions, but the format of most advance directives does not reflect this priority [11, 54]. Similarly, older people repeatedly show the desire to allow trusted others some level of leeway in decision making [5, 11]. However, traditional advance directive forms do not allow this leeway to be conveyed. Most dementia-specific ACP interventions and tools are designed to specifically address the extent of flexibility that patients wish to authorise their surrogates or physicians with in decision making (see for instance ref. 34).

#### **Challenges of advance care planning in dementia**

Despite the evidence of its benefits, ACP is yet to become widely used among patients with dementia. Currently, ACP in people with dementia presents specific challenges. These include, among others:

- Choosing the right moment to initiate ACP;
- Adapting the existing tools to patient's cognitive capacity; and

- Designating someone who is responsible for initiating and managing ACP.

The following paragraphs propose some potential ways of overcoming these challenges.

#### **Choosing the right moment to initiate ACP**

Typically, health professionals are unsure about when to broach the subject of advance directives or ACP [27] and are afraid of inducing anxiety in patients and their relatives [55]. However, there is currently no research to support this concern [56]. Reluctance to address ACP may arise from health professionals' commitment to people's health, whereby addressing complications and the end of life may be perceived as a therapeutic failure [57]. The lack of acknowledgement of dementia as a terminal disease may further contribute to this notion [35]. In addition, even when professionals, patients, and their relatives are willing to engage in ACP, it is challenging to complete a comprehensive ACP process during the rather narrow window between the diagnosis of dementia and patient's loss of DMC [43, 58].

Along with improving healthcare providers' training [27, 59], the literature on breaking bad news and psychological coping may provide avenues to identify the window of opportunity to initiate ACP. Once the diagnosis is understood and accepted, ACP could be presented when addressing the next steps – diagnostic or therapeutic – in order to give the patient some sense of control and promote a solution-based coping strategy [60, 61]. In addition, in some clinical care pathways, the patient and their relatives meet an advance practice nurse several days after the communication of the diagnosis by a physician. The aim of this meeting is to assess whether the patient understood the diagnosis and its implications [62]. Such interviews may also provide opportunities to probe readiness to engage in ACP.

#### **Adapting existing tools to patient's cognitive capacity**

A second key challenge in dementia-specific ACP is the difficulty of adapting the existing tools to the patient's cognitive capacities [43]. In order to be effective, ACP should take the patients' cognitive and communication impairments into account and thus support the expression of their autonomy. Several programmes take learning impairment characteristics of the early stages of dementia into account through the use of video, audio and adapted written decision aids to support patients' understanding of the information upon which to make decisions [32, 40, 43]. During ACP discussions, videos have also been used with written decision aids to help people envision future scenarios [32, 63]. Another strategy to improve their sustained understanding and involvement in the ACP process may be to give patients something to take home after the interview [31]. Brochures or written discussion protocols are common examples. Audio and video recordings of the discussion with the facilitator may also be of particular interest for older people [63]. Regardless of the model, oral information over multiple sessions has been shown to be the most successful intervention to promote advance directives among older adults [6]. This practice also allows ACP professionals to assess the patient's DMC repeatedly and confirm it in a timely way [15, 16]. This may increase the validity of advance decisions and improve their use.

### Designating who is responsible to initiate and manage ACP

Advance care planning requires all parties involved to be committed to a longitudinal process [12]. However, people with dementia are typically older and possibly treated for several concurrent diseases. Many caregivers are responsible for their wellbeing and may potentially benefit from ACP to tailor their care. For this reason, it seems particularly important to discuss here who should bear the responsibility of initiating ACP and how ACP documents should be transmitted to the persons and institutions that may need them later.

There is a consensus in the literature that, in order to improve ACP, healthcare professionals should be responsible for providing patients and their relatives with opportunities to discuss ACP [44, 56]. Moreover, it is likely that the patient and their surrogate would be more open to discussing ACP with someone they have a good relationship with [27], and it can therefore be argued that it is best to train people that are already involved in the patient's routine care. Therefore, the "Serious illness conversations" [2] programme involved the creation of a 2.5 hour programme to train healthcare providers that are routinely involved in patients' primary care to initiate a conversation about ACP. In Switzerland, the Zurich University Hospital also trains primary care providers to lead ACP in acute care settings [15]. In Germany, an ACP programme inspired by Respecting Choices modules has been successfully piloted in nursing homes since 2009 [16]. Up to five nurses or social workers per nursing home were trained as facilitators for this project. On the other hand, the effectiveness of ACP discussions is increased when the facilitator has the opportunity to practice. Moreover, physicians report a lack of time to train for and address ACP in their daily practice [27, 44]. Thus, the Respecting Choices programme trains facilitators who are not involved in the patient's routine care but are available on call [64].

With regard to dementia, it can be argued that the most important factor in improving patient autonomy is having professionals who are specifically trained to communicate effectively with patients with dementia and that ACP interventions are adapted to patients' cognitive impairments [65, 66]. In the future, specific training for facilitating ACP with people at an early stage of dementia may be created.

It is not clear where the advance decisions that arise from ACP discussions should be documented in order to be accessible when they are required. In Switzerland, as in many other countries, electronic patient files are still not interoperable. Thus, whilst waiting for solutions to this problem, key persons such as the surrogate or the primary healthcare provider may be needed to ensure that ACP documents are adequately transmitted to the right persons and institutions.

### Creation and evaluation of a dementia-specific intervention of advance care planning

A dementia-specific intervention of advance care planning (ADIA) tool has been developed and is in the process of being piloted in the Lausanne University Hospital. It has been conceived as a healthcare intervention following the International Patient Decision Aids Standards (IPDAS) criteria for decision aids [67] and the standards of the UK Medical Research Council for complex interventions [68], since it targets more than one population group (patients and their family caregivers), has multiple aims (empower patients and their relatives and improve ACP), and involves a longitudinal process with multiple steps of intervention (described in table 3).

The development of the ADIA intervention was based on a literature review of dementia-specific ACP interventions and ACP for dementia. As part of this process, core values, aims and challenges inherent to dementia-specific ACP were identified, based on the leading bioethical framework of the Principles of Biomedical Ethics and of Care Ethics [69, 70]. Following these steps, a tool that had been developed for ACP in the general population by the Zurich University Hospital [15] was adapted to the situation of people with dementia. The Zurich ACP model framework, called MAPS (Multiprofessional Advance Care Planning and Shared decision making in End of Life situations), is based on the model "Respecting Patient Choices" developed at the Austin Hospital, Melbourne, Australia [20, 64, 71]. We chose to base ADIA on MAPS because the MAPS tool is action-centred [72], it is consistent with the Swiss legal framework and the recommendations of the Swiss Federal Public Health Office [49], and it contains medical orders and decisions aids applicable to people at an early stage of dementia. Moreover, it involves a specific health professional training module.

**Table 3:** ADIA pilot trial schedule and contents.

Visit	0	1	2	3	4
Timing	T0		T1	T1 + 4-6 weeks	T0 + max 3 months
Description	Inclusion	Baseline assessment	Intervention		Post-intervention assessment
Information and consent	X				
Eligibility	X		X	X	X
Sociodemographics		X			
Collect existing advance directives		X			X
Semi-structured interview		X			X
Hospital anxiety and depression scale (HADS)		X			X
Psychological autonomy inventory		X			X
Decisional conflict scale		X			X
Explanation of the intervention			X		
Reflection on values and preferences			X	X	
Documentation				X	
Leader	Principal investigator		Facilitators		Principal investigator

The pilot trial of the ADIA tool aims to assess the acceptability and feasibility of this dementia-specific ACP intervention.

#### Adaptation of the MAPS model

The tool developed by the Zurich University Hospital during the first and second MAPS trials [15, 73] does not specifically address advance decision making for people who have dementia. Therefore, the decision aids, medical orders and advance directives from this tool were adapted specifically for a population of people with dementia.

MAPS includes extensive information-based decision aids about cardiopulmonary resuscitation, respiratory distress, dialysis, artificial nutrition and place of death. Decision aids were forward translated into French (by native French speakers) and backward into German (by native German speakers) [74], following the UNESCO guidelines for informing people with cognitive impairments [75]. Moreover, we added information about dementia and its stages based on documentation issued by Alzheimer Switzerland and the “Goals of care” framework [42]. Since the MAPS model is also partially inspired by the latter, the decision aids about dementia shown in “Goals of care” were an obvious choice to ensure consistency. This information specifically discusses cases in which the behaviour the patient displays seems inconsistent with previously stated advance directives.

As for medical orders and medical advance directives, we adapted MAPS documentation to include dementia-specific decisions. Thus, we added two new sections. The first section allows the patient to indicate whether they want to prioritise comfort treatments, as opposed to life-saving ones, if they fall seriously ill during the moderate and advanced stages of dementia. In addition, it allows them to identify symptoms or situations that they judge to be unbearable. The second section allows the person with dementia to decide whether to give priority to the observed behaviour or the stated advance directives if and when inconsistencies between their behaviour and advance directives are observed in the future [5]. Other medical orders and advance directives provided by the Zurich University Hospital were left unchanged. MAPS decision aids were simplified following the recommendations released by Inclusion Europe and the European Commission on Lifelong Learning Program [76] and experts in the field of communication with people with dementia [66]. In parallel with the development of the ADIA tool, ACP facilitators were selected and underwent the Zurich ACP training in order to be facilitators in the ADIA pilot intervention.

#### Selection and creation of tools to assess the intervention

The primary objectives of this pilot trial are to test the effectiveness of the ADIA tool in supporting patient autonomy through disease-specific ACP, improving participants’ satisfaction and perceived control, and increasing planning decisions and surrogate knowledge of patient preferences. In addition, in light of a lack of consensus about the best outcome measures for ACP interventions [77], this pilot study aims to explore additional appropriate outcome criteria for a future randomised controlled trial. Thus, based on the literature review of pilot studies and randomised con-

trolled trials of dementia-specific ACP, several psychometric scales were selected to test variations in dyad anxiety and depression (Hospital Anxiety and Depression scale [78]), patient autonomy (Psychological Autonomy Inventory [79]), perceived control (Decisional conflict scale [80]), and proxy burden (Zarit Burden scale [81]). In addition, we developed interview guides to explore intervention feasibility, acceptability, documentation of advance directives and proxy knowledge of patient values and preferences. Additional information about this trial can be found in the clinical trials international database [clinicaltrials.gov](http://clinicaltrials.gov).

#### Intervention proceedings and assessment

This intervention involves up to five patient visits (see [table 3](#)). During the first visit, a semi-structured interview will be conducted with the patient and their closest relative, focusing on the patient’s values and treatment preferences, the caregiver’s knowledge of the patient’s preferences, and care planning decisions that have already been made. The researcher will also ask to see any existing advance directives or other advance care planning documents. After the interview, the patient and her/his relative will be asked to fill in the previously described psychometric scales.

During the second visit, the dyad will meet with a trained ACP facilitator who informs them about the intervention. The first conversation between the facilitator and the dyad aims to explain the goals and components of the ADIA intervention and prompt the patient to reflect upon his or her values and preferences for healthcare and discuss them with the caregiver. The patient will be encouraged to name a healthcare surrogate and to invite them to the next meeting. In addition, the facilitator will provide the dyad with written decision aids that they can read at home.

During the third meeting, the facilitator will start by asking to the dyad whether any questions have arisen since the second visit. After that, the conversation with the dyad aims to help the patient to express their preferences and translate them into actionable documentation. This conversation also aims to empower the surrogate to speak for their relative. If necessary, a fourth meeting will be set up with the dyad and the surrogate in order to pursue the conversation and documentation.

The last meeting will involve a semi-structured interview, conducted by a researcher, about the dyad’s subjective experience with the intervention, positive and negative effects, and challenges and suggestions for modifying the intervention. Participants will also be asked to show any documents produced during the intervention or after it. After the interview, the researcher will ask the patient and her/his relative to fill out the psychometric scales outlined previously. [Table 3](#) summarizes the schedule and components of the pilot trial of the ADIA intervention. The intervention started in September 2018 (first dyad included) and will end in September 2019 (last dyad’s last visit). Results will be published thereafter.

#### Conclusions

Patient autonomy is an essential feature of patient-centred care. Advance care planning (ACP) provides the possibility of a prospective, relational autonomy when patients are no longer able to make decisions for themselves. For this

reason, ACP is an appropriate and effective way to improve patient care and prepare surrogates and professionals to make decisions in unanticipated situations. A pre-emptive longitudinal approach fostering open communication of values and wishes, increasing understanding between patients and their surrogates and health care professionals and which includes, but is not limited to, the documentation of an advance directive, is particularly relevant for older people with dementia. The aforementioned ADIA tool aims to investigate the possibility of introducing ACP in this specific population with the aim of mainstreaming ACP and thus promoting patient autonomy and improving care.

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#### Potential competing interests

The authors declare no conflict of interest.

#### References

- Perkins HS. Controlling death: the false promise of advance directives. *Ann Intern Med.* 2007;147(1):51–7. doi: <http://dx.doi.org/10.7326/0003-4819-147-1-200707030-00008>. PubMed.
- Bernacki R, Hutchings M, Vick J, Smith G, Paladino J, Lipsitz S, et al. Development of the Serious Illness Care Program: a randomised controlled trial of a palliative care communication intervention. *BMJ Open.* 2015;5(10):. Available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4606432/>. doi: <http://dx.doi.org/10.1136/bmjopen-2015-009032>. PubMed.
- Jox R. Preparing existential decisions in later life. *Advance care planning.* In: *Planning Later Life Bioethics and Public Health in Ageing Societies.* London and New York: Routledge; 2017. p. 164–80.
- Fagerlin A, Schneider CE. Enough. The failure of the living will. *Hastings Cent Rep.* 2004;34(2):30–42. doi: <http://dx.doi.org/10.2307/3527683>. PubMed.
- Gaster B, Larson EB, Curtis JR. Advance Directives for Dementia: Meeting a Unique Challenge. *JAMA.* 2017;318(22):2175–6. doi: <http://dx.doi.org/10.1001/jama.2017.16473>. PubMed.
- Bravo G, Dubois M-F, Wagneur B. Assessing the effectiveness of interventions to promote advance directives among older adults: a systematic review and multi-level analysis. *Soc Sci Med.* 2008;67(7):1122–32. doi: <http://dx.doi.org/10.1016/j.socscimed.2008.06.006>. PubMed.
- ProSenectute Suisse. Perte de la capacité de discernement: en Suisse, seule une personne sur 10 a pris ses dispositions [Internet]. ProSenectute Suisse; 2017 [cited 2017 Dec 19]. Available from: [https://www.fegems.ch/content/files/2017\\_10\\_03\\_communique-ps-dir-anticipees.pdf](https://www.fegems.ch/content/files/2017_10_03_communique-ps-dir-anticipees.pdf)
- Pautex S, Gamondi C, Philippin Y, Gremaud G, Herrmann F, Camartin C, et al. Advance directives and end-of-life decisions in Switzerland: role of patients, relatives and health professionals. *BMJ Support Palliat Care.* 2015;. doi: <http://dx.doi.org/10.1136/bmjspcare-2014-000730>. PubMed.
- Dempsey D. Advance care planning for people with dementia: benefits and challenges. *Int J Palliat Nurs.* 2013;19(5):227–34. doi: <http://dx.doi.org/10.12968/ijpn.2013.19.5.227>. PubMed.
- Hardy L. La mort incertaine. 2013. <http://www.afif.asso.fr/francais/chronique/hardy/hardysommaire.html>
- Hawkins NA, Ditto PH, Danks JH, Smucker WD. Micromanaging death: process preferences, values, and goals in end-of-life medical decision making. *Gerontologist.* 2005;45(1):107–17. doi: <http://dx.doi.org/10.1093/geront/45.1.107>. PubMed.
- Gessert CE, Forbes S, Bern-Klug M. Planning end-of-life care for patients with dementia: roles of families and health professionals. *Omega (Westport).* 2001;42(4):273–91. doi: <http://dx.doi.org/10.2190/2MT2-5GYU-GXVV-95NE>. PubMed.
- Hammes BJ, Rooney BL. Death and end-of-life planning in one mid-western community. *Arch Intern Med.* 1998;158(4):383–90. doi: <http://dx.doi.org/10.1001/archinte.158.4.383>. PubMed.
- Sabatino CP. The evolution of health care advance planning law and policy. *Milbank Q.* 2010;88(2):211–39. doi: <http://dx.doi.org/10.1111/j.1468-0009.2010.00596.x>. PubMed.
- Loupatatzis B, Krones T. Die Patientenverfügung «Plus» – das Konzept des Advance Care Planning (ACP). *Praxis (Bern 1994).* 2017;106(25):1369–75. doi: <http://dx.doi.org/10.1024/1661-8157/a002854>. PubMed.
- in der Schmitt J, Rothärmel S, Mellert C, Rixen S, Hammes BJ, Briggs L, et al. A complex regional intervention to implement advance care planning in one town's nursing homes: Protocol of a controlled inter-regional study. *BMC Health Serv Res.* 2011;11(1):14. doi: <http://dx.doi.org/10.1186/1472-6963-11-14>. PubMed.
- Christman J. Relational Autonomy, Liberal Individualism, and the Social Constitution of Selves. *Philos Stud Int J Philos Anal Tradit.* 2004;117(1/2):143–64. doi: <http://dx.doi.org/10.1023/B:PHIL.0000014532.56866.5c>.
- Walter JK, Ross LF. Relational autonomy: moving beyond the limits of isolated individualism. *Pediatrics.* 2014;133(Suppl):S16–23. doi: <http://dx.doi.org/10.1542/peds.2013-3608D>. PubMed.
- WHO. Dementia. A public health priority. [Internet]. Geneva: World Health Organisation; 2012 [cited 2017 Jul 26] p. 112. Available from: [http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458\\_eng.pdf?ua=1](http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1)
- Schmitter-Edgecombe M, Parsey CM. Assessment of functional change and cognitive correlates in the progression from healthy cognitive aging to dementia. *Neuropsychology.* 2014;28(6):881–93. doi: <http://dx.doi.org/10.1037/neu0000109>. PubMed.
- Hugo J, Ganguli M. Dementia and cognitive impairment: epidemiology, diagnosis, and treatment. *Clin Geriatr Med.* 2014;30(3):421–42. doi: <http://dx.doi.org/10.1016/j.cger.2014.04.001>. PubMed.
- Berghmans R. Advance directives and dementia. *Ann N Y Acad Sci.* 2000;913(1):105–10. doi: <http://dx.doi.org/10.1111/j.1749-6632.2000.tb05165.x>. PubMed.
- de Boer ME, Hertogh CPM, Dröes R-M, Jonker C, Eefsting JA. Advance directives in dementia: issues of validity and effectiveness. *Int Psychogeriatr.* 2010;22(2):201–8. doi: <http://dx.doi.org/10.1017/S104161020990706>. PubMed.
- Dworkin R. Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom. Reprint. New York: Vintage; 1994. 288 p.
- OFSP. CDS. Stratégie nationale en matière de soins palliatifs 2013-15 [Internet]. 2012 [cited 2017 Oct 4]. Available from: <https://www.bag.admin.ch/bag/fr/home/themen/strategie-politik/nationale-gesundheitsstrategien/strategie-palliative-care.html>
- OFSP. CDS. Stratégie nationale en matière de démences 2014-2019 [Internet]. 2016 [cited 2017 Oct 4]. Available from: <https://www.bag.admin.ch/bag/fr/home/themen/strategie-politik/nationale-gesundheitsstrategien/nationale-demenzstrategie-2014-2017.html>
- Poppe M, Burleigh S, Banerjee S. Qualitative evaluation of advanced care planning in early dementia (ACP-ED). *PLoS One.* 2013;8(4):. doi: <http://dx.doi.org/10.1371/journal.pone.0060412>. PubMed.
- Dening KH, King M, Jones L, Sampson EL. Healthcare decision-making: past present and future, in light of a diagnosis of dementia. *Int J Palliat Nurs.* 2017;23(1):4–11. doi: <http://dx.doi.org/10.12968/ijpn.2017.23.1.4>. PubMed.
- Brooke J, Kirk M. Advance care planning for people living with dementia. *Br J Community Nurs.* 2014;19(10):490–5. doi: <http://dx.doi.org/10.12968/bjcn.2014.19.10.490>. PubMed.
- United Nations, Department of Economic and Social Affairs, Population Division. World population ageing: highlights [Internet]. United Nations; 2017 [cited 2018 Aug 24]. Available from: <http://www.un.org/en/sections/issues-depth/ageing/>
- Butler M, Ratner E, McCreedy E, Shippee N, Kane RL. Decision aids for advance care planning: an overview of the state of the science. *Ann Intern Med.* 2014;161(6):408–18. doi: <http://dx.doi.org/10.7326/M14-0644>. PubMed.
- Volandes AE, Paasche-Orlow MK, Barry MJ, Gillick MR, Minaker KL, Chang Y, et al. Video decision support tool for advance care planning in dementia: randomised controlled trial. *BMJ.* 2009;338:b2159. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2688013/>. doi: <http://dx.doi.org/10.1136/bmj.b2159>. PubMed.
- McCabe MS, Wood WA, Goldberg RM. When the family requests withholding the diagnosis: who owns the truth? *J Oncol Pract.* 2010;6(2):94–6. doi: <http://dx.doi.org/10.1200/JOP.091086>. PubMed.
- Bamford C, Lamont S, Eccles M, Robinson L, May C, Bond J. Disclosing a diagnosis of dementia: a systematic review. *Int J Geriatr Psychiatry.* 2004;19(2):151–69. doi: <http://dx.doi.org/10.1002/gps.1050>. PubMed.
- Arcand M. Enjeux de fin de vie dans les cas de démence avancée: Ire partie : objectifs des soins, processus de prise de décision et éducation des proches. *Can Fam Physician.* 2015;61(4):e178–82. Article also available in English: *Can Fam Physician.* 2015;61(4):330–4.
- van der Steen JT, Radbruch L, Hertogh CM, de Boer ME, Hughes JC, Larkin P, et al.; European Association for Palliative Care (EAPC). White paper defining optimal palliative care in older people with de-

- mentia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med.* 2014;28(3):197–209. doi: <http://dx.doi.org/10.1177/0269216313493685>. PubMed.
- 37 Harrison Denning K, King M, Jones L, Vickerstaff V, Sampson EL. Advance Care Planning in Dementia: Do Family Carers Know the Treatment Preferences of People with Early Dementia? *PLoS One.* 2016;11(7):. doi: <http://dx.doi.org/10.1371/journal.pone.0159056>. PubMed.
- 38 Poole M, Bamford C, McLellan E, Lee RP, Exley C, Hughes JC, et al. End-of-life care: A qualitative study comparing the views of people with dementia and family carers. *Palliat Med.* 2018;32(3):631–42. doi: <http://dx.doi.org/10.1177/0269216317736033>. PubMed.
- 39 Lord K, Livingston G, Cooper C. A systematic review of barriers and facilitators to and interventions for proxy decision-making by family carers of people with dementia. *Int Psychogeriatr.* 2015;27(8):1301–12. doi: <http://dx.doi.org/10.1017/S1041610215000411>. PubMed.
- 40 Stirling C, Leggett S, Lloyd B, Scott J, Blizard L, Quinn S, et al. Decision aids for respite service choices by carers of people with dementia: development and pilot RCT. *BMC Med Inform Decis Mak.* 2012;12(1):21. doi: <http://dx.doi.org/10.1186/1472-6947-12-21>. PubMed.
- 41 Rietjens JAC, Sudore RL, Connolly M, van Delden JJ, Drickamer MA, Droger M, et al.; European Association for Palliative Care. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *Lancet Oncol.* 2017;18(9):e543–51. doi: [http://dx.doi.org/10.1016/S1470-2045\(17\)30582-X](http://dx.doi.org/10.1016/S1470-2045(17)30582-X). PubMed.
- 42 Hanson LC, Zimmerman S, Song M-K, Lin F-C, Rosemond C, Carey TS, et al. Effect of the Goals of Care Intervention for Advanced Dementia: A Randomized Clinical Trial. *JAMA Intern Med.* 2017;177(1):24–31. doi: <http://dx.doi.org/10.1001/jamainternmed.2016.7031>. PubMed.
- 43 Denning KH, Jones L, Sampson EL. Advance care planning for people with dementia: a review. *Int Psychogeriatr.* 2011;23(10):1535–51. doi: <http://dx.doi.org/10.1017/S1041610211001608>. PubMed.
- 44 van der Steen JT, van Soest-Poortvliet MC, Hallie-Heierman M, Onwuteaka-Philipsen BD, Deliens L, de Boer ME, et al. Factors associated with initiation of advance care planning in dementia: a systematic review. *J Alzheimers Dis.* 2014;40(3):743–57. doi: <http://dx.doi.org/10.3233/JAD-131967>. PubMed.
- 45 Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: a systematic review. *Arch Intern Med.* 2006;166(5):493–7. doi: <http://dx.doi.org/10.1001/archinte.166.5.493>. PubMed.
- 46 Jox RJ, Denke E, Hamann J, Mendel R, Förstl H, Borasio GD. Surrogate decision making for patients with end-stage dementia. *Int J Geriatr Psychiatry.* 2012;27(10):1045–52. doi: <http://dx.doi.org/10.1002/gps.2820>. PubMed.
- 47 Ladin K, Buttafarro K, Hahn E, Koch-Weser S, Weiner DE. “End-of-Life Care? I’m not Going to Worry About That Yet.” Health Literacy Gaps and End-of-Life Planning Among Elderly Dialysis Patients. *Gerontologist.* 2018;58(2):290–9. doi: <http://dx.doi.org/10.1093/geront/gnw267>. PubMed.
- 48 Winzelberg GS, Hanson LC, Tulskey JA. Beyond autonomy: diversifying end-of-life decision-making approaches to serve patients and families. *J Am Geriatr Soc.* 2005;53(6):1046–50. doi: <http://dx.doi.org/10.1111/j.1532-5415.2005.53317.x>. PubMed.
- 49 OFSP. Palliative ch. L’anticipation en lien avec la santé, en particulier en cas d’incapacité de discernement (Advance care planning). Cadre général pour la Suisse [Internet]. OFSP; 2018 [cited 2018 Apr 25]. Available from: <https://www.bag.admin.ch/bag/fr/home/themen/strategien-politik/nationale-gesundheitspolitik/koordinierte-versorgung/patientengruppen-und-schnittstellen-koordinierte-versorgung/hochbetagte-multimorbide-menschen-koordinierte-versorgung.html>
- 50 Ripich DN, Wykle M, Niles S. Alzheimer’s disease caregivers: the focused program. *Geriatr Nurs.* 1995;16(1):15–9. doi: [http://dx.doi.org/10.1016/S0197-4572\(05\)80073-4](http://dx.doi.org/10.1016/S0197-4572(05)80073-4). PubMed.
- 51 Orange JB, Colton-Hudson A. Enhancing Communication in Dementia of the Alzheimer’s Type. *Top Geriatr Rehabil.* 1998;14(2):56–75. doi: <http://dx.doi.org/10.1097/00013614-199812000-00007>.
- 52 Ripich D, Ziol E, Fritsch T, Durand E. Training Alzheimer’s Disease Caregivers for Successful Communication. *Clin Gerontol.* 2000;21(1):37–56. doi: [http://dx.doi.org/10.1300/J018v21n01\\_05](http://dx.doi.org/10.1300/J018v21n01_05).
- 53 Horton-Deutsch S, Twigg P, Evans R. Health care decision-making of persons with dementia. *Dementia.* 2007;6(1):105–20. doi: <http://dx.doi.org/10.1177/1471301207075643>.
- 54 Teno JM. Looking beyond the “form” to complex interventions needed to improve end-of-life care. *J Am Geriatr Soc.* 1998;46(9):1170–1. doi: <http://dx.doi.org/10.1111/j.1532-5415.1998.tb06662.x>. PubMed.
- 55 De Vleminck A, Houttequier D, Pardon K, Deschepper R, Van Audenhove C, Vander Stichele R, et al. Barriers and facilitators for general practitioners to engage in advance care planning: a systematic review. *Scand J Prim Health Care.* 2013;31(4):215–26. doi: <http://dx.doi.org/10.3109/02813432.2013.854590>. PubMed.
- 56 Green MJ, Schubart JR, Whitehead MM, Farace E, Lehman E, Levi BH. Advance Care Planning Does Not Adversely Affect Hope or Anxiety Among Patients With Advanced Cancer. *J Pain Symptom Manage.* 2015;49(6):1088–96. doi: <http://dx.doi.org/10.1016/j.jpainsymman.2014.11.293>. PubMed.
- 57 Lafontaine C. Regenerative Medicine’s Immortal Body: From the Fight against Ageing to the Extension of Longevity. *Body Soc.* 2009;15(4):53–71. doi: <http://dx.doi.org/10.1177/1357034X09347223>.
- 58 Riva M, Caratozzolo S, Cerea E, Gottardi F, Zanetti M, Vicini Chilovi B, et al. Diagnosis disclosure and advance care planning in Alzheimer disease: opinions of a sample of Italian citizens. *Aging Clin Exp Res.* 2014;26(4):427–34. doi: <http://dx.doi.org/10.1007/s40520-014-0195-1>. PubMed.
- 59 Tulskey JA. Beyond advance directives: importance of communication skills at the end of life. *JAMA.* 2005;294(3):359–65. doi: <http://dx.doi.org/10.1001/jama.294.3.359>. PubMed.
- 60 Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist.* 2000;5(4):302–11. doi: <http://dx.doi.org/10.1634/theoncologist.5-4-302>. PubMed.
- 61 Narayanan V, Bista B, Koshy C. ‘BREAKS’ Protocol for Breaking Bad News. *Indian J Palliat Care.* 2010;16(2):61–5. doi: <http://dx.doi.org/10.4103/0973-1075.68401>. PubMed.
- 62 Warnock C, Tod A, Foster J, Soreny C. Breaking bad news in inpatient clinical settings: role of the nurse. *J Adv Nurs.* 2010;66(7):1543–55. doi: <http://dx.doi.org/10.1111/j.1365-2648.2010.05325.x>. PubMed.
- 63 Jain A, Corriveau S, Quinn K, Gardhouse A, Vegas DB, You JJ. Video decision aids to assist with advance care planning: a systematic review and meta-analysis. *BMJ Open.* 2015;5(6):. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4480030/>. doi: <http://dx.doi.org/10.1136/bmjopen-2014-007491>. PubMed.
- 64 Moorman SM, Carr D, Kirshhoff KT, Hammes BJ. An assessment of social diffusion in the Respecting Choices advance care planning program. *Death Stud.* 2012;36(4):301–22. doi: <http://dx.doi.org/10.1080/07481187.2011.584016>. PubMed.
- 65 Robinson L, Dickinson C, Rousseau N, Beyer F, Clark A, Hughes J, et al. A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. *Age Ageing.* 2012;41(2):263–9. doi: <http://dx.doi.org/10.1093/ageing/afr148>. PubMed.
- 66 Haberstroh J, Neumeier K, Krause K, Franzmann J, Pantel J. TANDEM: Communication training for informal caregivers of people with dementia. *Aging Ment Health.* 2011;15(3):405–13. doi: <http://dx.doi.org/10.1080/13607863.2010.536135>. PubMed.
- 67 Elwyn G, O’Connor A, Stacey D, Volk R, Edwards A, Coulter A, et al.; International Patient Decision Aids Standards (IPDAS) Collaboration. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. *BMJ.* 2006;333(7565):417. doi: <http://dx.doi.org/10.1136/bmj.38926.629329.AE>. PubMed.
- 68 Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ.* 2010;340(mar23 1):c1345. doi: <http://dx.doi.org/10.1136/bmj.c1345>. PubMed.
- 69 Tronto JC. Un monde vulnérable: pour une politique du care. Paris, France: Découverte; 2009. 238 p.
- 70 Beauchamp TL, Childress JF. Principles of Biomedical Ethics. 7 edition. New York: Oxford University Press; 2012. 480 p.
- 71 Detering K, Silvester W. Implementierung von Advance Care Planning in Australien: das Programm “Respecting Patient Choices.” In: Coors M, Jox R, in der Schmitt, editors. Advance Care Planning Von der Patientenverfügung zur gesundheitlichen Vorausplanung. Stuttgart: W. Kohlhammer; 2015. p. 196–206.
- 72 Bridges JFP, Lynch T, Schuster ALR, Crossnohere NL, Smith KC, Aslakson RA. A review of paper-based advance care planning aids. *BMC Palliat Care.* 2018;17(1):54. doi: <http://dx.doi.org/10.1186/s12904-018-0298-0>. PubMed.
- 73 Krones T, Biller Andorno N, in der Schmitt J, Mitchell C, Spirig R, Zaugg K. Shared decision making and advance care planning—underpinnings, similarities and differences. *BMJ Support Palliat Care.* 2012;2(2):173. doi: <http://dx.doi.org/10.1136/bmjspcare-2012-000250.10>.
- 74 Tsang S, Royle CF, Terkawi AS. Guidelines for developing, translating, and validating a questionnaire in perioperative and pain medicine. *Saudi*



- J Anaesth. 2017;11(5, Suppl 1):S80–9. doi: [http://dx.doi.org/10.4103/sja.SJA\\_203\\_17](http://dx.doi.org/10.4103/sja.SJA_203_17). PubMed.
- 75 Audiau A. L'information pour tous. Règles européennes pour une information facile à lire et à comprendre. [Internet]. Programme pour l'éducation et la formation tout au long de la vie; 2009 [cited 2018 Apr 24]. Available from: [http://www.unapei.org/IMG/pdf/Guide\\_Regles-FacileAlire.pdf](http://www.unapei.org/IMG/pdf/Guide_Regles-FacileAlire.pdf)
- 76 Inclusion Europe. Information for all. European standards for making information easy to read and understand [Internet]. European Commission on Lifelong Learning Program; 2014 [cited 2018 Aug 28]. Available from: [http://easy-to-read.eu/wp-content/uploads/2014/12/EN\\_Information\\_for\\_all.pdf](http://easy-to-read.eu/wp-content/uploads/2014/12/EN_Information_for_all.pdf)
- 77 Sudore RL, Heyland DK, Lum HD, Rietjens JAC, Korff J, Ritchie CS, et al. Outcomes That Define Successful Advance Care Planning: A Delphi Panel Consensus. *J Pain Symptom Manage*. 2018;55(2):245–255.e8. doi: <http://dx.doi.org/10.1016/j.jpainsymman.2017.08.025>. PubMed.
- 78 Snaith RP. The Hospital Anxiety And Depression Scale. *Health Qual Life Outcomes*. 2003;1(1):29. doi: <http://dx.doi.org/10.1186/1477-7525-1-29>. PubMed.
- 79 Dubé M, Lamy L, Lalande G, Lapierre S, Alain M. L'autonomie psychologique des personnes âgées: Le concept et son opérationnalisation. 41e Congrès Int Gérontologie Francoph [Internet]. 1990; Available from: <http://www.rqrv.com/fr/instrument.php?i=34>
- 80 Légaré F, Leblanc A, Robitaille H, Turcotte S. The decisional conflict scale: moving from the individual to the dyad level. *Z Evid Fortbild Qual Gesundhwes*. 2012;106(4):247–52. doi: <http://dx.doi.org/10.1016/j.zefq.2012.02.021>. PubMed.
- 81 Piette P. Validation de la version française de l'échelle Zarit Burden Interview pour l'évaluation du retentissement émotionnel des parents d'enfants porteurs d'autisme: étude préliminaire. *Kinésithérapie Rev*. 2015;15(158):41–2. doi: <http://dx.doi.org/10.1016/j.kine.2014.11.047>.