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Advance directives

Ethical considerations concerning
the new adult protection law,
with particular reference to dementia

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Foreword

Advance directives are concerned with a fundamentally important – and highly sensitive – stage in a person’s life: people wish to ensure that their power to decide which medical and nursing interventions they will accept or refuse – i.e. their self determination – is preserved in situations where this decision-making capacity is seen to be at risk.

Obviously, self-determination is at risk when, because of illness, people are no longer able to make such decisions themselves. This is the case, notably, when they have progressively lost their mental abilities. A particular source of concern is the possibility of dementia.

With regard to health care, patients with dementia are a particularly vulnerable group. In anticipation of this eventuality, one can use an advance directive to specify the medical and nursing care which one wishes to receive, given this diagnosis.

Neither the professionals concerned nor relatives or other people close to the patient are absolved, by an advance directive, from their duties of beneficence. Above all, no one should receive inadequate care. In fact, however, patients tend to be more afraid of being “overtreated”, but sometimes also of falling victim to rationing measures.

The medical profession, for its part, is concerned about a “loss of physician autonomy”. But it should be recalled that, in accordance with the time-honoured principle of (informed) consent, it is patients who ultimately decide what medically indicated treatments they wish or do not wish to receive. The following point must also be borne in mind: what is good for a particular person cannot be determined independently of that individual’s attitudes to life, to illness and to dying. Naturally, these attitudes are to be taken into account – especially when they are recorded in an advance directive. Rather than depriving medical and nursing staff of autonomy, an advance directive thus serves to inform and at the same time to alleviate the burden on them.

Relief is also provided for relatives and other people close to the patient. The emotional stresses which they face are not of course thereby eliminated, but considerably reduced.

The present Opinion, prepared by the Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE), discusses ethical issues arising in particular from the new adult protection law. In accordance with its remit, the Commission does not address specific cases but seeks to arrive at general conclusions – exploring, for example, the possibilities for self determination which advance directives offer in cases of dementia. However, the recommendations also consider to what extent the new adult protection law sets limits to the authority of advance directives, and how these limits are to be assessed in ethical terms. Here, it is emphasized that – with the exception of protective placement – essentially the same limits apply for people with dementia as for those with other disorders.

Otfried Höffe, Chairman

1 Summary of recommendations

In this Opinion, the Commission deals with the advance directive, an instrument that is to be regulated at the federal level for the first time in the new adult protection law, which in accordance with a Federal Council decision will come into effect on 1 January 2013. The Commission welcomes these regulations, as advance directives can open up a new area of self-determination for patients. They enable a person with mental capacity to express in advance his or her wishes concerning medical treatments, in the form of binding instructions. People who draw up an advance directive specify which medical interventions they consent to and which they wish to forgo in the event that, because of illness, they are no longer able to express a preference themselves. In an advance directive, wishes concerning nursing interventions may also be included; however, legally and ethically, instructions concerning medical interventions have greater binding force than those concerning nursing interventions. An advance directive can also be used to designate a person who is to represent the patient, incapacitated by illness, in decision-making on medical and nursing matters.

Against this background, the Commission investigates whether advance directives also allow people with dementia to exercise self-determination in dealing with future disease situations. In view of the increasing incidence of dementia and the growing number of people drawing up advance directives, questions concerning their validity and authority in cases of dementia are increasingly relevant. **The Commission concludes that advance directives help to safeguard respect for the autonomy of people with dementia, as long as certain limits to their authority and scope are taken into account.** The Commission's reflections are based on the new adult protection law, and its key conclusions are as follows:

*Cf. chapter
3.1, p. 15f.*

1 The advance directive is primarily the expression of a right to refuse medical interventions that violate a person's (physical and psychological) integrity. This right, based on the principle of patient autonomy, is to be recognized from an ethical viewpoint. The decision to draw up an advance directive must always be **voluntary**; it must not be a precondition for admission to an institution providing treatment or care.

*Cf. chapter
3.2.1, pp. 16ff.*

2 "Continuity of the person", which is a fundamental ethical requirement for the validity of an advance directive, is to be regarded as applicable in cases of dementia. In patients with dementia, therefore, the validity of an advance directive cannot be called into question by claiming that the person who drew up the directive is not the same person as is affected by the instructions it contains.

*Cf. chapter
3.2.2, p. 18 f.*

3 Capacity is crucial to the validity of an advance directive: only a person who has mental capacity can draw up a legally valid advance directive; and the directive is only to be used as a basis for decision-making in cases where the person has become incapacitated or cannot express any preferences owing to loss of consciousness. The Commission wishes to stress the following point: **incapacity is not to be deduced automatically from a diagnosis, e.g. of dementia.** Capacity always needs

to be carefully assessed with reference to a specific situation. **It should be documented in writing who carried out the assessment and how it was carried out (i.e. what criteria and methods were used).**

4 To draw up an advance directive, people must be able to imagine future illnesses. Only then can they formulate their wishes in advance. The Commission assumes that **mental capacity includes the power of anticipation – also with regard to dementia. The Commission does not recommend mandatory counselling.**

*Cf. chapter
3.2.3, p. 19f.*

5 **In the Commission’s view, there are indisputably certain areas where binding instructions cannot be given in an advance directive.** For example, it is not permissible either to request illegal acts or medical/therapeutic or nursing interventions which are not indicated, or to refuse interventions designed to prevent a state of serious neglect or intolerable pain. These restrictions are to be accepted on grounds relating to social ethics, professional integrity and harm to others. **This also means that physicians, nursing staff and other healthcare professionals, as well as relatives and other people close to the patient, cannot be absolved from their duties of beneficence towards the patient.** In general, however, **it is always permissible to refuse invasive measures which violate physical or psychological integrity.** These considerations lead to the following conclusions:

*Cf. chapter
3.3.1, pp. 20ff.*

- The patient’s usual diet, personal hygiene, exercise and other activities are always to be *offered*. An advance directive must not give instructions to the contrary.
- However, measures supporting activities of daily living must not be applied coercively. For example, a person with dementia still has the right to refuse food. But it should be investigated whether the patient’s behaviour is attributable to organic causes or irrational fears, which should then first be resolved.
- Artificial nutrition as an acute medical intervention may, however, be legitimately refused in an advance directive.
- The administration of medicines may be legitimately refused in an advance directive, unless such treatment is designed to relieve intolerable pain or to address the underlying causes of self-harmful behaviour (e.g. pharmacotherapy for delusions of poisoning associated with a refusal to eat in the context of protective placement¹).

6 **An advance directive may only be corrected by verbal statements under certain conditions.** The Commission thus criticizes the provisions of the new adult protection law concerning revocation and amendment of an advance directive. In addition, these provisions seem to the Commission to create an inappropriate incentive for presumed wishes to be too readily taken as a corrective to the advance directive. **As regards the determination of presumed wishes, the Commission assumes that:**

*Cf. chapter
3.3.2, pp. 23ff.*

- only people favourably disposed towards the patient will be involved in this process,
- their own interests will be subordinated to the patient’s welfare or wishes, and the process will include reflection on their own values

¹ The term “protective placement” (fürsorgerische Unterbringung), introduced in the new adult protection law, will be used in future instead of “protective custody” (fürsorgerische Freiheitsentziehung).

and attitudes so as to ensure that decisions are taken in accordance with what the patient would have wanted, and

- the people concerned are aware that presumed wishes may be at variance with the patient's objective welfare (i.e. defined in purely medical terms).

In addition, the Commission proposes special due-care criteria:

- Verbal statements made by the patient to the physician are to be documented in the patient's records. Verbal statements made outside the patient-physician relationship must be attested by several people.
- The degree of dementia is to be carefully assessed by a professional so as to ensure that the verbal statement was made at a time when the person concerned had mental capacity.

*Cf. chapter
3.3.3, p 27f.*

7 The Commission takes the view that, while the current habits and needs of a person lacking capacity are to be taken into account in the implementation of an advance directive, this does not mean that binding instructions given in an advance directive are invalidated.

*Cf. chapter
3.3.4, pp. 28ff.*

8 Under the new adult protection law, an advance directive cannot always prevent psychiatric treatment, if such treatment is ordered in the context of protective placement. For the Commission, such a restriction of the right to refuse treatment and hence of the self-determination of people with a mental disorder is acceptable in cases where compliance with an advance directive would result in the person concerned ending up in precisely the condition which is to be avoided by means of the protective placement.

In addition:

- it is advisable for decisions to be taken only in consultation with the treatment and care team, and
- instructions in a valid advance directive which do not relate to the grounds for protective placement must still be complied with.

*Cf. chapter
3.4, pp. 30ff.*

9 The Commission essentially welcomes the fact that the new adult protection law provides for a shared decision-making model, involving physicians and patients' representatives. To ensure that appropriate decisions are taken for the person concerned, it is desirable to involve, or at least seek the views of, as many people as possible (the entire treatment and care team, trusted third parties, the authorized representative and other people close to the patient). **For the Commission, it appears problematic that the decision-makers specified in the law should also take "objective interests" into account in their decision-making.** This is because "objective interests" are defined from a purely medical viewpoint. But reference to such interests may result in a decision which diverges markedly from the advance directive or presumed wishes. The Commission believes that **the advance directive and presumed wishes should unequivocally take precedence over "objective interests"**. Decisions should only be guided by the patient's "objective" welfare in cases where no advance directive is available and presumed wishes cannot be determined.

2 Introduction

2.1 Thematic focus

Advance directives can open up a new area of self-determination for patients.² With this document, people with mental capacity can express in advance their wishes concerning medical treatments, in the form of binding instructions.³ People who draw up an advance directive specify which medical interventions they consent to and which they wish to forgo in the event that, because of illness, they are no longer able to express a preference themselves.⁴ In an advance directive, wishes concerning nursing interventions may also be included; however, such instructions cannot be strictly binding.⁵ An advance directive can also be used to designate a person who is to represent the patient, incapacitated by illness, in decision-making on medical and nursing matters.⁶ Individual motives for preparing an advance directive are varied. In general terms, the growing importance and prevalence of advance directives in recent decades is attributable to three developments: firstly, to medical advances, which may also prolong the dying process; secondly, to the associated fears of “overtreatment”; and, thirdly, to the fact that autonomy or self-determination has become one of Western society’s central values, which now also – in the form of “informed consent” – shapes the physician-patient relationship.⁷ Informed consent is designed to ensure that greater attention is paid to the patient’s wishes, with less emphasis on unilateral medical decisions as to what is “good for” the person concerned. The medical perspective on the patient’s welfare has thus lost its former primacy in medical decision-making. With the advance directive, the ethical and legal concept of informed consent – according to which a medical intervention can only legitimately be performed if voluntary consent has been obtained from the patient – is now being extended to *future* decision-making situations in which, because of incapacity, the person concerned can no longer express his or her wishes.⁸

In Switzerland, advance directive forms are made available, mainly free of charge, by a variety of organizations, institutions and authorities. Around 40 different forms are currently available.⁹ The providers of advance directives include hospitals, cantonal and communal health authorities, professional associations, patient centres and organizations, foundations, associations and other institutions. As regards form and content, these documents vary widely. Some advance directives are only one page long, while others – covering several pages – include highly detailed instructions on medical treatment and on handling of the body (after death). By way of example, mention may be made here of the planned advance directive forms – a short and a longer version – which are to be issued in the early summer of 2011 by the Swiss Academy of Medical Sciences (SAMS) and the Swiss Medical Association (FMH).

The prevalence and management of advance directives in medical and nursing practice vary across Switzerland. The differences are no doubt partly due to the lack of uniform legal regulations. However, practices also vary according to the region and institution, and they appear to be determined by custom, experience and the particular culture. No comprehensive surveys are available to answer the question of how many people in Switzerland have prepared an advance directive, or how such directives are managed in

² A recent US study showed that there was strong agreement between the care received and the preferences expressed by patients who had prepared an advance directive (Silveira et al. 2010).

³ Cf. Leuba/Tritten 2005 and Hatam 2007. The legal authority of advance directives was noted as early as 1988 (Guillod/Guinand 1988).

⁴ This is what distinguishes an advance directive from advance care planning: while the former is formulated once and then only implemented when the person becomes incapacitated, a treatment plan is continually adapted and is put into effect while the person still has capacity.

⁵ Cf. Section 3.3.1.

⁶ Cf. Guillod/Meier 1995 and Babaianz 1998, 46.

⁷ Cf. Verrel/Simon 2010, 88.

⁸ Thus, advance directives do not relate exclusively to end-of-life situations but concern all conditions involving incapacity or loss of consciousness. On this point cf. also Martin 2009.

⁹ According to a study by Zellweger et al. 2008 and information provided by the DVSP (umbrella organisation for Swiss patient centres).

¹⁰ Cf. Harringer et al. 2009: 25% of respondents (75 people) already had an advance directive, 56% (168) decided to complete one for the first time, and 19% (57) chose not to do so. Of the existing 75 advance directives, 58 were simple (1-page) and 17 detailed (several pages). Of the 168 people who decided to complete an advance directive, 81% preferred a simple and 19% a more detailed version.

¹¹ Schwarzenegger et al. 2010.

¹² Schwarzenegger et al. 2010, 14.

¹³ Cf., for example, Meran et al. 2002.

¹⁴ Dementia is a progressive disorder, involving memory impairment and disturbances in one or more other cognitive domains – language disturbance; impaired ability to carry out motor activities despite intact motor function; failure to recognize or identify objects despite intact sensory function; disturbance in executive functioning (i.e. planning, organizing, sequencing, abstracting). These deficits are sufficient to impair day-to-day functioning. Various degrees of dementia are distinguished: mild, moderate and severe. In general, mental capacity is only restricted by the moderate and severe forms. The most common type of dementia is Alzheimer's disease, which is diagnosed in around 50% of all cases.

¹⁵ Cf., for example, the report entitled "Taking Care: Ethical Caregiving in Our Aging Society" by The President's Council on Bioethics (2005) and the report of the Nuffield Council on Bioethics (2009) on "Dementia: ethical issues".

¹⁶ Cf. Meyer 2009, 128.

¹⁷ Cf. Monod-Zorzi et al. 2007; Meyer 2009, 124ff.; Swiss Federal Statistical Office/Bundesamt für Statistik 2010.

¹⁸ On the relationship between dementia and law cf. also Geiser 2003.

practice. In 2008, the Rorschach Physicians' Quality Circle ZOC carried out a survey involving 300 elderly male or female patients from ten primary care practices in the St Gallen region, in order to investigate the prevalence of advance directives and whether short or more detailed forms are preferred.¹⁰ The results suggest that while the proportion of elderly patients with an advance directive is fairly low, there is a relatively high level of interest in completing such a directive. The results of a survey conducted in 2010 by the Zurich University Institute of Criminology¹¹ were rather different: the proportion of the population with an advance directive was reported to be 17% overall, although the percentage rose sharply with increasing age. According to this research group's data, one in three respondents aged over 70 had an advance directive.¹²

The preparation and implementation of advance directives raises numerous ethical questions, which are hotly debated among professionals and the public alike.¹³ These issues are to be addressed by the Commission in the present Opinion. They include questions concerning the application of advance directives in general, such as the requirements for valid, binding advance directives and the limits to their authority in practice:

- Does the application of an advance directive require "continuity of the person"?
- What is meant by mental capacity/incapacity, and how is it to be determined?
- Is a person actually able to imagine future illnesses and medical decision-making situations?
- Should an advance directive be strictly binding, or merely serve as an indication of presumed wishes?
- Should it be possible for an advance directive to be revised, even in a state of incapacity?
- What can an advance directive cover (scope)?
- What role is to be played by authorized representatives, and by what criteria should their decisions be guided?

These points are particularly controversial with regard to dementia.¹⁴ Some people take the view that the advance directive represents an obstacle to the exercise of self-determination in a person already suffering from dementia, if he or she is to be bound by previously specified instructions without any possibility of revision; others, however, support the advance directive as a welcome means whereby provision can be made in advance for dealing with dementia in a self-determined manner. **With regard to dementia, there is thus a particular need to clarify questions relating to the authority and implementation of an advance directive.** This issue is especially pressing in view of demographic trends:¹⁵ as mentioned above, advance directives are of particular relevance for older people. As the main risk factor for dementia is age – 1–2% of people aged 65–69 and more than 30% of those aged over 90 are affected by dementia – it is natural and advisable to consider the topic of dementia when preparing an advance directive.¹⁶ In addition, Switzerland is likely to see a further increase in life expectancy and a corresponding rise in the incidence of dementia.¹⁷ This Opinion will therefore focus on issues relating to dementia, although the Commission is well aware that the ethical questions mentioned above also arise for advance directives in general, regardless of the specific type of disease.¹⁸

2.2 Background and target readership

The preparation of this Opinion was occasioned by the revision of the Swiss Civil Code (adult protection, personal law and child law, hereafter: new adult protection law). The Commission had already commented on the preliminary draft of the new adult protection law during the consultation procedure in 2004, and some of its concerns, e.g. regarding the right of relatives to act as representatives in medical matters, are raised here once again.¹⁹ The new adult protection law, which in accordance with a Federal Council decision will come into effect on 1 January 2013, will for the first time provide a legal basis at the federal level for the management of advance directives. A further increase in their prevalence is to be expected as a result. **The Commission stresses that it is largely in agreement with the new adult protection law.** In this Opinion, it considers from an ethical viewpoint what requirements an advance directive should meet if it is to be valid and where the limits to its authority lie. The Opinion can thus be read as an ethical assessment of the new adult protection law, aiming – with particular reference to dementia – to review the law from an ethical perspective and, on this basis:

- to inform people who wish to prepare an advance directive about possible uncertainties, e.g. as regards its authority,
- to provide guidance on implementation for those to whom the instructions in an advance directive are addressed (physicians, nursing staff and other professionals, relatives or others close to the patient and representatives), and
- to inform those healthcare institutions in which advance directives are relevant (e.g. hospitals, care homes and hospices) about questions concerning the authority and the scope of advance directives under the new adult protection law.

Depending on their specificity and degree of detail, advance directives may leave room for interpretation when they are applied in medical and nursing decision-making; accordingly, those who have to implement an advance directive are very much in need of decision-making support. **This Opinion, however, cannot offer concrete guidance for individual cases. Instead, it seeks to define a general ethical framework; the specifics for a particular case will then need to be worked out by the people concerned.** In approaching this issue, the Commission has been guided by the idea that an advance directive can help to safeguard respect for the autonomy of people with dementia, as long as certain limits to its authority and scope are taken into account.

2.3 Legal situation

2.3.1 Existing cantonal legislation and medical-ethical guidelines of the Swiss Academy of Medical Sciences

Advance directives are not uniformly regulated in Switzerland since federal legislation has yet to be introduced and the treatment of incapacitated patients falls under cantonal legislation.²⁰ However, this situation will change when the new adult protection law comes into effect.²¹ At present, the majority of cantons have patient laws in which advance directives are regulated; however, these regulations vary widely as regards the validity and scope of advance directives. Certain cantons accord independent

¹⁹ See the Commission's submission to the consultation procedure (in German) at: www.nek-cne.ch

²⁰ On cantonal regulations cf. Arter 2007, 660, Footnote 6.

²¹ See Section 2.3.2 below.

authority to the advance directive²²; for others, it merely provides an indication of presumed wishes. In a few cases, advance directives are mentioned in connection with life-prolonging measures. To date, key points in the preparation and application of advance directives are wholly or partly unregulated – e.g. the formal and substantive requirements to be met by advance directives, their validity and authority, the circumstances in which they are not to be complied with, where they are to be kept, who is required to check whether an advance directive exists, and what role is to be played in medical and nursing decision-making by a person designated in an advance directive to act as a representative. These aspects will be clarified by the new adult protection law. However, it may already be noted that, even today, the more clearly an advance directive is formulated and the more specifically it applies to the actual medical or nursing decision-making situation, the more weight will be accorded to it.

In 2009, the Swiss Academy of Medical Sciences (SAMS) issued medical-ethical guidelines and recommendations on advance directives, thus establishing a standard for physicians and also for nurses and other professionals who offer advice on drafting or are involved in implementing advance directives. If the SAMS guidelines are incorporated into the Code of the Swiss Medical Association (FMH), they will become binding for all members of the FMH. In these guidelines, the situations in which advance directives are prepared or implemented are examined for practitioners. It should be emphasized that a description of personal values and the goals of treatment is considered by the SAMS to be useful for the implementation of an advance directive. The guidelines also consider in detail the circumstances in which information and advice is provided for the preparation of an advance directive. Particular importance is attached to the formulation of wishes on the basis of detailed information, but also to the function of the advance directive as a tool facilitating communication between the patient, the treatment and care team, relatives and a trusted third party or authorized representative.

2.3.2 *The new adult protection law*

The amendment of the Swiss Civil Code (ZGB) with regard to adult protection, personal law and child law²³ was approved by the National Council and the Council of States on 19 December 2008. It was subject to an optional referendum, with a deadline of 19 April 2009, but no referendum was requested. The new adult protection law will come into effect on 1 January 2013, to allow the cantons sufficient time to amend their legislation. The key goals of the regulations are to promote the right to self-determination and to strengthen family solidarity.²⁴ In the section on “Personal provision for the future”,²⁵ two new legal institutions are introduced which address these goals: *establishment of power of attorney*, which allows people to make arrangements for the management of their personal and financial affairs in the event of incapacity, and the *advance directive*, which allows people both to specify which medical measures they consent to and which they wish to forgo in the event of incapacity, and to appoint a natural person to represent them in medical decision-making situations and make decisions on their behalf.²⁶ Under this law, people are thus enabled to make provision for a possible future state of incapacity and to extend the right of autonomous decision-making on medical matters into this phase of their life.

²² Since 1996, this has been the case in all French-speaking cantons (Ummel 2009, 141 and 146).

²³ nArt. 360–455 ZGB.

²⁴ Dispatch of the Federal Council of 28 June 2006 on the amendment of the Swiss Civil Code (adult protection, personal law and child law), Federal Gazette (BBl) 2006, 7001–7138, specifically 7002.

²⁵ nArt. 360–373 ZGB.

²⁶ Ibid.

In the new adult protection law, advance directives are thus regulated at the federal level.²⁷ The formal criteria which have to be met for an advance directive to be valid are voluntariness and capacity; in addition, the directive must be prepared in writing, dated and signed. It may be revoked at any time (in a state of capacity), and its existence and the deposit location may be recorded on the insurance card.²⁸ For the first time, it is also stipulated that, in the case of a patient lacking capacity, the attending physician must establish, on the basis of the insurance card, whether or not an advance directive exists.²⁹ The physician is required to comply with the advance directive “unless it contravenes legal requirements or there are reasonable doubts as to whether it was voluntary or still reflects the patient’s presumed wishes”.³⁰ In cases where the patient’s instructions are not complied with, the reasons are to be documented in the patient’s records; this promotes transparency and control of decision-making processes. In the event of a conflict, the case can be submitted to the newly established Adult Protection Authority.³¹

The new adult protection law deals not only with advance directives, but also with the *representation of people lacking capacity in the event of medical interventions* if no advance directive is available. The right to represent a person lacking capacity in cases where medical interventions are planned – and thus the authority to grant or withhold consent to such outpatient or inpatient procedures – is accorded to relatives and other people close to the patient in an order of precedence specified by the law.³² If there is no advance directive, or if an advance directive contains no relevant instructions, then the authorized representative, having been involved in the development of the treatment plan, has to decide in accordance with the incapacitated person’s presumed wishes and interests.³³ **Except in urgent cases (i.e. in emergencies or where there is objective uncertainty as to who is entitled to represent the patient),³⁴ decision-making authority is thus transferred from physicians to the authorized representative.**

In summary, with regard to advance directives, it may be noted that with the new adult protection law:

- the patient’s right to autonomous decision-making is strengthened, as the person concerned can preserve his or her current wishes for a future state of incapacity;
- for the treatment and care team, the advance directive represents a binding expression of wishes which must be complied with, in the absence of important reasons to the contrary;
- physicians have to establish, on the basis of the insurance card, whether an advance directive exists;
- the authorized representative now has decision-making authority regarding medical interventions; and
- the Adult Protection Authority assumes a supervisory and enforcement function.

2.3.3 *The European Biomedicine Convention and the legal situation in other countries*

In the US, advance directives have been applied in practice for more than 20 years; in European countries, however, they have only recently become

²⁷ Cf. Guilloid 2010.

²⁸ nArt. 371 Para. 2 ZGB.

²⁹ nArt. 372 Para. 1 ZGB.

³⁰ nArt. 372 Para. 2 ZGB.

³¹ nArt. 373 Para. 1 ZGB.

³² nArt. 378 Para. 1 and 2 ZGB.

³³ nArt. 377 Para. 1, 2 and 3 ZGB and nArt. 378 Para. 1, 2 and 3 ZGB.

³⁴ Cf. nArt. 379 ZGB and BBl 2006, 7037.

widespread and been included in national legislation.³⁵ A significant milestone in these developments for Europe is the European Biomedicine Convention (Council of Europe Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, 4 April 1997, in force in Switzerland since 1 November 2008). Article 9 deals with the right of patients who lack capacity to have their previously expressed wishes “taken into account” in medical decision-making.³⁶ However, it is not clear what is to be understood by “taking into account” – i.e. what authority is to be accorded to an advance directive and what an advance directive may legitimately cover: it thus remains open whether the advance directive merely provides an indication of presumed wishes or whether it has independent authority. Different positions are also taken on whether an advance directive may only relate to medical end-of-life decisions, or whether it may cover all medical and – though not with the same authority – nursing interventions, or whether it may also relate to acts of euthanasia. Accordingly, national laws within Europe vary widely in this regard. Overall, European countries can be divided into four groups:³⁷ 1. countries where advance directives are *prima facie* binding and may only be overridden for compelling reasons (e.g. Austria, and since 2009 also Germany); 2. countries which assign a merely advisory value, rather than independent authority, to advance directives (e.g. France); 3. countries where legislation on advance directives is still at the planning stage (e.g. Italy); 4. countries with no such legislation or plans (e.g. Greece). It is to be assumed that these legal disparities will persist, given the cultural differences in the relationship between physician, patient and relatives across Europe.³⁸

³⁵ On the following cf. Andorno et al. 2009.

³⁶ “Previously expressed wishes: The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account.”

³⁷ Cf. Andorno et al. 2009, 210–212.

³⁸ For literature on legal regulations or professional codes, on empirical studies, and on the debate concerning advance directives in 19 European countries and the US, cf. the report by Brauer et al. 2008a. With regard to Switzerland’s neighbours, the following selected literature may be mentioned: Germany: Sass/Kielstein 2001; Meran et al. 2002; Wiesing et al. 2010. France: Mémeteau 2000; Dreifuss-Netter 2006; Raoul-Cormeil 2006. Italy: Turoldo 2006; Aramini 2007; Boraschi et al. 2007; de Tilla et al. 2007; Senato della Repubblica Italiana 2007. Austria: Körtner et al. 2007.

3 Ethical considerations

Below, the Commission explains how the advance directive can be used as a tool for dealing with future situations involving illness in a self-determined manner. In the Commission’s view, it should also be open to people with dementia to use an advance directive in this way. The intention is not to suggest that autonomous decisions and self-determination in medical and nursing contexts are *only* possible with an advance directive. However, for the Commission, it is important that the option of an advance directive should also be available for people with dementia – although this view has aroused controversy among medical ethicists.

The first question to be considered is the ethical basis for the advance directive: here, as well as the patient’s right to refuse medical and possibly also nursing interventions, duties of beneficence towards the person concerned need to be mentioned (Section 3.1). Also discussed are the requirements which must be met so that an advance directive can serve as an instrument for the expression of wishes in advance (Section 3.2). Section 3.3 deals with the limits to the authority of an advance directive: here, legal discussions concerning the scope of an advance directive, presumed wishes, non-verbal signs and gestures made by people with advanced dementia, and protective placement are analysed from an ethical viewpoint. Finally, the Commission considers surrogate decisions – an increasingly important issue in the light of the new adult protection law, and

the fact that an authorized representative can be designated in an advance directive (Section 3.4).

3.1 Normative grounds: patient autonomy and beneficence

The advance directive is primarily the expression of a right to refuse medical interventions that violate a person's (physical and psychological) integrity. This right, based on the uncontentious principle of patient autonomy, is to be recognized from an ethical viewpoint. However, it does not absolve physicians, nurses and other healthcare professionals, or relatives or other intimates, from their duties of beneficence towards the patient. Moreover, the right to refuse treatment is to be distinguished from a right to request medical and nursing interventions.

Everyone with mental capacity has the right to withhold consent to a medical intervention of a therapeutic, diagnostic or preventive nature. This right forms part of the personal freedom which is enshrined in the Federal Constitution.³⁹ Accordingly, a medical intervention undertaken without consent – regardless of the medical indication or the outcome of the procedure – represents a violation of personal integrity and may be subject to prosecution. Whether the decision of the person concerned appears reasonable to others, or not, is immaterial. However, there is no right to request interventions which are not indicated – i.e. not necessary from a medical or nursing perspective.

With the introduction of the advance directive in the new adult protection law, the right to determine what is done to one's own body, and to refuse medical interventions, is extended to situations calling for medical decisions in which the patient no longer has decision-making capacity. Here too, on pain of prosecution, treatment must be discontinued if this is necessitated by the occurrence of a situation described in a valid advance directive. Once again, the binding force of an instruction in the directive does not depend on its "reasonableness". People remain at liberty to damage their own health. **However, while the right to refuse treatment must be respected, an advance directive cannot be used to request interventions which are not necessary in medical or nursing terms. The right to withhold consent is crucial to patient autonomy and is now of central importance both legally and in medical practice.**

But this does not mean that the ethic of beneficence can be played off against patient autonomy, or that the latter is conceived in a manner oblivious to social realities.⁴⁰ The Commission rejects any concept of autonomy that is detached from interpersonal relations and cultural, social contexts. Such an individualistic conception of autonomy would be inappropriate particularly in the case of the advance directive. For an advance directive is also testimony to personal values and ideas about dignified, or at least acceptable, illness and dying, and such attitudes and ideas can only be developed within a framework of certain cultural, religious and social values. In this sense, autonomy as a good is culturally determined and, as such, pre-established for the individual.

The fact that individuals, in exercising their autonomy, are dependent on other people is particularly evident in the case of the advance directive – whether the wishes of a person in a state of incapacity are actually implemented depends entirely on other people. They are responsible for

³⁹ Cf. Art. 10 Para. 2 Federal Constitution (BV) in conjunction with Art. 28 ZGB.

⁴⁰ Cf. Eibach/Schaefer 2001.

translating the provisions of the advance directive into instructions relating to the actual situation, and acting so as to ensure that the person concerned receives treatment in a self-determined manner. Careful implementation of the advance directive, in accordance with the wishes of the person concerned and meeting the demands of the situation, is to be understood as a duty of beneficence, contravention of which would have far-reaching consequences for the medical/therapeutic relationship of trust.⁴¹ For the sphere of medical treatment and nursing care, such a violation would send out the wrong message – that vulnerable, incapacitated patients no longer able to refuse medical interventions are at the mercy of third parties applying their own notions of what is good and right.

The principle of beneficence is also applicable in another respect. The physician (and also, under the new adult protection law, the authorized representative) continues to have responsibility for the treatment and care of patients who lack capacity. The advance directive serves to “weight” the perspective from which the medical or nursing decision is to be taken – namely, primarily from the perspective of the patient, whose wishes have been formulated in advance. However, this does not absolve the people who implement the decision from the duties of beneficence mentioned above.

It must also be ensured that advance directives are in fact prepared voluntarily, and that a climate does not arise in which people who are elderly or seriously ill feel “compelled” to provide in an advance directive for premature discontinuation of treatment, so as to avoid “becoming a burden”. To prevent any such state of affairs, an advance directive must never be made a precondition for admission to an institution providing treatment or care. The decision to leave future treatment decisions to physicians, or to trusted third parties or authorized representatives, is also to be respected as an autonomous decision. It would, however, be regrettable if a person decided not to draw up an advance directive solely out of fear that, in times of resource scarcity, it might unduly restrict medical care for the person concerned. This fear could become significant in view of the care-provision situation for patients with multimorbidity and dementia; however, data on care provision for people with dementia is scant and requires further investigation – also in order to increase confidence in the advance directive instrument.⁴²

⁴¹ Cf. Brauer 2008b.

⁴² Research yielded only the following results: a study conducted by the German Hospice Foundation in 2008 found the following situation: »Patients with multiple symptoms and disorders are denied the integrated provision of care, attention and medicine which would be needed. But patients with dementia in particular, 80% of whom spend the last months of their lives in a nursing home, require palliative care» (cf. Deutsche Hospiz Stiftung 2009, 2). The 2008 National Survey of Palliative Care in Switzerland, commissioned by the “palliative ch” association, indicates marked cantonal and regional differences in the provision of palliative care (cf. Eychmüller et al. 2009). A 2004 study on dementia prevalence and care, commissioned by the Swiss Alzheimer’s Association, had already concluded that there are substantial gaps in the provision of care for people with dementia in Switzerland (cf. the report entitled “Substantial underprovision”; Schweizerische Alzheimervereinigung/gfs.bern 2004).

3.2 Fundamental requirements for advance directives

Certain fundamental requirements must be met so that advance directives can serve as an instrument for the formulation of wishes in advance. These include certain assumptions concerning “continuity of the person”, mental capacity/incapacity and the power of anticipation. If these assumptions were disputed, then advance directives could not be used to formulate binding instructions for future medical decision-making situations.

3.2.1 Continuity of the person

“Continuity of the person” is a fundamental ethical requirement for the validity of an advance directive. The Commission takes the view that such continuity is always applicable, even in cases of dementia.

In ethical terms, continuity of the person is a necessary condition for the validity of an advance directive. In other words, the instructions contained in an advance directive may only be carried out if the person affected by implementation is the same person as the author of the directive. This requirement may appear to be trivial. However, with regard to dementia, doubts have been expressed as to whether such continuity is in fact present. Progressive dementia may be associated with marked or radical changes in behaviour: for example, people with dementia may be found to be more aggressive or gentle, more cheerful or anxious, so that for relatives they seem to have become a “different person”. The sense of “estrangement” is compounded by the fact that people with dementia may no longer appear to recognize their relatives and other caregivers and even in relation to themselves seem to have no memories or ideas extending across time. Philosophical positions which take psychological continuity to be the essential criterion for personal identity⁴³ would deny continuity of the person in cases of severe dementia. This has certain ethical consequences: it is indisputable that no one is entitled to decide the fate or damage the interests of another person in matters of vital importance – this would represent an unacceptable form of heteronomy. It is thus concluded that an advance directive has no claim to be strictly binding in cases of dementia.⁴⁴

A different view is taken by the new adult protection law: it assumes continuity of the person, irrespective of illness or change of personality. The Commission shares this viewpoint. Without wishing to enter into the philosophical debate in any depth at this point, the Commission would adduce the following considerations in support of its position.

First, it should be pointed out that, regardless of dementia, a person continues as the same biological organism. This biological persistence is in itself considered by some ethicists to provide a sufficient basis for continuity.⁴⁵ As a result of dementia, people do not lose the life history which continues to individuate them as a person. Becoming aware of people’s life history can be helpful in understanding their current utterances and be very important for the provision of appropriate care. Another pertinent observation relating to the lifeworld is that, in spite of changes in behaviour, a person will continue to bear the same name and fulfil the same social roles, e.g. father or sister. In terms of social relationships, a person’s identity is thus preserved despite the “estrangement” mentioned above. Recent studies have shown that people with severe dementia may well still be capable of empathetic behaviour and of appropriate emotional responses to communicative situations and other people.⁴⁶ The same conclusion is also reached by all ontological approaches to the philosophy of personhood.⁴⁷

Against this background, the Commission wishes to support the right of people with dementia to play their part in medical decision-making with the aid of an advance directive. The Commission accepts that, in principle, there may be grounds for doubting the validity of an advance directive or limits to its authority.⁴⁸ In the Commission’s view, however, these do not include the alleged discontinuity of the person. On the contrary, there is a danger that this argument will be used to set aside an advance directive all too readily. For this reason, it must also be opposed on ethical grounds.

⁴³ Cf., for example, Locke 1975 [1690] and Parfit 1984.

⁴⁴ Cf., for example, Dresser 1995, contra Dworkin 1993. For an account of the philosophical debate see also Brauer 2008c.

⁴⁵ Cf., for example, DeGrazia 1999 and Quante 2002.

⁴⁶ Cf. Kruse 2008.

⁴⁷ On the concept of a person cf., for a historical overview and further literature, also Housset 2007 and Putallaz/Schumacher 2008.

⁴⁸ See Section 3.3 below.

3.2.2 *Mental capacity*

Capacity is crucial to the validity of an advance directive: only a person who has mental capacity can draw up a legally valid advance directive; and the directive is only to be used as a basis for decision-making in cases where the person has become incapacitated or cannot express any preferences owing to loss of consciousness. The Commission wishes to stress the following point: incapacity is not to be deduced automatically from a diagnosis, e.g. of dementia. Incapacity always needs to be carefully assessed with reference to a specific situation. It should be documented in writing who carried out the assessment and how it was carried out (i.e. what criteria and methods were used).

Both ethically and legally, the validity of an advance directive and the point at which it is to be applied depend respectively on the presence, in the person concerned, of mental capacity and incapacity.⁴⁹ Only people with capacity can prepare an advance directive. This means that they must be able to understand relevant information and relate it to their own specific situation, and also to comprehend and weigh up alternatives to their decision.⁵⁰ "Capacity" thus does not denote a general ability. Rather, it is decision- and/or task-specific. A person may thus have capacity in relation to certain matters but not in relation to others. With regard to advance directives, having capacity means being able to make decisions concerning one's own possible future medical care. These decisions need not be "reasonable" in the eyes of third parties. What is crucial, therefore, in assessing whether a person has the capacity to decide is not the result of the decision, but how it is reached.

Equally, an advance directive is only taken into consideration in a medical or nursing decision if the person concerned lacks capacity, at least with regard to this decision. With regard to other matters, the same person could still have capacity. Likewise, an advance directive takes effect if the person concerned cannot express a preference owing to loss of consciousness.

The Commission emphasizes that incapacity is not to be deduced automatically from a diagnosis of dementia or another mental disorder. The fact that, statistically, capacity is frequently impaired in patients with dementia provides reasonable grounds for doubt; from an ethical viewpoint, however, there is a duty to assess capacity in each individual case.

Reversibility of incapacity can sometimes be observed in progressive disorders such as dementia, but more typically in other mental disorders. Given the possibility of fluctuating capacity in dementia, the Commission recommends that capacity should be carefully assessed at the time an advance directive is prepared and before it is implemented; assessments should be performed during lucid intervals so as to promote the patient's autonomous decision-making ability. The Commission is aware that medicine lacks a uniform standard for the assessment of capacity, and that the results of an assessment depend crucially on the concept of capacity employed and the methods of measurement used.⁵¹ Here, it would be desirable for conceptions of capacity and assessment methods to be standardized so as to prevent subjective misjudgments and abuses. It is at least to be recommended that written records should be kept of who

⁴⁹ nArt. 370 Para. 1 ZGB.

⁵⁰ According to Art. 16 ZGB, people have capacity if they act "in accordance with reason". However, this does not mean that they do what is reasonable and correct in other people's eyes.

⁵¹ Cf., for example, Vollmann et al. 2003 and 2004.

carried out the assessment of capacity, and of the criteria and methods used; if any doubts remain, another expert should be consulted.

3.2.3 *Power of anticipation*

To draw up an advance directive, people must be able to imagine future illnesses. Only then can they formulate their wishes in advance. The Commission assumes that mental capacity includes the power of anticipation – also with regard to dementia. The Commission does not recommend mandatory counselling.

In practice, medical professionals sometimes call into question the validity of an advance directive by asking: When writing the advance directive, did the patient actually envisage the clinical situation which has now arisen? Were they able to project themselves into and adequately imagine the condition they are now in? And would implementation of their prior instructions really reflect their wishes? Such doubts arise in particular with regard to patients with dementia, since a disorder of this kind may not appear to involve suffering. Some people deny as a matter of principle that it is possible to imagine the life of a person with dementia, and they therefore regard an advance directive merely as one indication, among others, of “presumed wishes”. They deny that the advance directive can be strictly binding.

In response to these doubts, it may be objected that there is always a discrepancy between reality as it is imagined and experienced, and that decisions are never made with full knowledge of the facts. Even so, people with capacity are not disqualified from making life-altering decisions themselves – e.g. to become pregnant or have an operation – even if the consequences are irreversible or possibly even fatal. In addition, advance directives are generally prepared by elderly people.⁵² It can be assumed that they have already experienced illness – perhaps also dementia – among their relatives or friends, and that they may also have been seriously ill themselves. These experiences will have shaped their ideas of a good life and a good death, and the advance directive will be an authentic expression of these values. It should also be borne in mind that a person confronted with early-stage dementia retains mental capacity and thus still has the opportunity to draw up an advance directive, in the knowledge that dementia leads to a loss of capacity and aware of the likely course of the disease.⁵³ Initial experience and knowledge of illness are thus present.

For these reasons, but also in the interests of preventing a loss of self-determination, the Commission emphasizes that wishes for the future, as formulated by the person concerned according to his or her values, personal experience and preferences, are of greater weight than an assessment by third parties of what the person concerned would have decided in this situation if he or she had had mental capacity. For an assessment of this kind remains tied to an external perspective.⁵⁴ **The Commission therefore endorses the new adult protection law, in which the advance directive no longer serves merely as an indication of “presumed wishes” but takes the place of the wishes which cannot be expressed by a person lacking capacity.**

According to the Dispatch, it is permissible for people who draw up an advance directive not to seek information on the interventions they wish to refuse for future illnesses.⁵⁵ This could give rise to uncertainties

⁵² Cf. Schwarzenegger et al. 2010.

⁵³ Cf. Vollmann 2001, 163.

⁵⁴ Cf. also Section 3.3.2 below.

⁵⁵ Cf. BBl 2006, 7033.

when advance directives are to be implemented. It could be doubted that by implementing the advance directive one is actually acting as the person concerned would wish, if that person was not aware of the circumstances of the illness and the consequences of the instructions at the time the advance directive was drawn up. The Commission is opposed to the idea of addressing this concern by introducing a requirement to obtain information⁵⁶ or requiring reasons for instructions to be stated in an advance directive. In many cases, this could lead to an advance directive being too readily disregarded. While it is true that information is needed for wishes to be freely formulated, this condition may already be met by a person's experience of disease and death, or strong personal or religious values which influence ideas about illness and dying. The Commission therefore rejects any requirement for "formal" checking of whether a person is appropriately informed; rather, this is presupposed as part of mental capacity. Under no circumstances is it necessary for the author of an advance directive to justify the instructions it contains.⁵⁷

3.3 Limits to the authority of advance directives

The starting point for reflections on the limits to the authority of an advance directive is the fact that conflicting ethical obligations arise in practice. **Alongside the obligation to respect the patient's right to refuse interventions, there is an ethical obligation to satisfy the basic needs of the person concerned.** With this Opinion, the Commission wishes to help address the question of how, from an ethical viewpoint, these two obligations can be weighed up against each other, or how far the patient's right to refuse interventions may legitimately extend. The overarching goal remains that of strengthening the autonomy of a person with dementia – by ensuring that the instructions in an advance directive are either followed or, conversely, corrected.

In the Commission's view, the new adult protection law thus rightly sets limits to the authority of advance directives, and these limits are to be assessed from an ethical viewpoint below. Limits arise in relation to the scope of advance directives (what can they legitimately cover?) and to situations where their validity may be challenged. The new adult protection law discusses the grounds for such challenges and proposes presumed wishes and the patient's welfare as alternative criteria for decision-making. Protective placement of people with mental disorders is another type of clinical situation where the authority of the advance directive is limited. In this section, the limits specified and the alternative decision-making criteria proposed in the new adult protection law are discussed from an ethical perspective and an additional issue is raised, namely the question of whether third parties may restrict the application of an advance directive by invoking the patient's current needs and habits.

⁵⁶ On this point cf. also, for example, Lack 2009. Mandatory counselling is not proposed in the SAMS guidelines on advance directives either.

⁵⁷ Both under the 1997 Biomedicine Convention and under the revised ZGB, people with capacity have the right to refuse a treatment, even without being informed about its effects, merely on the grounds that they do not wish to be treated (cf. also Petermann 2007, 141).

3.3.1 *The scope of an advance directive*

In the Commission's view, there are indisputably certain areas where binding instructions cannot be given in an advance directive. For example, it is not permissible either to request illegal acts or medical/therapeutic interventions which are not indicated, or to refuse interventions designed to prevent a state of serious neglect or intolerable pain. In general, however,

it is always permissible to refuse invasive measures which violate physical or psychological integrity. An exception to this rule is pain relief in extreme pain situations.

Limits to the authority of an advance directive arise from its content, i.e. the matters concerning which a person wishes to give instructions with regard to future illnesses. People can of course include whatever they choose to in an advance directive. The important question, however, is what instructions may or must be followed by third parties when an advance directive is implemented. Here, three groups of instructions are to be distinguished:

1 Instructions that must be followed:

- a refusal of medical interventions, even if they are medically indicated;⁵⁸
- b expression of wishes concerning organ, tissue or cell donation;⁵⁹
- c instructions concerning use of the cadaver for research or teaching purposes;⁶⁰ and
- d instructions concerning autopsy, depending on cantonal legislation, with the exception of autopsies ordered by a court or by the authorities.⁶¹

2 Instructions that must not be followed:

- a instructions that contravene the law;⁶²
- b requests for medical interventions that are not medically indicated;
- c refusal of nursing interventions in cases where compliance would result in a state of serious neglect⁶³ for the person concerned; and
- d refusal of pain relief measures in extreme pain situations.

3 Instructions that may be complied with but do not have to be followed:

Any instructions that do not fall under (1) or (2).

With this classification, the Commission is largely following the approach taken in the new adult protection law and in other cantonal and national legislation. It also thereby endorses the position of the Swiss Academy of Medical Sciences.⁶⁴ For the Commission, it is important to emphasize, on the one hand, the need to accept the patient's right to refuse interventions (1a). For example, refusal of chemotherapy as an acute intervention is to be respected, even if such treatment is medically indicated. On the other hand, the professional integrity of the treatment and care team is to be respected (2a–d): it is not permissible for an advance directive to call for criminal offences such as killing on request, and an attending physician cannot be compelled to take medical measures that would contravene professional medical principles. However, patients' requests for non-mainstream interventions should be complied with, even though they are not strictly binding (3). These include, for example, individual wishes such as the provision of home care by relatives. There is a need to set limits to patient's demands so that they remain acceptable in social, institutional and economic terms, and also for the people affected by the decision. There is, however, a moral obligation to attempt to accommodate patients' wishes as far as possible.

⁵⁸ An exception is compulsory treatment in connection with protective placement (cf. Section 3.3.4 below).

⁵⁹ Such wishes fall under the Federal Act of 8 October 2004 on the Transplantation of Organs, Tissues and Cells (SR 810.21). It is, however, advisable to complete a donor card in addition. Individuals who have reached the age of 16 may declare their intention to donate (Art. 8 Para. 7 Transplantation Act).

⁶⁰ By law, use of the cadaver or parts thereof for training of healthcare staff and/or research is only permissible if express consent has been given.

⁶¹ Cf. SAMS guidelines on advance directives (SAMW 2009, 8).

⁶² Killing on request is an offence under Art. 114 of the Swiss Penal Code (StGB). Assisted suicide cannot be covered by an advance directive since, legally, the patient is required to have mental capacity at the time assisted suicide is carried out.

⁶³ In the Dispatch on the new adult protection law, "serious neglect" is defined as a state "in the presence of which it would be simply contrary to the human dignity of the person in need of assistance to deny him or her provision of the necessary care in an institution" (BBI 2006, 7062).

⁶⁴ Cf. SAMW 2009.

Under certain conditions, the Commission wishes to exclude nursing interventions and pain relief measures from the scope of an advance directive (2c and 2d). This exclusion represents a curtailment of the patient's right to refuse interventions.⁶⁵ Given that wishes concerning nursing interventions and pain relief measures are an important topic for patients, this exclusion, recommended by the Commission, needs to be justified in more detail.

The Commission assumes that activities of daily living⁶⁶ and sensations of pain are key areas determining a person's physical and mental well-being. In these key areas, people have the freedom to harm themselves, as long as the person concerned has capacity and others are not seriously harmed or endangered as a result. However, the Commission believes that there is a greater duty of beneficence vis-à-vis those who lack capacity. Here, nursing staff or the attending physician should investigate whether self-harmful behaviour is attributable to physical or mental factors. For example, in a patient refusing to eat, such factors could be mouth ulcers or delusions of poisoning. But even if such factors can be ruled out, instructions given in an advance directive which concern these key areas of human well-being are not to be (fully) complied with, on the following grounds:

1. *Professional integrity argument:* For physicians and nursing staff, failure to prevent a patient from entering a state of serious neglect or suffering intolerable pain would conflict with their professional ethic of beneficence. This is not acceptable for the groups concerned and would violate their professional integrity. In other words, patients cannot expect an institution providing care, for example, to permit – or even to create the conditions for – states of serious neglect or intolerable pain.
2. *Harm-to-others argument:* Measures regulating activities of daily living may only be discontinued at the request of the person concerned if no harm is caused to others as a result (e.g. risk of accidents with unrestricted freedom of movement). Arrangements for dealing with safety risks are specified in the care plan of an institution providing treatment or care.
3. *Social ethics argument:* People who care for and treat patients with dementia in a domestic or institutional setting must not, as a result of an advance directive, find themselves in a position where they are not allowed to fulfil their duty to attend to key areas of human well-being. For if it were possible for them to be absolved from duties of beneficence in these areas, this would send out the wrong message for the management of patients with dementia within the healthcare system and exacerbate possible underprovision.⁶⁷ In the Commission's view, the endeavour, in a spirit of beneficence, to protect these patients against third-party interests and rationing tendencies justifies a curtailment of freedom for this group of patients.

In view of these considerations, the following conclusions can be drawn regarding the scope of an advance directive:

- The patient's usual diet, personal hygiene, exercise and other activities are always to be *offered*. An advance directive must not give instructions to the contrary.

⁶⁵ In the new adult protection law, reference is made only to medical interventions. No reasons are given for this restriction of the scope of an advance directive.

⁶⁶ There are various, slightly different, lists of activities of daily living, which generally include the following items: communicating, moving about, maintaining vital functions (breathing...), washing and grooming, eating and drinking, excretion, getting dressed, resting and sleeping, occupying oneself (meaningful activities, working, playing), expressing one's sexuality, maintaining a secure environment, protecting social aspects of one's life, coping with existential experiences in life.

⁶⁷ Cf. Footnote 42 above.

- However, measures supporting activities of daily living must not be applied coercively. For example, a person with dementia still has the right to refuse food. But it should be investigated whether the patient's behaviour is attributable to organic causes or irrational fears, which should then first be resolved.
- Artificial nutrition as an acute medical intervention may, however, be legitimately refused in an advance directive.
- The administration of medicines may be legitimately refused in an advance directive, unless such treatment is designed to relieve intolerable pain or to address the underlying causes of self-harmful behaviour (e.g. delusions of poisoning in a patient refusing to eat).

3.3.2 Presumed wishes

In the Commission's view, an advance directive may only be corrected by verbal statements under certain conditions. The Commission thus criticizes the provisions of the new adult protection law concerning revocation and amendment of an advance directive. In addition, these provisions seem to the Commission to create an inappropriate incentive for presumed wishes to be too readily taken as a corrective to the advance directive. For the determination of presumed wishes, the Commission proposes special due-care criteria.

3.3.2.1 Presumed wishes in the new adult protection law

By definition, people who lack capacity can no longer formulate legally relevant wishes and are therefore unable to consent to medical interventions which violate their physical and psychological integrity. However, such consent is required to justify medical activities. Here, the advance directive assumes the important legal function of recording the patient's wishes. The directive is treated as a current expression of the patient's wishes.⁶⁸

Among the possible legal forms of proxy consent, the advance directive – representing the wishes of the person concerned formulated in advance – is accorded the highest priority in the new adult protection law. Nonetheless, the advance directive may be overridden.⁶⁹ In particular, it is not to be complied with if it leads to illegal actions (e.g. assisted suicide, which can only be carried out if the person concerned has capacity), or if there are "reasonable doubts" as to whether the advance directive was voluntary or still reflects the patient's presumed wishes. In doubtful cases or if the advance directive contains no instructions concerning the current medical or nursing decision-making situation, the patient's presumed wishes take the place of the advance directive as the criterion for decision-making in the current medical situation.⁷⁰

Under the new adult protection law, the physician and the authorized representative (generally relatives) are responsible, if necessary, for determining the presumed wishes with regard to a specific treatment situation. They do so on the basis of the values, major life decisions, convictions and ideas about quality of life and the end of life associated with or expressed by the person concerned. Here, what is to be taken into account are previous statements – made while the person still had capacity – to relatives or friends or to the treatment and care team. These earlier statements are taken into consideration in the current medical decision-making process.

⁶⁸ Cf. BBI 2006, 7033.

⁶⁹ nArt. 372 Para. 2 ZGB.

⁷⁰ nArt. 378 Para. 3 ZGB and nArt. 379 ZGB are problematic in this respect, as here the authorized representative and the physician are bound not only by the presumed wishes but also by the patient's interests ("objective" interests, according to the Dispatch; BBI 2006, 7037). The tensions involved are addressed in Section 3.3.2.

The presumed wishes are thus determined on an individual basis – i.e. the question asked is what treatment option this specific person would choose in this specific situation if he or she had capacity (e.g. what risks or what future scenarios the person would be prepared to accept). Given this individual approach, the presumed wishes determined for two people in a comparable disease situation may differ. Essentially, it is assumed that a person would consent to treatment that is necessary – i.e. indicated from a medical or nursing perspective (patient’s objective welfare) – unless there are reasons to suppose that the person is opposed to such treatment. Here, the presumed wishes need not appear reasonable to third parties;⁷¹ indeed, they may well be at variance with the patient’s objective welfare (sometimes also known as objective interests). The patient’s objective welfare is based on what would be medically necessary and advisable from a curative and palliative perspective.⁷²

For some legal experts, the introduction of the concept of presumed wishes in the new adult protection law represents a flagrant contradiction, which – contrary to the original intention of the legislation – negates the authority of the advance directive.⁷³ It is argued that this restriction of its authority is not necessary, since an advance directive is a voluntary expression of wishes, and the standard procedure specified in the new adult protection law for cases where there is no advance directive calls, anyway, for the authorized representative, together with the physician, to make decisions on medical matters on behalf of the person lacking capacity in accordance with his or her presumed wishes. In short, those who do not wish to commit themselves through an advance directive with regard to their own future are not required to do so.

Others maintain that, in the process of balancing the endeavour to allow the greatest degree of self-determination against concerns as to whether instructions in a directive are (still) valid, presumed wishes are indeed required as a corrective. In support of this position, it may be adduced that, in the interests of protection of personality against excessive commitment, a person is prohibited by law from alienating his or her liberty.⁷⁴ But an absolutely binding advance directive, in which a future scenario is specified unalterably for the person concerned, could represent precisely this kind of (impermissible) alienation.⁷⁵

3.3.2.2 Assessment and criticism

The Commission is sceptical with regard to the procedure whereby, under the new adult protection law, presumed wishes can take the place of an advance directive in decision-making. At the same time, the Commission certainly supports the idea that it should be possible for an advance directive to be corrected, in view of the following consideration: the inclusion of the advance directive in the Swiss Civil Code should not mean that only written, signed and dated advance directives are taken into consideration in medical decision-making for people who lack capacity. It is an ethical requirement that clearly expressed verbal instructions should also be taken into consideration by the attending physician. If arrangements for the future are made in discussions with the treatment and care team – instructions which are also documented in the patient’s records – then this also counts as an expression of wishes by the person concerned.

⁷¹ Cf. Vollmann 2001, 162.

⁷² As Margot Michel (cf. Michel 2009, 122) points out, “the Federal Supreme Court does not clearly [distinguish] between presumed and objective wishes, but takes the patient’s interests – by which the representative is to be guided in decision-making – to include both objective circumstances and the patient’s presumed wishes [Federal Supreme Court Decision BGE 114, Ia 350, 363]. [...] It is particularly difficult to decide to what extent the presumed wishes should be binding in cases where these wishes conflict with the patient’s objective welfare.”

⁷³ Cf. Geth/Mona 2009.

⁷⁴ Art. 27 Para. 2 ZGB.

⁷⁵ Frank Th. Petermann argues, however, that “the provisions in question [do not cover] unilateral legal transactions, such as drawing up a will” and are therefore not applicable to the advance directive either (Petermann 2007, margin no./Rz 57).

In the new adult protection law, this is not adequately taken into account. Thus, verbal instructions can only correct an existing advance directive if they express the presumed wishes of the patient.⁷⁶ However, in legal practice written documents have a higher binding status than verbal statements, which are harder to prove. This means that the legislation disadvantages those who draw up an advance directive but subsequently make verbal statements on this subject; since, by contrast, the verbally expressed wishes of a person who has not prepared a written advance directive are more easily taken to be the presumed wishes of the patient and thus have to be followed. To this extent, the Commission criticizes the provisions of the new adult protection law concerning the revocation of an advance directive.⁷⁷ According to these provisions, an advance directive can only be revoked in the form in which it was prepared, or torn up, or replaced by a new advance directive. The Commission recommends that a verbal cancellation or amendment of the advance directive should also be valid.

However, changing the provisions of the new adult protection law concerning the revocation of an advance directive, should not lead attending physicians, for legal reasons, to routinely seeking to verify the advance directive by determining the presumed wishes; since this would mean that, in terms of practical significance, the advance directive would merely serve as an *indication* of presumed wishes. In the Commission's view, this would be regrettable, for the advance directive bears witness to a person's actual wishes and thus is to be accorded greater weight than the reconstruction of presumed wishes, even though this reconstruction takes place at the time of the current medical decision. By preparing an advance directive, a person assumes – and wishes to assume – responsibility for future decisions. Verification by others is only required in justified exceptional cases.⁷⁸

Another cause for concern, in the Commission's view, is the fact that reasonable doubts as to whether an advance directive still reflects the patient's wishes can arise all too rapidly under the new adult protection law. For the mere fact that "the advance directive was prepared quite a long time ago"⁷⁹ can raise doubts. But this is to accept a vague, subjective assessment (what does "quite a long time ago" mean?) as grounds for doubt.⁸⁰ In practice, an existing advance directive is generally updated every 2 years. Neither the new adult protection law nor the SAMS guidelines on advance directives (SAMW 2009) call for a general limit on the period of validity, such as is specified by the Austrian law, for example (5-year clause). In the Commission's view, the imposition of a legal limit on the period of validity could mean that individuals were unduly deprived of the responsibility for keeping an advance directive up to date themselves. For the Commission, factors other than the age of an advance directive would appear to be more relevant to its currency – for example, a fundamental, non-health-related (positive or negative) change in the circumstances of the person concerned (e.g. pregnancy, loss or acquisition of a partner).⁸¹

3.3.2.3 Recommended due-care criteria for determination of presumed wishes

The Commission emphasizes, however, that special due-care criteria are to be applied in the determination and implementation of presumed wishes. For it can never be completely ruled out that presumed wishes do

⁷⁶ Cf. BBI 2006, 7031 and also Martin 2010.

⁷⁷ nArt. 371 Para. 3 ZGB in conjunction with Art. 362 ZGB.

⁷⁸ Against this background, a provision of the new adult protection law which is to be welcomed is that the attending physician is required to state the reasons for non-compliance with an advance directive in the patient's records, so that the decision is transparent, e.g. in the event of an appeal to the Adult Protection Authority (BBI 2006, 7034).

⁷⁹ BBI 2006, 7033.

⁸⁰ On this point cf. also Geth/Mona 2009, 172.

⁸¹ On this point cf. also the critical comments of Schwab (2006) on self-determination in the elderly.

not accord with the actual wishes of the person concerned.⁸² For example, several empirical studies showed that the agreement between presumed and actual wishes was not markedly higher than would be expected by chance, and that decisions based on presumed wishes corresponded more closely to the preferences of surrogates than patients.⁸³ The authenticity of presumed wishes can be called into question merely on the grounds that they involve a third-party hypothesis or extrapolation, which becomes necessary precisely because, with regard to the given medical decision-making situation, the wishes of the person concerned have not been unequivocally expressed. Presumed wishes are thus based on the external perspective of third parties vis-à-vis the incapacitated person. They should not be confused with the person's "current wishes" or actual internal perspective. Despite the impossibility of being completely objective, third parties must always endeavour to determine the patient's presumed wishes in an appropriate manner.

In order to avoid a loss of patient self-determination as far as possible, it is important for third parties to be aware of the conditions under which presumed wishes are to be determined.⁸⁴ These include, firstly, the epistemological restrictions on access to another person's internal perspective and emotional world. Secondly, people cannot determine a patient's presumed wishes in isolation from their own values, preferences and interests, or from their feelings for and relations with the patient.⁸⁵ This is particularly true of intimates and relatives who – as potential authorized representatives under the new adult protection law – are to play an active part in determining the patient's presumed wishes. As a result, they may possibly become involved in conflicts of interest and conscience.⁸⁶ Judgments made by the treatment and care team are not value-free either, because it has a professional obligation to act in accordance with the ethic of healing and alleviation of suffering, and because its freedom of action is partly restricted by institutional requirements. As far as possible, the influence of one's own interests, values and ideas of reasonableness should be the subject of conscious reflection in the process of determining presumed wishes. Thirdly, the reconstruction of presumed wishes is guided by considerations of consistency. In other words, third parties are required to determine presumed wishes on the basis of known values, attitudes to life, etc. of the person concerned. However, this presupposes a consistency of values, which is not necessarily the case. Even if a third party knows the person concerned very well, it is possible that the person has silently changed his or her views as a result of the experience of illness.⁸⁷ Although the decisions of elderly subjects have been shown to be highly stable⁸⁸ (and dementia is primarily a disorder of later life), the determination of presumed wishes will always involve uncertainties and inadequate knowledge. The Federal Council appears to wish to address these concerns, in that the Dispatch mentions the possibility of "points of view" being included in an advance directive so as to facilitate the determination of presumed wishes.⁸⁹ The Commission assumes that:

- only people favourably disposed towards the patient will be involved in the determination of presumed wishes,
- their own interests will be subordinated to the patient's welfare or wishes, and the process will include reflection on their own values and

⁸² In the Dispatch, the Federal Council also clearly distinguishes between presumed wishes and current wishes, which can no longer be determined owing to the onset of incapacity (BBI 2006, 7034).

⁸³ Quoted after Jox 2004, 407. In addition, a US review concluded that neither patient designation of surrogates nor prior discussion of patients' treatment preferences improved surrogates' predictive accuracy (cf. Shalowitz et al. 2006).

⁸⁴ On the criteria for determination of presumed wishes cf. also Wunder 2004.

⁸⁵ Cf. Brückner 1999, Moore et al. 2003 and Jox 2004. For Andreas Kick, determination of the patient's presumed wishes is a therapeutic process involving empathy, diagnostic objectification and recognition of intentions, which cannot be replaced by a legal procedure (cf. Kick 2007).

⁸⁶ Cf. Section 3.4 below.

⁸⁷ Cf. Sailors 2001, 187.

⁸⁸ Cf. Bosshard et al. 2003.

⁸⁹ Cf. BBI 2006, 7012.

attitudes so as to ensure that decisions are taken in accordance with what the patient would have wanted, and

- the people concerned are aware that presumed wishes may be at variance with the patient's objective welfare.

A careful approach to the determination of presumed wishes also includes the following:

- Verbal statements made by the patient to the physician are to be documented in the patient's records. Verbal statements made outside the patient-physician relationship must be attested by several people.
- The degree of dementia is to be carefully assessed by a professional so as to ensure that the verbal statement was made at a time when the person concerned had mental capacity.

If no advance directive is available and presumed wishes cannot be determined, decisions should be made in accordance with the patient's objective welfare.

3.3.3 *Current habits and needs*

The Commission takes the view that, while the current habits and needs of a person lacking capacity are to be taken into account in the implementation of an advance directive, this does not mean that binding instructions given in an advance directive are invalidated.

In the Commission's view, the advance directive should serve to strengthen the autonomy of people with dementia. This can happen in two different ways. Firstly, the autonomous decisions of the person concerned are respected if instructions given in an advance directive are followed. Secondly, the treatment and care team should also seek to take account of current expressions of needs and habits in the day-to-day management of a person with dementia. In the course of their illness, people with dementia may develop habits or needs which – from the viewpoint of the treatment and care team or of relatives – appear to conflict with instructions given in an advance directive. From an ethical perspective, however, self-determination includes the freedom to change one's wishes, needs and habits over time.

At this point, the question arises whether it should be possible to revise an advance directive in a state of *incapacity*. This possibility is not provided for in the new adult protection law: presumed wishes, which may act as a corrective to an advance directive, are reconstructed solely on the basis of statements made by the person concerned in a state of *capacity*.⁹⁰ But from an ethical perspective, should there not also be a "right of veto for the incapacitated"⁹¹ with regard to the advance directive, as is found in other areas of Swiss law?⁹²

In dealing with people with dementia, it is a central and uncontroversial ethical requirement that they should be valued and respected in essentially the same way as people who are healthy.⁹³ This includes taking their expressed wishes seriously and taking account of their needs and habits, as far as this is possible for an institution and acceptable for other people.⁹⁴ In the Commission's view, however, it would not be legitimate to conclude from certain types of behaviour and responses – such as shaking one's head, turning one's body away, shying away or offering resistance – but also from supposed enjoyment of life, which may be manifested in everyday habits, that a person's attitudes to medical interventions have changed.

⁹⁰ See Section 3.3.2 above.

⁹¹ For example, regenerative tissue or cells may not be removed against the will of an incapacitated person (Art. 13 Para. 2 lit. h Transplantation Act), and similar provisions are included in the draft Human Research Act (Art. 21).

⁹² In German law, such utterances are known as natural wishes (*natürlicher Wille*) and have binding force – i.e. they can invalidate an advance directive containing provisions to the contrary (cf. Richter-Kuhlmann 2009). On the concept of natural wishes in the bioethical and legal literature cf. also Jox 2006 and Kirsch/Steinert 2006. The view that current signs of a will to live should always have greater weight than an advance directive is also supported by Dabrock 2007 and Wunder 2008. For criticism of attempts to formulate the problem in terms of a conflict of wishes cf. Merkel 2004. The concept of natural wishes is not found in Swiss law. In addition, the Commission finds the term misleading since a person lacking capacity can no longer formulate legally relevant wishes. Instead, the Commission recommends that the phrase "current expressions of needs and habits" should be used.

⁹³ Cf. Nuffield Council on Bioethics 2009.

⁹⁴ For carers, the duties of care include making sure that observable behaviour (e.g. refusal to eat) is not due to a physiological problem (e.g. dysphagia) or a mental problem (e.g. delusions of poisoning). Cf. also Müller-Blaser 2007.

⁹⁵ On the concept of the Ulysses contract in psychiatry cf. Atkinson 2007, 40–43.

⁹⁶ Art. 27 Para. 2 ZGB. Cf. Section 3.3.2 above on presumed wishes.

⁹⁷ From an ethical perspective, a majority of Commission members see this as a restriction of the right to refuse treatment and hence of the self-determination of people with a mental disorder.

From a medical perspective, however, a minority within the Commission argues that, rather than restricting the patient's autonomous decision-making ability, protective placement permits the treatment of a disorder which has incapacitated the patient. The Commission is agreed that the restriction of the validity of an advance directive requires ethical justification.

⁹⁸ nArt. 372 Para. 2 ZGB.

⁹⁹ On the current situation regarding advance directives in psychiatry cf. Drozdek 2007 and 2008.

¹⁰⁰ BBl 2006, 7043.

¹⁰¹ Section 3: Protective placement, nArt. 426–439 ZGB.

¹⁰² In cases of voluntary admission, the advance directive remains binding for the treatment and care team.

¹⁰³ nArt. 372 Para. 2 ZGB, emphasis added.

¹⁰⁴ nArt. 433 Para. 3 second sentence ZGB. The new adult protection law – subject to cantonal regulations – also provides for the possibility of involuntary outpatient treatment. In such cases, an advance directive will also have to be taken into account. Cf. Bridler/Gassmann 2010, 1752.

¹⁰⁵ nArt 380 and 433ff. ZGB, cf. BBl 2006, 7068.

¹⁰⁶ nArt. 434 Para. 1 ZGB. According to the Dispatch, the measures ordered will generally involve pharmacotherapy, but also compliance with a daily routine, interviews and force-feeding. Cf. BBl 2006, 7070.

The utterances of an incapacitated person are to be taken into account – but only with regard to those areas of life to which these utterances actually relate. If, for example, a person with dementia develops a healthy appetite, this is not to be taken as an indication of a “general will to live”, which would allow a binding refusal of medical interventions in an advance directive to be called into question. The Commission takes the view that instructions in an advance directive concerning medical matters, e.g. refusal of antibiotic treatment, are still to be followed. It would not be legitimate, in the Commission's eyes, to challenge the validity of such instructions – by definition, people who are incapacitated are no longer in a position to make decisions on medical matters, because they are unable to understand the content, implications and possible consequences of such a decision.

It should be stressed that this does not make the advance directive a “Ulysses contract”, whereby a person with capacity gives binding instructions that all future expressions of wishes are to be ignored.⁹⁵ Legally, this would not even be possible, given that people are prohibited from alienating their liberty and do not have the power to predetermine their future comprehensively.⁹⁶ Ultimately, in the Commission's view, no irreconcilable conflicts can arise between current habits and needs and the binding instructions given in an advance directive, since the subject matter of an advance directive differs from the matters to which the habits and needs of a person with dementia can relate. An advance directive is only triggered when the person concerned has been declared to lack capacity with regard to *medical decisions*.

3.3.4 Protective placement

Under the new adult protection law, an advance directive cannot always prevent psychiatric treatment, if such treatment is ordered in connection with protective placement. This means that the rights of people with a mental disorder to self-determination and autonomous decision-making are restricted,⁹⁷ which requires ethical justification.

The new adult protection law introduces the advance directive without distinguishing between different types of disorder.⁹⁸ Nonetheless, according to the new adult protection law, the scope and authority of an advance directive, under certain conditions, are not the same in psychiatry as in somatic medicine.⁹⁹ Mental disorders are taken to include dementia.¹⁰⁰

Under the new adult protection law, the authority of an advance directive is limited in cases where, in connection with a protective placement,¹⁰¹ a person is admitted involuntarily to a psychiatric hospital.¹⁰² In such cases – in contrast to somatic disorders – the physician is not obliged to “comply with” the directive.¹⁰³ An advance directive merely has to be “taken into account” in the development and approval of a treatment plan.¹⁰⁴ This means that the treatment preferences of the person concerned are to be respected as far as possible, but with the crucial proviso that an advance directive cannot always prevent treatment.¹⁰⁵ Thus, under the new adult protection law, a chief physician is authorized to order treatment – contrary to the instructions given in an advance directive – under certain conditions, such as imminent danger to the patient or others, incapacity and a lack of alternative treatment options.¹⁰⁶ The intention is to allow the purpose of the

protective placement to be achieved in an appropriate manner. The purpose of such a placement is to ensure that a person with a mental disorder or disability, or in a state of serious neglect, receives such treatment and care as is required from the perspective of beneficence.¹⁰⁷

In the Commission's view, an ethical justification needs to be found for this procedure: on what grounds could it be ethically acceptable, in certain situations involving mental illness, to give the principle of beneficence precedence over the principle of patient autonomy and to fail to comply with an advance directive?¹⁰⁸

Let us suppose that an advance directive has been prepared in accordance with the requirements specified in the new adult protection law to ensure validity: the patient had capacity at the time the advance directive was prepared, it was prepared voluntarily, it contains no instructions which contravene the law, and it meets the formal requirements (written, signed and dated). **From an ethical and legal viewpoint, the disorder from which the author of the advance directive subsequently suffers is of no relevance to its validity.**

If a valid advance directive is now to be applied in a specific clinical situation, the following points are always to be assessed:

1. the patient must be in a state of incapacity;
2. there must be no doubts as to whether the advance directive is still "current" (i.e. the directive reflects the wishes of the person concerned); and
3. the instructions in the advance directive must relate to the clinical situation which has arisen or to the decision to be taken on a medical/therapeutic intervention.

In the Commission's view, these three points should be assessed both for somatic and for mental disorders, but the last point requires a nuanced approach in cases of mental illness. Here, problems may arise which call for individual solutions. If an advance directive includes a refusal of artificial nutrition, this instruction is binding in principle (refusal of a medical intervention). However, if food is refused in a case of psychosis (e.g. delusions of poisoning), involuntary treatment could be permissible in order to resolve the delusions. This could be justified on the grounds that the person concerned had not envisaged this specific clinical situation when the advance directive was prepared.

Under the new adult protection law, only *refusals* of medically indicated interventions are generally binding for the treatment and care team. *Requests* for medical interventions do not have the same binding force. This position is supported by the Commission. In psychiatric practice, however, the latter situation arises quite frequently: after a manic episode, for example, a patient may give instructions that he or she is to be treated involuntarily, if necessary, when the next episode occurs. For ethical as well as other reasons, such instructions are not to be automatically followed. Such an intervention is only permissible if alternative treatment methods have been considered and involuntary treatment is also justified on other grounds (e.g. imminent danger to oneself or others, or serious neglect).

Against this background, the question arises whether it is also permissible from an ethical viewpoint to give binding instructions in an

¹⁰⁷ nArt. 426 ZGB. An additional condition specified is that this treatment or care can only be provided in an appropriate institution.

¹⁰⁸ On coercive measures in medicine cf. also the relevant SAMS guidelines (SAMW 2005a).

advance directive refusing involuntary treatment which is deemed to be medically necessary.¹⁰⁹ With protective placement, no provision is made for such a possibility in the new adult protection law. In the interests of beneficent protection, the right of people with a mental disorder to refuse interventions is restricted:

- The Commission can support this approach in the event of danger or serious harm to others.
- If failure to carry out treatments which are refused in an advance directive would lead to serious neglect or threaten the life of the person concerned, it is justified in the Commission's view to carry out these treatments contrary to the person's instructions. This is because the treatment and care team cannot be reasonably expected to contribute, by omission, to a state of serious neglect in the person concerned.¹¹⁰
- For the Commission, this approach is also justified if areas are concerned with regard to which a person cannot, in the Commission's view, issue binding instructions.¹¹¹

The Commission is well aware that arguments based on beneficence leave considerable room for interpretation and leeway for action. What the Commission advocates is a responsible weighing-up of the demands of beneficence against those of autonomy (which generally has priority). It recommends that decisions should only be taken in consultation with the treatment and care team and the authorized representative/trusted third party.

However, the Commission emphasizes that instructions in a valid advance directive which do not relate to the grounds for protective placement must still be complied with. If a person refuses cardiopulmonary resuscitation, this instruction is also binding in the context of protective placement and is not to be invalidated by invoking the risk of "serious damage to health"¹¹².

3.4 Surrogate decisions

The Commission essentially welcomes the fact that the new adult protection law provides for a shared decision-making model, involving physicians and patients' representatives. In its view, it is advisable to consult all members of the treatment and care team who are in direct contact with the patient. The Commission also believes that the advance directive and presumed wishes should unequivocally take precedence over "objective interests". Decisions should only be guided by the patient's "objective" welfare in cases where no advance directive is available and presumed wishes cannot be determined.

The new adult protection law marks a paradigm shift: in future, in cases where a patient is incapacitated and no advance directive is available, the attending physician is no longer to have the final say in medical decision-making, but is to make such decisions "in consultation" with the "authorized representative".¹¹³ The law also specifies an order of precedence for groups of people authorized to represent an incapacitated patient in medical matters.¹¹⁴ Among the first groups listed – apart from a person who may be designated by an advance directive or establishment of power of attorney, or an advisory guardian – are close relatives or partners, and friends who are part of the same household.

¹⁰⁹ Coercive measures and involuntary treatment generally involve the administration of psychotropic agents.

¹¹⁰ Cf. the beneficence argument in Section 3.1 above.

¹¹¹ Cf. Section 3.3.1 above.

¹¹² nArt. 434 Para. 1 No. 1 ZGB.

¹¹³ nArt. 377 Para. 1 ZGB.

¹¹⁴ nArt. 378 ZGB.

¹¹⁵ Cf. BBI, 7036. From a legal viewpoint, a legal right of representation would always necessitate the consent of the legal representative to medical interventions. This follows from the principle that, in legal terms, any medical intervention represents a violation of personal rights, which needs to be justified by the consent of the subject or his/her representative. In cases where consent is refused without justification, it is possible – as in cases involving children – to appeal to the Adult Protection Authority, which may either grant consent itself or appoint an advisory guardian to act as a representative (nArt. 381 Para. 2 No. 3 ZGB).

The goals of this change in the decision-making procedure are, firstly, to strengthen patient self-determination and, secondly, to promote family solidarity. In accordance with the principle of self-determination, an authorized representative designated by the patient him/herself takes precedence over legal representatives. Family solidarity is supported by making it possible for relatives and others close to the patient to become authorized representatives, thereby taking the place of the attending physician as *sole* decision-maker. Despite the potentially misleading wording to the effect that the treatment plan is to be drawn up “in consultation” with the authorized representative, the consent of the authorized representative will be required.¹¹⁵

The changeover to shared decision-making (involving physicians and family members or others close to the patient) is in accordance with the provisions of the European Biomedicine Convention and brings the Swiss Civil Code into line with this Convention, which has been ratified by Switzerland.¹¹⁶ From an ethical perspective, there are also good reasons to recognize the moral authority of people close to the patient in medical decision-making situations concerning people in a state of incapacity. It has been argued that family members and other intimates are well acquainted with the patient, involved in his or her care, primarily motivated by the patient’s welfare in their decision-making, and affected by such decisions themselves.¹¹⁷

The Commission essentially welcomes the development of a shared decision-making model.¹¹⁸ However, it also has some concerns about this model and recommends certain amendments: for example, it would be desirable if the circle of those participating in decision-making were expanded to include nursing staff, so that the entire treatment and care team would be involved in decisions. Often, nursing staff have close contacts with the patient and are thus familiar with his or her condition and current needs and habits. As care work is guided by beneficence and the welfare of the person concerned, nursing staff could also be accorded the “moral authority” of being involved in decision-making. If a “trusted third party” has been appointed in accordance with the new adult protection law, this person should also be involved in the decision-making process.¹¹⁹

To the Commission, it appears questionable whether the new provisions calling for relatives or other intimates to represent the patient in medical matters are ideal in all cases.¹²⁰ If major decisions are to be taken on behalf of someone who is seriously ill, this can also give rise to feelings of guilt or accusations. Precisely because of their closeness to the patient, relatives or intimates may possibly feel overburdened by the responsibility of making decisions for this person.¹²¹ This should be taken into consideration when an authorized representative is selected in an advance directive – for example, by talking to the person and making it clear that he or she can also refuse to take on this role.

Another point which underlines the need for caution in the handling of surrogate decisions is the fact that representatives cannot make decisions in a disinterested and value-free manner and may even be caught up in conflicts of interest.¹²² This applies to physicians just as much as to authorized representatives. It would be a mistake – both theoretically and empirically – to assume objectivity on the part of decision-makers. Empirical studies

¹¹⁶ Article 6 of the Biomedicine Convention states that if “an adult does not have the capacity to consent to an intervention because of a mental disability, a disease or for similar reasons, the intervention may only be carried out with the authorisation of his or her representative or an authority or a person or body provided for by law.” In Switzerland, the situation at present is that, since in most cases of incapacity in adults there is no legal representative, decisions are taken by the attending physicians. This is contrary to the provisions of the Biomedicine Convention.

¹¹⁷ Cf., for example, Moore et al. 2003, 4.

¹¹⁸ Cf., for example, also Vollmann 2001.

¹¹⁹ The “trusted third party” is not assigned a particularly significant role in the new adult protection law (nArt. 432 ZGB and BBl 2006, 7067f.). Specifically, the duties of the trusted third party are to participate in the preparation of the treatment plan (nArt. 433 Para. 1 ZGB) and to assist in the procedure specified in nArt. 434 Para. 2 ZGB. According to nArt. 378 ZGB, the authorized representative could take a decision against the will of a trusted third party. This dispels the concerns expressed by the Commission in its submission to the consultation procedure regarding the status of the trusted third party vis-à-vis the authorized representative designated in an advance directive. Naturally, the person concerned is at liberty to designate a trusted person as his or her authorized representative in an advance directive (nArt. 370 ZGB) or in the establishment of power of attorney (nArt. 360 ZGB) (nArt. 378 Para. 1 No. 1 ZGB).

¹²⁰ The Commission had already expressed concerns on this point during the consultation procedure.

¹²¹ Dreyer et al. 2009, 675.

¹²² Cf. Section 3.3.2 above on presumed wishes.

reveal high levels of inaccuracy in surrogate decision-making.¹²³ This makes it all the more important to specify on what basis people's decisions are to be made. Here, the new adult protection law provides guidance. If an advance directive is available, decisions are to be made on this basis. The instructions given in an advance directive are thus binding both for physicians and for authorized representatives.¹²⁴ However, if there is no advance directive, or if it contains no instructions relating to the current medical or nursing decision-making situation, or if its validity is challenged, then decisions are to be taken in accordance with the presumed wishes and (objective) interests of the person concerned.¹²⁵ In the Commission's view, special criteria and requirements need to be met in the determination of presumed wishes.¹²⁶

For the Commission, it is problematic that the decisions made by the people specified in the law are also to be guided by the patient's (objective) interests,¹²⁷ as it may make a substantial difference which of the two criteria is used for decision-making. While a person's presumed wishes do not have to satisfy any criteria of reasonableness, objective interests are always tied to such criteria. For this reason, presumed wishes could conflict with the patient's objective welfare. For example, a blood transfusion could be considered reasonable from a medical standpoint and conducive to the patient's objective welfare and yet, according to the presumed wishes of the person concerned (e.g. a Jehovah's Witness), precisely this intervention is not to be undertaken.

The Commission is afraid that, while the legislation is intended to strengthen patients' right to self-determination, the invocation of objective interests could lead to a step in the opposite direction – away from the principle of freedom, back to the paternalistic care model. This would be a violation of the right to self-determination, which also involves being able to deviate from one's objective interests and hence from criteria of reasonableness.¹²⁸ The Commission therefore recommends that presumed wishes should take precedence over objective interests: decisions should only be guided by objective interests in cases where presumed wishes cannot be determined. This should also apply to the intervention of the Adult Protection Authority, which some legal experts believe would have grounds for intervening – according to the letter of the law – merely if the patient's objective interests were considered to be at risk.¹²⁹

Given the impossibility of truly objective, value-free and disinterested decision-making, it also appears important to the Commission that it should be possible for surrogate decisions to be challenged.¹³⁰ This should be done by invoking the advance directive, presumed wishes or the patient's current needs and habits. To ensure that the decision taken is, as far as possible, balanced and appropriate for the person concerned, it would be desirable to involve, or at least seek the views of, as many people as possible (the entire treatment and care team, trusted third parties, the authorized representative and others close to the patient). Ideally, these people should reflect on their own interests and values in the decision-making process.¹³¹ In addition, relatives or others close to the patient should always take on the role of representative voluntarily and not under pressure: as well as enabling them to act with particular empathy, their relationship with the person concerned may well place a burden on them.

¹²³ Cf. literature in Jox 2004, 407 and Shalowitz 2006.

¹²⁴ Cf. Geth 2010, 117f. The authority accorded to advance directives can also be observed in practice, at least in the US, where 29% already have an advance directive. A survey of relatives indicated a high level of agreement between patients' preferences, as expressed in an advance directive, and subsequent medical decisions (cf. Gillick 2010).

¹²⁵ nArt. 378 Para. 3 ZGB, and in urgent cases, where a decision is to be taken by the physician alone (nArt. 379 ZGB).

¹²⁶ Cf. Section 3.3.2 above.

¹²⁷ Problematic points associated with the concept of presumed wishes have already been discussed in Section 3.3.2.

¹²⁸ Cf. also the SAMS guidelines on patients' right to self-determination (SAMW 2005b).

¹²⁹ Cf. Geth/Mona 2009, 178.

¹³⁰ While the physician is not required to comply with an advance directive if the patient's presumed wishes are believed to be different (nArt. 372 Para. 2 ZGB), the physician is bound by the decision of the authorized representative (nArt. 378 ZGB). Here, however, it would be possible for the Adult Protection Authority to intervene in accordance with nArt. 381 Para. 2 No. 3 ZGB.

¹³¹ Cf., for example, Ho 2009.

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Working methods of the Commission

In Spring 2009, the Commission decided to establish a working group on “Advance directives and dementia”, charged with preparing a draft Opinion. In its activities, the working group received technical and organizational support from the Secretariat. The results of its work, including drafts of parts of the Opinion, were regularly discussed at plenary meetings of the Commission.

To gain an overview of various positions, the Commission also held two hearings, attended by the following experts:

- Dr Martin Conzelmann, Chief Physician, Geriatric Competence Center, Felix Platter-Spital, Basel.
- Shirin Hatam, lic. iur., attorney, Pro Mente Sana (French-speaking Swiss association).
- Settimio Monteverde, lic. theol., MAE, Head of Ethics Department, Seminar am Bethesda, Basel, and Head of Pastoral Care and Communication and Internal Continuing Education, Hospiz im Park, Arlesheim.
- Christoph Schmid, Education Officer, CURAVIVA (Swiss Association of Retirement and Nursing Homes).
- Dr Andreas Studer, Vice-President, Swiss Alzheimer’s Association and Head of Psychogeriatrics Department, Felix Platter-Spital, Basel.
- Professor Marie-Jo Thiel, Faculty of Catholic Theology, University of Strasbourg. Director of the European Center for the Study and Teaching of Ethics (CEERE/ECSTE), University of Strasbourg.
- Filip Uffer, Director, Pro Senectute, Canton Vaud.

The Opinion was adopted by the Commission on 24 February 2011.

