

## Central Position of Autonomy of the Patient as a „Right“

- Focus arose largely from problems coming from medical **research**
- Autonomy, Informed consent in the **practice** of medicine (litigation climate..)

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## Research against the will ..



- The ‚Doctors Trial‘, events much later in the USA

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## Revisit: Decision Making Process

1. Recognize the problem
2. Medical history; feasible options; **CH Law: PHYSICIAN MUST FIND OUT IF AN ADVANCED DIRECTIVE EXISTS?**
3. Who are the stakeholders
4. Stakeholder “perspective” analysis
5. Who .... wants what ....why....?
6. Evaluate and reflect using principles: what should we do?
7. Formulate a judgment and a decision. Justify the decision.
8. Make recommendation. **Obtain informed consent for the intervention / action**

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## Why „Autonomy“ (of Patient) as „Right“

QUESTION: right to do what exactly?



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## Why „Autonomy“ (of Patient) as „Right“

QUESTION: right to what exactly?

- right to be fairly heard and have opinion considered (PEG case)?
- right to say no (to what is being offered)
- Right to agree to what is on the table
- Right to require something else?
- Who decides limits of rights to autonomy



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## Why „Autonomy“ (of Patient) as „Right“

- **Philosophical origins**

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## „Informed Consent „

- One nice outline: The Belmont Report, Ethical Principles and Guidelines for the protection of human subjects of research, USA, 1979
- (after research/practise scandal in the USA)



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## Belmont Report echoed in Helsinki etc; CH laws Principle of Respect for Persons

- “Informed Consent” is an expression of the principle of respect for persons
- Respect for persons incorporates at least two ethical convictions: first, that individuals should be treated as autonomous agents, and second, that persons with diminished autonomy are entitled to protection.
- the requirement to acknowledge autonomy requires that subjects, to the degree that they are capable, be given the opportunity to choose what shall or shall not happen to them.
- This opportunity is provided when adequate standards for **informed consent** are satisfied.

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## Model of Informed Consent

1. Threshold elements (work of physician)
  - Is the patient competent? Need to involve/replace with proxy?
  - Voluntariness?
2. Information Elements (Obligation of physician)
  - Clarification of medical facts; risks, benefits
  - Information on current status diagnosis, prognosis (*only if pat. knows the truth can consent be informed*)
  - Outline options, **make medical recommendation**, say why
  - Patient understanding
3. Counselling Elements
4. Elements of Relationship (involve others, allow time)
5. Consent elements (consensus would be optimal)



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## „Informed Consent „

Consent to what:

- research
- medical practice
- Degree of formality necessary varies according to type of intervention and context



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## Questions

- ❖ has the (moral, legal) ‘right’ to have autonomy respected as expressed in informed consent taken a TOO important place, masking other important principles...
- ❖ Is the principle of respect for persons being: over – interpreted - too complex formalities, forms etc.. - in informed consent?

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## Revisit: Elements of Medical Context Ethics Decision Making Process

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2. Medical history; feasible options; CH Law: PHYSICIAN MUST FIND OUT IF AN ADVANCED DIRECTIVE EXISTS?
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## Respecting Autonomy

- It is well documented that many patients have problems taking a decision and prefer to trust the „expert“: question: what would you do doctor?
- This in no way weakens the importance of the principle behind informed consent

## Questions

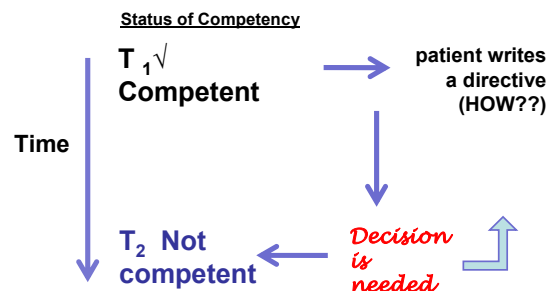
- Who really takes final decision?
- Who has the responsibility?



## Revisit: Decision Making Process

1. Recognize the problem
2. Medical team to confirm medical history; identify feasible options; **CH LAW: FIND OUT IF DOES AN ADVANCED DIRECTIVE EXIST?**
3. Who are the stakeholders
4. Stakeholder „perspective“ analysis
5. Who .... wants what ....why....?
6. Evaluate and reflect using principles: what should we do?
7. Formulate a judgment and a decision. Justify the decision.
8. Make recommendation. Obtain informed consent

## Right to Self Determination, Autonomy



Schweizerisches Zivilgesetzbuch Die Patientenverfügung  
Swiss Civil Code, Revision 2008

Art. 370

**2 A physician must respect the directive unless it infringes a law or in the event that a reasonable doubt exists that it was an act of free will or that it really expresses the presumed wishes of the patient**

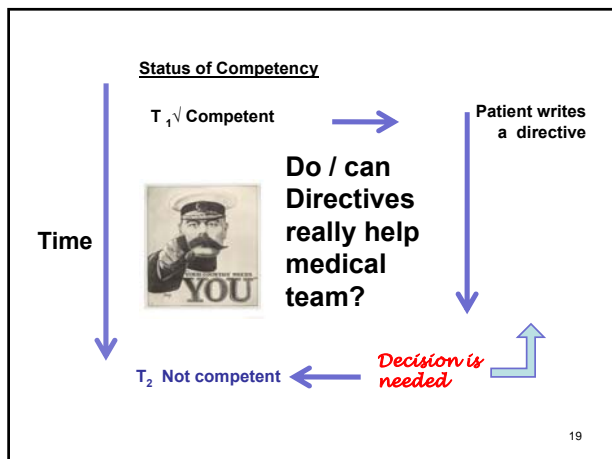
**3 The physician must document the reasons not for respecting the directive.**

## Directives Versus Physician's Ethos Standesordnung FMH

Art. 2: Aufgaben des Arztes und der Ärztin

„Es ist Aufgabe des Arztes und der Ärztin, menschliches Leben zu schützen, Gesundheit zu fördern und zu erhalten, Krankheiten zu behandeln, Leiden zu lindern und Sterbenden beizustehen.“

- Protect, support, give back health.. reduce suffering.. Stand by the dying...



## Advanced Directives

- What however can a (future) patient really include in a Directive?
- How much autonomy is really expressed?

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## Die Patientenverfügung Swiss Civil Code, Revision 2008

Art. 370

1 A competent person can establish in an advanced directive which medical intervention they will accept or reject in the event that they are not capable of deciding at the time that a decision needs to be taken.

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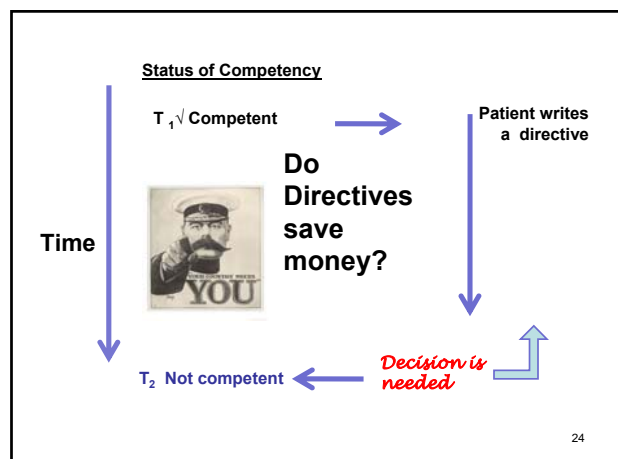
Betreuung von Patientinnen und Patienten am Lebensende Medizinisch-ethische Richtlinien der SAMW 2004.

### 4. Grenzen des ärztlichen Handelns

„Die Respektierung des Patientenwillens stösst dann an ihre Grenzen, wenn ein Patient Massnahmen verlangt, die unwirksam oder unzweckmässig sind oder die mit der persönlichen Gewissenshaltung des Arztes, mit der ärztlichen Standesordnung oder dem geltenden Recht nicht vereinbar sind. „ Ende Zitat

- Unwirksam, unzweckmässig, AND unwirtschaftlich?

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### Swiss Civil Code, Revision 2008

(Erwachsenenschutz, Personenrecht und Kindesrecht)

Art. 378

The following persons are authorised in the order in which they appear below to represent a person who is not capable of taking a decision to accept or reject any out-patient or in-patient interventions:

1. The people named in an advanced directive
2. legal representatives who have a power of attorney for medical matters
3. A spouse or ,official' partner who shares a household or has regular personal supportive contact
4. Any other person who shares a household or have a regular personal supportive contact accompanying role
5. Children if they have a regular personal supportive contact
6. Parents if they have a regular personal supportive contact
7. Siblings if they have a regular personal supportive contact



### Palliative Care Medizinisch-ethische Richtlinien und Empfehlungen SAMW 2006

- „Autonomie beinhaltet auch Verantwortung anderen gegenüber.“
- If we have this ,autonomy': how do we use this right; autonomy includes responsibility towards others

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### „Autonomy“ of Physician

- To follow deeply held convictions and NOT do something i.e. not to perform an abortion that is part of ,professional' duties in some contexts
- To follow deeply held personal convictions and DO something not usually felt to be appropriate

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