

Conference 3

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Decisions at the sick bed - What do we do if the patient can no longer decide?

'Salus aegroti suprema lex' - the good of the patient is the supreme law. This maxim has held true for thousands of years since Hippocrates, as the guiding principle for doctors' decisions. In the middle ages in Europe, medical ethics bore the stamp of Christian love for your neighbour and compassion. The maxim: '*Guérir quelquefois, soulager souvent, consoler toujours*' - translated as: 'Heal sometimes, relieve often and always console', comes from the 16th century.

In more recent times this basic principle has been much neglected. The criminal abuse of medical knowledge or personal, pathological ambition have led to the human experiments and euthanasia programmes of the Third Reich, to the abuse of psychiatry in the former Soviet Union and other dreadful developments. In the Nuremberg doctors' trials in 1947, doctors were accused of non-voluntary experiments on humans, the killing of prisoners in order to create a collection of skeletons (August Hirt), and the murder of the mentally ill or disabled in the T4 Action.

As a consequence, following the judgements, the Nuremberg Code of 1947 established 10 principles which today still serve as valid preconditions for taking part in medical experiments, including: voluntary agreement based on information about the trial; the ability of the patient to reach a decision and make a judgement without undue influence; the unconditional avoidance of harm to the subject of experimentation; the ability of the subject to withdraw from the study at any time. It was ratified in Helsinki in June 1964 in the 18th general assembly of the World Medical Association.

The 'Salus aegroti' was broadened in 1977 with the publication of Tom Lamar Beauchamp and James F. Childress '*Voluntas aegroti suprema lex*': The will of the patient is the supreme law. The four ethical principles of medical treatment are nowadays the most often quoted:

- Respect for the autonomy of the patient
- Non-maleficence
- Beneficence
- Justice

The four principles have equal status with one another and therefore always require, when making medical decisions, an evaluation that takes them all into account, and consideration of the patient's opinion - above all, when opinions about 'medical care' do

not coincide with those of the patient with respect to further treatment. The doctor is not just responsible for the good of the patient; he must, to a greater degree, respect the wishes of the patient. The relationship between doctor and patient has to move away from well-meaning paternalism - 'the consultant alone knows what's right for the patient' - to a doctor-patient relationship predicated on partnership. So far so good - but what does it look like in reality?

How can we respect, or better, facilitate autonomy? What does a patient need to be able to make an autonomous decision, that is to say, a decision based on understanding?

With the best of intentions, an asymmetry in the relationship becomes clear: on the side of the doctors there is expert knowledge; organisational procedures are routine, yet simply not knowing your way round the buildings of a major hospital is enough to make a patient feel lost. On the other hand, the hopes and wishes of a patient in need are directed towards the team looking after them. How can a patient in this situation keep his autonomy and self-determination?

In everyday life we experience uncertainties:

- Whether a patient can make a decision independently, e.g. in the case of a stroke, brain metastases, short-term delirium, more and more frequently we are encountering geriatric patients with the onset of dementia;
- When a patient requests a treatment that is not indicated (lack of knowledge about the disease?)
- When people don't want the patient to learn the 'full truth' (Relatives: 'Don't tell him!')
- In the case of Muslims, the family wants to make the decisions (collective autonomy?)
- In rare cases the patient doesn't want to know his diagnosis (the right not to know?)
- The patient is not capable of giving consent - do non-verbal expressions help here? (The stroke patient who keeps on pulling at the nasogastric tube with his non-paralysed hand?)

We can differentiate 4 stages when considering a patient's wishes in making a medical decision:

1. The patient is able, after a full explanation, to express his will - 'informed consent'. If this is not the case, then
2. We ask if there is a **living will** which is applicable to this particular situation. If there is none, then
3. We attempt to find out about his **presumed will** from earlier statements, general wishes regarding treatment and his values. Only when this is unsuccessful, then
4. The treatment team must make a decision for the **good of the patient**. In this situation, protection of life is paramount: in case of doubt, a decision must be made to continue life and not to discontinue treatment.

Before any medical intervention, doctors have a duty to explain and inform, so that the patient can have a meaningful sense of his right to self-determination. Through the explanation, the patient should understand in outline the object, essence, significance and scope of the treatment. No special medical knowledge is hereby required to make a decision; rather, he should understand what the intervention or treatment means for his **personal situation** - both the consequences if he consents, and the implications if he refuses. He doesn't need specialist competence, but he does need to be capable of making a decision.

My first example from everyday reality: advanced stomach cancer had been diagnosed in a 75-year-old patient, Mr. P. There was significant frailty caused by anaemia and the loss of weight of 15kg in the last 2 months. After the oncology board reviewed the case, a palliative gastrectomy was recommended to remove the source of the bleeding, followed

by palliative chemotherapy. Mr. P. is in his second marriage to a much younger wife; his first wife died from cancer. He is a qualified chemist and has worked in a large company. He has been informed about his test results: a tissue sample from the gastroscopy and CT results showing advanced metastatic disease involving the liver and the suspicion of peritoneal carcinomatosis. I discuss with him the recommendation of the board. He asks first of all how long he has left to live - statistically this is an easy question to answer, but on an individual basis it is problematic: the average survival rate with palliative chemotherapy is 9-11 months. Without chemotherapy it will be significantly shorter. "This average survival rate applies to no one," I explain to the patient. It means that one half of patients lives longer, the other half shorter than that. Which group he'll belong to is not decided by us doctors, but by a 'higher power'. I throw a question back at him: what does he mean when he asks how long he has left to live?

In the case described above, we have it easy when making the decision: the test results, the possible forms of treatment with the burden they will place on the patient (side effects) and the prognosis associated with each of them are validated, the patient has full capacity and is able to make a decision, and he has had personal experience of cancer. After discussing the pros and cons of the various possibilities, Mr. P. decides against an operation and chemotherapy and is sent home after a blood transfusion, with advice on diet and adjusting his pain killers. He's given the leaflet from our outpatient palliative care team to take with him; this team supports GPs and relatives looking after seriously ill and dying patients in making their time at home as bearable as possible until the end of their life. The basic requirements are in place to allow a patient suffering from onerous symptoms to stay in their own home until their death.

Another case : Mrs. N. is 74 years old and has been treated for renal cancer for over 10 years. Treatment has hitherto consisted mainly of the surgical removal of the diseased kidney and later of metastases in the lung and thyroid gland. In the summer of 2018 she notices a reduction in her cognitive capabilities (she had been a maths teacher) - in October brain metastases are found and treated in November with a special form of radiation, the so-called cyberknife. She spends Christmas with her 82 year old husband and her daughter in New York. As further metastases of the renal cancer come to light, she begins medical treatment at the beginning of January with a tyrosine kinase inhibitor. On the 12th January, she's admitted as an emergency with an epileptic fit, after which she is barely rousable. The CT scan shows bleeding in the area of the metastases with a rise in intracranial pressure. She receives the usual treatment with steroids and mannitol infusions. The neurosurgeon turns her down for an operation to relieve the pressure: this isn't possible when there are brain metastases, as the actual source of bleeding cannot be removed without risk of further damage to the brain.

We ask her daughter and husband, who spend all day by her bedside, what the patient's wishes were regarding further treatment. There is a written living will and power of attorney for health care: her husband and daughter now have a role to play. In the living will there is the sentence: if there is brain damage, and she is no longer able to communicate with those around her, all life-sustaining measures are to be discontinued. Despite this, the 82-year-old husband hopes for improvement and thinks we should exhaust all possible treatments to keep her alive. The daughter, however, tells of a conversation with her mother just a few weeks previously: in no circumstance did she want to be kept alive as someone heavily dependent upon care. As there were no signs of improvement, we plan to discharge her home, in accordance with her wishes. Her daughter took leave of absence from her work to this end. One day before she was due to be discharged, the patient suddenly woke up and was able to say some short sentences, to the utter surprise of all concerned. As the doctor in charge, I have doubts about whether I can now discharge her to die at home in accordance with her living will. The next morning she is in a deep coma; she dies towards evening on our palliative care ward.

What exactly is a living will? Since 2009 there has even been a law in Germany, in the Federal Law Book (BGB para. 1901 ff.) that aims at strengthening the rights of a patient with a living will. A living will is the will of a patient expressed in writing: in the first section, the description of the situation as it were, it notes the conditions of illness in which the living will is to be applied. These are always scenarios where the patient can no longer express their wishes themselves. In a second section, instructions are listed as to

how the treatment team is to proceed - the so-called treatment guidelines. Wishes are noted as to which treatments may be used and those which are to be rejected. The adult person then has to sign the will himself. Although the law does not stipulate that there must be a date next to the signature, it is desirable. A living will always remains valid. Even if the signature goes back a very long time, its credibility must not be cast in doubt. Notarisation is not required. It is, however, good practice to take advice from people you trust when writing it, such as a family doctor or voluntary helpers from an outpatient hospice group. In as much as the living will clearly stipulates the patient's wishes - that is to say, that the scenario described is clearly relevant to the current situation - the will is binding upon the doctors treating him, as long as what has been decided does not contravene the law (for example, killing on demand or active assisted suicide). The most frequent controversy about using an available living will arises from the question: has the current situation been clearly covered in the description of possible scenarios? If a doctor acts expressly against the will of a patient, he is committing assault!

An example of how a living will works : an 86-year-old, Mr.P., has been living for several months in a care home. Prior to that, he had been looked after by his daughter-in-law at home; his son had pre-deceased him. In the home he had lost all desire to live and had made a written declaration that did not wish under any circumstances to be readmitted to hospital. He developed a high fever secondary to a urinary tract infection resulting from an indwelling urinary catheter. The emergency doctor called in by the care home staff telephoned the daughter-in-law who asked for him be admitted to hospital. He was transferred via A&E to our palliative care unit, very seriously ill, close to death. The only treatment administered was to put him on a drip for circulatory shock. My colleague, who was on call over the weekend, said to me: "Take a look and see whether Mr. P. is still alive." On my Monday rounds I found a sick patient whose circulation had improved, who opened his eyes on request and, apart from feeling weak, had no other complaints. As a specific organism had been isolated in his urine, we started him on an antibiotic regime. On my next visit on Thursday he was awake and knew where he was. In the meantime, the care home had faxed us his living will at our request. I described to Mr. P. the hitherto successful course of treatment and asked him if we should continue with it. Mr. P. considered a moment before answering: "Even if I am making a decision contrary to my living will, keep doing what you are doing ...". If the patient is capable of giving his consent, I don't need a living will, since he can express his own wishes based on the current situation with regard to his illness.

How do we decide in stage 3 : there is no living will and also no possibility of the patient being able to articulate their wishes?

As a consultant I was asked to see the 86-year-old Mr.N. Diagnosed with dementia, he had been admitted after a fall at home. To our surprise, the x-ray of his spine showed both bone and lung metastases not previously diagnosed. In bed I found a very corpulent elderly gentleman, who, on being addressed by name and touched, merely established eye contact and increased the rate of his breathing. He showed no other flicker of emotion.

I telephoned his 78 year old wife: she had just been informed of the new discovery of malignant disease: cancer with spread to the lungs, bladder and bones. Until then she had looked after her husband at home. She wanted to have him back home and look after him there until the end of his life. One of the three daughters had power of attorney; another was on hand for support.

We agreed with the hospital doctor to reduce the amount of the infusion, to treat pain and breathing difficulties with opiates, and to carry out no further blood tests. Social services helped order the necessary equipment and looked for a care service to support him at home. When the hospital bed was delivered, Mr. N. could be transferred - on the one hand, in accordance with the wishes of his relatives (and power of attorney) and with his presumed wishes; on the other hand, there was no medical indication to pursue treatment with side-effects in a sick patient in the advanced stages of dementia.

Powers of attorney are people the patient trusts, and whom he mentions by name in his living will. They have the task of being an advocate: if the patient himself is no longer capable of making a decision, they should make that decision as his representatives.

Relatives must always be made aware of the fact that they are not to decide in the way they would wish for themselves, but in accordance with the will and wishes of the patient.

It's a similar situation with **guardians**: the patient asks the guardianship court to appoint the person he trusts, proposed by him, to be his representative (guardian) in matters relating to his health. The guardianship court checks at a given time whether the proposal corresponds with the current will of the person concerned and whether the proposed person is suitable as a guardian - it takes time, but gives control!

The gastroenterology department ask me for a consultation: Mrs. F. is 87 years old, has dementia and has had cholecystitis for the last few weeks which has been treated conservatively. Now comes the request for shared care with the palliative care team.

After 3 weeks of hospital treatment with antibiotics for acute cholecystitis (inflammation of the gall bladder), Mrs. F. was discharged back to the care home where she had been for a long time. The GP sent her back to the clinic after a few hours on account of breathing difficulties. In A&E, the old but strong lady refuses any investigation or treatment. Although the daughter, with power of attorney, demanded on the telephone that all possible treatment be carried out, including admission to intensive care and resuscitation, she did not wish for this to be done forcibly against the will of the patient. I try to establish contact with Mrs. F. On asking where she was, to check whether she is orientated in place, she answers curtly: "In bed". Her correct answer causes amusement among her fellow patients in the surrounding beds. She's not able to give further details about her origins, age, her current state of health - she just wants to sleep and be left in peace. According to the care staff she's refusing to take any food. On attempting to drink from the feeding cup, the drink goes down the wrong way. Her medicines lie untouched on her bedside table. Clinically she is clearly overloaded; her breathing is laboured; the x-ray of her lung shows pulmonary congestion, bilateral pleural effusions and cardiomegaly. The hospital doctor is asked to bring in the daughter with power of attorney and discuss with her the situation: a seriously ill patient, not capable of understanding, who is resisting, and therefore making impossible, any treatment with her aggressive behaviour. Furthermore, he is to inform the GP about the situation to prevent any further admission. To alleviate the symptoms of shortage of breath, a low dose Fentanyl patch is applied, and all drips removed.

In the last two cases described, advanced dementia prevented any capacity for decision making on the part of the patient. Physical ailments could only be ascertained from behaviour and autonomic reactions. These ailments must also be treated or alleviated: for example, by reducing drips given with the intention of improving or maintaining kidney function. The argument that it is to avoid thirst is also given. Unfortunately, these treatments have produced additional stressful symptoms - for the patient: excess water retention has created additional breathing difficulties and exacerbated immobility. The medical intention to do good has turned into its opposite because of the side effects of the treatment.

Mrs. R. is 57 years old and has been treated in our gynaecological clinic for the last three years for advanced ovarian cancer. From the beginning it manifested itself as an aggressive form with spread to the liver, and therefore could not be completely removed surgically. Following several courses of chemotherapy, there is increasing frailty and dependency: Mrs. R. who lives on her own has, as a result, moved in with her 27-year-old daughter. Mrs. R. is transferred to us on the palliative care ward because increasing liver and kidney failure has made any further chemotherapy impossible. On admitting her, I ask Mrs. R. if she has a living will or power of attorney for health matters. She has appointed her daughter as power of attorney; there is no written living will. We speak with her about her increasing organ failure. At the same time, the patient complains of severe twitching in both hands: she cannot lift a coffee cup up to her lips properly anymore. We suspect a side effect caused by the accumulation of metabolites of her pain killer Oxycodone with her renal failure. We take her off a drip because she is very fluid overloaded. Instead she gets a pump with hydromorphone - an opiate which has fewer side effects in liver and kidney failure. The patient expresses her satisfaction with the pain relief. Only her daughter is unhappy: her mother is so tired and hardly speaks. This tiredness increases in the following days, although we increasingly reduce the dosage of the hydromorphone

pump. Laboratory tests show end-stage renal failure. In a conversation the daughter asks for dialysis to be tried. I try to make clear to the daughter that there is no point replacing an organ - the kidneys - with a machine when another vital organ - the liver - is failing. There is also no possibility of further treatment for her cancer. Finally I ask the daughter if her mother would have wanted dialysis. She reflects briefly before admitting that her mother had, a few weeks before, said that she did not wish to be connected to machines any longer - her cancer was too far advanced. I offer the daughter support from a hospice volunteer for herself and her 7-year-old daughter - she'll think about it. Three days later Mrs. R. dies without having regained consciousness.

An 86-year-old patient, Mr. M. is transferred to us on the palliative care ward from cardiology. More than two weeks previously, he had been admitted as an emergency with a syncopal episode. He was known to have had coronary heart disease with bypass grafting 10 years ago, and had a posterior myocardial infarction in January 2018 - from which, according to his daughter, he had recovered well. An urologist was also treating him for prostate cancer, latterly with a hormone injection every 4 weeks and Abiraterone for bone metastases, which cause him no problems apart from shoulder pain. Colleagues in cardiology had examined his heart and found good ventricular function and atrial fibrillation.

On admission Mr M. was lying flat in bed with his eyes closed; when spoken to he tried to speak, which he managed only with difficulty and incomprehensibly. Fortunately, the daughter and a sister-in-law were present and were able to answer my questions. His illness had begun the previous autumn: he had less appetite and was losing weight. The children supposed that his wife, suffering from advancing dementia, was no longer able to look after the house properly. Finally, vomiting started. Mr. M. refused to have a gastroscopy. For days now he hadn't drunk anything, and he was in renal failure. A short examination confirmed that there was something not right in his abdomen: very bloated, scarcely any bowel sounds, painful to pressure. An ultrasound test was unable to show anomalies apart from gut distended with wind in his mid-abdomen and a small amount of ascites.

Laboratory tests showed worsening renal failure and rising levels of inflammatory markers despite ongoing antibiotic treatment.

It was impossible to gather from Mr M. himself whether he would consent to or refuse further treatment. He was showing increased restlessness and was continually asking for help - but what help? The daughter had a living will with her dating from 2016. His wife, she and her brother had been appointed powers of attorney. In the description of possible scenarios, terminal illness, serious brain damage, whether resulting from a stroke or dementia, were described. In the instructions for action for carers that followed, life prolonging measures were no longer wished for, including artificial feeding; however, measures to alleviate symptoms were. The daughter and I saw the scenario described as appropriate for his current condition: this was a serious disease of the abdomen with symptoms going back months which had steadily worsened. We would have had to agree to laborious and possibly, for the patient, stressful investigations, without being able to predict any consequences for treatment, but the disease was too far advanced with organ failure in its current state. Mr. M. had also refused a diagnostic test previously. We started treating the pain: Metamizole 1 gram every six hours as a short infusion and an ongoing low dosage opiate by pump. Following this, Mr. M. was noticeably more peaceful and relaxed.

We kept discussing the situation with the children; the questions they kept asking were answered again and again: is this the correct treatment in the current situation and does it correspond to the presumed will of the patient? Even a decision made consensually always needs to be reflected upon anew; emerging doubts need to be aired and discussed collectively. In the end, powers of attorney are laymen and women who carry the responsibility of participating in the decision. It's possible they have never before experienced such a situation. They mustn't be left alone to decide; the doctor's evaluation as to the prognosis is crucial to their decision-making. Some relatives refuse to give consent to supportive palliative procedures with the justification that people around

will say they are guilty of the death of the patient! On the daily ward rounds the patient needs just a few minutes to review the ongoing treatment. Relatives, on the other hand, clearly need more time, which the doctor must also give them.

Let's summarise together : how can I make it possible for a patient to make an autonomous decision?

- The first question - 'With what end in mind is the team treating this patient - this person?' - is often not asked! Instead, a disease - a diagnosis - is seen which must be treated in such and such a way according to protocol or the decision of experts!
- *Where is the patient hoping to end up by seeking treatment?*
- Is the purpose of the treatment realistic from both a medical AND a care perspective? Am I asking my colleagues caring for this patient for their evaluation of the situation? Experienced carers often have a more realistic evaluation of the situation through their longer contact with the patient.
- Which medical treatments and therapies (if necessary, physiotherapy, psychotherapy, etc.,) are necessary to achieve the end in mind?
- What are the potential harms (side effects) and benefits of the measures considered necessary?
- Are there alternatives - possibilities that my clinic is not able to offer (here too: harms and benefits).
- *What information does the patient need to make their decision?*
- Can he assess the meaning and consequences of his decision for his life? Where can the patient and I meet?

On the last point, I'd like to quote Soren Kierkegaard (born 5 May 1813, Copenhagen, died 11 November 1855) :

"If we wish to help someone, we first need to find out where he is. That's the secret of care. When we are unable to do this, it is an illusion to think we might help other people. Helping someone implies that we understand more than he does, but we first need to understand what he understands."

What are the common wrong decisions made by doctors for patients who have a limited prognosis?

- Treatment is simply started - the purpose is still unclear (according to the motto: 'Let's see, shall we ...').
- The purpose of the treatment is not communicated at all!
- There are differing treatment aims: from the doctor - carers - patient -his relatives.
- There are structural aspects, false financial incentives, to carry out a particular treatment - making treatment more costly than is actually necessary means greater income in the DRG (diagnosis related groups) system!

A leading surgeon was fired from his job after turning every normal tumour operation into a costly 'exenteration' resulting in longer stays in intensive care and more complications. Patients could be charged at a high rate, yet the surgeon's reputation prevented other patients being operated on in the hospital!

Let me sum up again :

- The best instead of the most, **in the view of the patient**, must be at the centre of all treatment: 'Choosing wisely', particularly in patients with a limited prognosis.
- The doctor's responsibility in assessing whether an intervention is clearly indicated needs to be strengthened (they should not simply follow 'guidelines').

- AND supporting the patient's ability to decide for themselves (explaining the situation is more than just passing on information): coming to a decision through collaboration.
- The key question is not **if** the patient's autonomy is to be respected, but **how** this can take place in an appropriate way (Marckmann).
- In this way, the relationship between doctors, carers and the patient is appropriate, with autonomy on the one side, and care on the other.

I thank you for your kind attention and welcome any questions you might have.