



# The troubling duty to inform

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## MEDISINSK ETIKK

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Equal treatment is an absolute requirement in the Code of Ethics for Doctors. How may oncologists and other doctors handle information on commercial treatment options if the requirement of equal treatment is to be respected?

The Medical Ethics Council recently deliberated a case concerning the doctors' duty to inform about medically approved cancer therapies that are not yet paid for by the state. One doctor had stated that no guidelines were available and that he assessed his patients – and their financial situation – before choosing to provide information on such options (1). The council did not criticise the doctor but pointed out that this strategy violates the requirement for equal treatment in the Code of Ethics for Doctors: All patients are entitled to equal treatment – and equal information – irrespective of their private finances (2).

However, the case leaves some questions unresolved, to which medical ethics cannot provide any clear answers. The requirement for equal treatment is fundamental in the Norwegian health services. Roughly speaking, the doctor's options can be presented as two extremes: Either all patients must receive all available information, including about

treatment possibilities that require self-payment, or no patients can receive information on treatment possibilities that are available for private purchase. In the ensuing debate, the doctor in question has requested the Medical Ethics Council to provide an answer to the question of what doctors can and should do if the patient does not ask about commercial options that the doctor knows may be relevant (2).

In this article, the Medical Ethics Council wishes to raise this discussion to the level of principles by examining arguments for and against these extremes, assessed in light of fundamental ethical principles and the Code of Ethics for Doctors (the text refers to relevant sections in Chapter 1). If everybody should receive the same information, where are the boundaries of the doctor's duty to inform? In addition to the fundamental ethical principles of fairness, autonomy, non-maleficence and beneficence, many of the sections in Chapter 1 of the Code of Ethics for Doctors (3) will be applicable: Section 1 on fairness, Section 2 on protection of the patient's best interest and informed consent, Section 3 on the patient's entitlement to information, Section 8 on due regard for the patient's financial situation, Section 9 on sound medical practice and use of scientifically proven methods, and Section 12 on due regard for the national economy, prioritisation and distribution of medical resources in accordance with generally accepted ethical norms.

## Maximum information to all

*Extreme 1: When the patient is in a situation where treatment options not provided by the state are available, the doctor will give information on private treatment options.*

Several arguments can be given in support of this approach: The information will be provided by a doctor who is familiar with the patient's diagnosis and treatment pathway (Section 3). The doctor can help the patient eliminate treatment options whose effectiveness is uncertain. The information can be provided in a sober and unbiased fashion, with no financial incentives on the part of the treating physician (Sections 1, 2 and 3). Patients who do not seek such information themselves may also obtain the information, so that knowledge is not restricted to the patients with the best resources (Sections 1, 3 and 12).

It might be difficult for the doctor to form an adequate impression of the patient's ability to pay (Section 8). Impecunious patients may have a network of relatives, friends or a local community that are willing to pay, and may – if they are provided with the information they need – make choices about their own finances whereby they prioritise paying for interventions that could prolong their life. The doctor's assessment of the patient's ability to pay cannot take precedence over the principle of equal treatment.

However, there are also arguments that speak against this approach: It can be argued that we act in contravention of the requirement for caring treatment and the fundamental ethical principle of beneficence and non-maleficence if we inform vulnerable patients about treatment options that they cannot afford to enjoy. Even if the patients were to choose to sell their house or take out a loan to cover the cost, they and/or their next of kin may sustain a considerable financial burden (Section 8). Patients in such situations may be desperate and feel that they are given an offer they cannot refuse. It is bad enough to be dying from cancer, but it may be perceived as even worse if the doctor on his or her own initiative has told you that you could prolong your life if you only could afford it (Section 3).

The question of providing information to everybody – about options that are not included in what Norway has chosen to provide through the public health services – also impinges upon the fundamental ethical principle of fairness. The health services' resources are limited, including in cancer care. As a health service, we need to prioritise among different patient groups, and the oncologists must prioritise among their patients and the healthcare options about which they will spend time imparting information (Section 12). If the oncologists choose to spend their time in consultations on providing information on private treatment options, this may come at the cost of other essential topics that ought to be discussed with the patients, such as information on withholding of treatment, and

palliative care.

## Refraining from giving information on commercial options

*Extreme 2: The doctor only provides information on treatment options that are approved and funded by the state and does not on his or her own initiative address treatment possibilities that require full self-payment.*

An argument in favour of this line of action is that the doctor should provide the patient with information that benefits him or her, and which the patient has a real opportunity to make use of (Sections 1 and 2). Publicly funded treatment is available to all those who fulfil the medical criteria. Treatment that requires self-payment can only be of benefit if the principle of equal treatment is violated. If doctors are to take the principle of equal treatment seriously, irrespective of personal finances, they are in practice barred from offering or promoting treatment that depends on the ability to pay.

Another argument is that theoretical information on private treatment options is a waste of time if the patient cannot afford to make use of it, and time is a scarce resource in the daily life of oncologists. Discussions on limitation of treatment at the final stage of oncological patient pathways might constitute a better use of this time. Some cancer patients suffer from overtreatment and delayed initiation of palliative care. It should be considered whether a focus on good palliative care at the end of life, with information on symptom relief and care provision by the next of kin as well as other important palliative measures, ought to be given priority over formalistic information on private treatment options.

A further point could be that in Norway, we have a system for assessing and prioritising the types of treatment that we can offer, and doctors employed in the public sector have a duty of loyalty barring them from actively promoting treatments that we have not (yet) found ourselves able to prioritise. Although individual oncologists may feel a strong responsibility for helping the patient sitting before them, they have an equally great responsibility for all the patients in the waiting room and all those who are waiting for an appointment (Sections 1, 12 and the principles of fairness and equal treatment).

However, there are also arguments that speak against restricting information to the options available in the public health services: Section 3 says that 'a patient is entitled to information on his or her condition and treatment [...]. The patient shall be informed to the extent he or she wishes. Information which may be thought to be particularly difficult to bear, shall be given with caution'.

On this basis it can be argued that all information on treatment shall be communicated to the patient, including information on commercial treatment, even though it might constitute a burden for patients to be aware of a treatment that they cannot afford. On the other hand, information shall be provided 'to the extent that the patient wishes'. One therefore cannot firmly adhere to Extreme 2 if the patient on his or her own initiative expresses a wish for information on commercial options.

## Can we provide information on commercial options?

If public-sector doctors are to provide information about commercial healthcare options to cancer patients, two main possibilities remain: If we assume Extreme 1, the information must be based on the doctor asking whether the patient wants to be made aware of commercial options. Assuming Extreme 2, the initiative to discuss commercially available options must come from patients themselves. The essential issue is to safeguard the patient's entitlement to information – but also the right not to know.

The Medical Ethics Council finds that the doctor cannot assume full and complete responsibility for ensuring that the patient obtains all available information on all conceivable treatment possibilities. The doctor's independent responsibility consists in providing the patient with a relevant selection of information adapted to the patient's

individual needs, while ensuring that no patients are discriminated against for economic reasons. The patient's role is to address topics that are of interest to them. In this way, the patient decides what kinds of information they want to receive, and the doctor must tailor the information to the patient's needs.

As regards treatment options provided by the public health services, the doctor is obligated to provide the same information to all patients. Information that goes beyond this, especially information on treatments that require self-payment, should not be provided by doctors on their own initiative. It is crucial that the patient be provided with an opportunity to steer the kinds of information he or she wishes to receive – if not, shared decision making will not be a real possibility.

## Is the treatment of benefit to the patient?

The case in question has revolved around treatments that have a documented effect, but that are either currently working their way through the bureaucracy for approval in Norway, or have been deemed too costly by Norwegian authorities for us to afford spending public funds on them. One may ask, however: Does this apply only to treatments that can be provided in Norway – what about commercially available treatments that can only be obtained abroad? If we feel an obligation to inform about treatments that you can 'shop for' in a private Norwegian hospital, shouldn't we then provide information on treatment that can be purchased in a hospital in the United States? And what about treatment that presupposes the social and financial potential to go abroad to take part in clinical testing of new and promising drugs? What about treatment methods offered by complementary medicine, how far does the doctor's duty to inform extend into this area?

Here it might appear as though Sections 3 and 12 contradict each other: on the one hand, the doctor shall inform to the extent that the patient wishes, but on the other hand the doctor shall have due regard for society's resources (read: the doctor's use of time) and not seek to provide individual patients with advantages in terms of prioritisation or otherwise. The Medical Ethics Council recognises that this is a difficult question that requires the exercise of discretionary judgement.

Treatment options in complementary medicine or other non-documented practices are ruled out by Section 9: 'A doctor must not use or recommend methods which lack foundation in scientific research or sufficient medical experience'. Doctors cannot therefore be expected to inform about such options. New knowledge indicates, however, that treatment within 'academic medicine' may also have a tenuous evidence base. A recent study in the *BMJ* showed that only half of all cancer drugs approved in the period 2009–2013 had a documented effect on survival and quality of life after a median follow-up time of 5.4 years (4). The boundary between complementary medicine and 'the latest new thing' from academic medicine may not be as clear-cut as we would wish it to be when it comes to their evidence base.

This is relevant to our discussion because the motivation of those oncologists who wish to provide information on commercially available options is the desire to serve the patient's best interest – beneficence. But can we rely on such an argument if we have no evidence that the treatment really will benefit the patient?

## Equal treatment

Equal treatment is a key principle in medical ethics and a general ethical norm in Norwegian society. Such a generally accepted principle and the application of medical codes of conduct may have widely differing effects depending on how they are applied to an ethical question. The Medical Ethics Council has no ready-made answer to give, but encourages the oncologists and other professional groups to reflect on how we can succeed in upholding the principle of equal treatment in an age where both differences and possibilities are growing.

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