

UiO : Institute of Health and Society University of Oslo



Manual for working in a Clinical Ethics Committee in secondary health services

Manual for working in a Clinical Ethics Committee

Contents

- Foreword 3
- 1.0 Background of the Clinical Ethics Committees (CEC)..... 4
 - 1.1 National mandate prepared by Department for Health and Care Services in partnership with The Centre for Medical Ethics and Clinical Ethics Committees..... 6
 - 1.2 Foundations and Resources 9
 - 1.3 Raising the profile of the committee amongst clinicians, management, and patients... 10
 - 1.4 Appointing members to the committee and composition of the committee..... 10
 - 1.5 Meeting frequency 16
 - 1.6 One or more committees in each hospital trust 17
- 2.0 Tasks and work organization..... 18
 - 2.1 Discussing cases related to individual patients..... 18
 - 2.1.1 Who can bring cases to CEC 19
 - 2.1.2 Written or oral referrals 19
 - 2.1.3 Is this problem for us? 20
 - 2.1.4 Preparing a case 20
 - 2.1.5 Where should the case be discussed? 22
 - 2.1.6 Who should participate in a case discussion?..... 22
 - 2.1.7 Should the patient or next of kin be present in the case discussion?..... 24
 - 2.1.8 Questions of impartiality 27
 - 2.1.9 Prospective cases 28
 - 2.1.10 Retrospective cases..... 29
 - 2.1.11 Central points of the ethical discussion (The Six-Step Model)..... 31
 - 2.1.12 Meeting minutes from the case discussion 34
 - 2.1.13 How should the minutes be written? 35
 - 2.1.14 Referring to cases in CEC’s annual report 37
 - 2.1.15 How to get cases 38
 - 2.2 Discussing cases that are not related to individual patients..... 39
 - 2.3 Seminars 39
 - 2.4 Working on guidelines..... 40
- 3.0 Clinical ethics committees and problematic practice 42
- 4.0 Possible collaborators..... 44

Foreword

Every Norwegian health care trust must have a Clinical Ethics Committee (CEC). The Centre for Medical Ethics (CME) at the University of Oslo is responsible for the national coordination and professional development of these committees. Clinical Ethics Committees are to be an aid in difficult ethical challenges that occur in the hospital through systematic discussions, promoting interdisciplinarity, and by ensuring that patients and their relatives' perspectives are adequately considered and included. Ensuring that clinical decisions properly take values into account is important to the quality of health services overall.

Since the time CECs were started as a trial project in 1996, the evaluation of their work shows the importance of good, systematic routines and procedures in committee work. The Ministry of Health and Care Services has signaled that the committees must follow certain principles, in order to promote and encourage quality and equal treatment. The National Mandate for Clinical Ethics Committees, passed in 2011, is also an important step, and adds essential guidelines for the committees' work. This manual gives new and old CEC members practical advice and tips for how CECs in health care trusts can function in the best way possible.

The CEC's work consists of different activities. Ethics work in a hospital can include the organizational values, guidelines elaboration, coworkers' questions, and dilemmas relating to patients and their relatives. Value-based decisions made on the organizational level have consequences on the service level. Lately it has become more common for CECs to be involved in discussing ethical dilemmas relating to the organization as a whole. This is an important area that we wish to focus more on in the future. However, in this manual, the main focus will be on the discussion of ethical dilemmas relating to patients and relatives.

This manual is based on experiences with CEC work in Norway, as well as Norwegian and international research. To suit busy clinicians and CEC members, this manual is as short as possible.

Although we emphasize structure and routines in committee work, there still needs to be room for flexible solutions to meet the needs of clinicians. The manual will be revised as work moves forward and experience is gained. To improve the manual we are dependent on feedback from the users. This is essential if we are to develop the work further.

Centre for Medical Ethics,

July 2012

Reidun Førde and Reidar Pedersen

1.0 Background of the Clinical Ethics Committees (CEC)

The Clinical Ethics Committees will contribute to raising ethical consciousness and to ensuring the quality of difficult value judgments in Norwegian health trusts, in the best way possible for health care workers, patients and relatives.

Ethical codes and awareness of professional ethics have existed since antiquity. Ethics in health services have traditionally been seen as an integrated part of health care workers' profession, and primarily something that clinicians themselves handled as part of their daily work.

The last world war showed us that doctors are capable of parting from central ethical ideals, both as independent actors and as obedient instruments of monstrous abuse in the name of medicine and medical research. An important lesson was that medical ethics, which above all had been the doctor's domain, needed to be strengthened through the involvement of non-medical participants, among other reasons, to ensure the interests of research subjects. There was a special focus on research ethics after the war, and the first organized multidisciplinary ethics committees were research ethics committees. These kinds of committees have been in use in Norway since the end of the 1980s.

In the 1960s and 1970s, clinical ethics became more of a focal point accompanying the increased importance of citizen's rights and patient's rights, especially in the USA. Ethics specialists, for example philosophers and theologians with an interest in health care, contributed to the development of medical ethics as its own academic subject. At the same time, the professional ethics codes of doctors, and later nurses and other health personnel, were strengthened. This professional ethics work has, amongst other things, consisted of creating and enforcing the professions' own ethical regulations. One challenge has been that the different professions who work together with the same goals, have somewhat differing professional ethics. Other challenges are that patients traditionally have limited influence on professional ethics, and that professional ethics have been managed by the trade unions.

One way to meet these challenges is to work for an increase in multidisciplinary handling of difficult ethical questions, increased involvement of patients and their relatives, and giving more responsibility to the employers. CECs are precisely the type of forum which can give time and space to clinical ethical dilemmas in the work place.

Over the past ten years, the amount of knowledge in the health field has steadily risen. Health services have become more specialized and complex, and the demands for cost control are rising. Today, clinicians are subject to pressure from many conflicting and demanding ideals and interests! Different cultures and values, increased expectations, and strengthened rights lead to an increased possibility of disagreement, uncertainty, and difficult clinical decisions. At the same time, the demand for efficiency seems to be lessening the opportunities for informal discussion and supervision, while more notice is given to the increase in moral stress among health care workers. These tendencies have made it more important to formalize ethics work in the work place, for example in the form of clinical ethics committees or reflection groups.

CECs have existed in the USA since the 1970s. The committees were established to strengthen the work with clinical ethics and to improve and strengthen patients' interests, but also to prevent excessive use of the legal system. In the USA and Canada, the existence of ethics guidance (through CECs, smaller teams or ethics consultants employed at hospitals) has been a prerequisite for hospitals receiving accreditation and contracts with insurance companies. Formalized and systematic ethics work is thereby

seen as an important part of quality assurance in hospitals. In Europe, the development has been slower, but today systematic ethics work is a component of many countries' quality assurance work in hospitals.

In Norway, clinical ethics committee work started in three hospitals (Gjøvik, Ullevål and Rikshospitalet) in 1996. Today, all hospital trusts are supposed to have at least one CEC. Three of the hospital trusts have a separate CEC dedicated to mental health and addiction (Oslo Universitetssykehus, Vestre Viken/Blakstad and Helse Innlandet HF/Sannerud).

The Centre for Medical Ethics (CME) was granted the national responsibility for coordination, professional development, and quality assurance of the committees' work. This work includes arranging courses and seminars for CEC members, an annual introductory course for new CEC members, an annual national seminar, and regular specialized seminars. Other duties are to run a national website for the committees,¹ inform the central health authorities and hospital trusts about the committees' work, as well as research on, and quality assurance of committee work. CME contributes with advice and guidance to the committees, and shares professional knowledge at local seminars, also as guest lecturers.

1.1 National mandate prepared by Department for Health and Care Services in partnership with The Centre for Medical Ethics and Clinical Ethics Committees

National Mandate for Clinical Ethics Committees (CEC) in Norwegian Health Trusts

The purpose of clinical ethics committees (CEC) is to:

- Contribute to increased ethical awareness and competency concerning value questions related to patient treatment.
- Contribute to increased understanding of value issues surrounding questions of resources and prioritization in the health trusts.

¹ <http://www.med.uio.no/helsam/tjenester/kunnskap/etikk-helsetjenesten>

- Help to ensure that the interests of patients and next-of-kin are properly taken into consideration by the hospital.
- Contribute to increased skills concerning identification, analysis, and clarification of ethical problems and dilemmas.
- Stimulate systematic ethical reflection, and aid the discussion of specific ethical dilemmas before and/or after decisions are made.
- Upon request, give advice about how to solve specific ethical problems.
- Be open and non-discriminatory in questions of religion.
- Be part of the institution's work with quality improvement.

Composition:

- A CEC must have a committee chair and a secretary
- A CEC must be multidisciplinary and must include clinicians as members
- A CEC should have a minimum of one lay person or patient representative as a member
- A CEC should have a member with competence in medical ethics.
- A CEC should have a member with competence in health law.

Organization, appointment, and finances:

- A CEC must be detached and independent from the hospital trust
- The members of a CEC are to be appointed by the hospital director
- The chair and the members are to be appointed for 3 – 4 years at a time, with the possibility of renewal
- A CEC must have its own budget and be given the necessary resources to succeed. The chair and secretary must be given a framework in which it is possible to adjust their working conditions to enable them to complete their CEC-work in their normal working hours, for instance by freeing time from their regular tasks.
- The members must be allowed to participate in CEC-work, and must be given the necessary resources in order to obtain clinical ethics competency.

Method

- Anyone can bring a case forward to a CEC

- CEC discussions should ensure patient confidentiality whenever possible. When departing from this rule, patient consent must be given before their case is discussed in a CEC. The members of CEC have a duty of confidentiality if they are privilege to identifiable patient information in the course of their CEC-work. Members of CEC that aren't covered by laws governing health care workers (for instance legal practitioners or user representatives) should sign a confidentiality form.
- The committee shall determine its own schedule and method within the framework of this mandate, but the committee should be able to meet on short notice in urgent matters.
- The committee must keep minutes of their meetings.
- The committee must write annual reports.
- The committee's work must be evaluated periodically according to current evaluation criteria in health trusts.

(Translated from The Norwegian Ministry of Health and Care Services' document of 2011)

Research ethics are not a part of CEC's responsibilities. The regional research ethics committee system is responsible for this.²

Furthermore, CEC is not a complaint body and has no power to sanction. Even when a case is discussed in a CEC, the treating physician is responsible for the clinical decision-making. The committee should have clinical ethics and patient-centered challenges as their main focus, but can also engage in more overall ethical questions in the organization. In recent years, the number of cases related to organizational ethics has risen.

² www.etikkom.no

1.2 Foundations and Resources

The institutionalization of ethics requires a commitment from management to provide the necessary conditions in which to work in the manner stated in the mandate.

Experiences from Norway and other countries show unambiguously that underlying conditions such as an independent budget and supportive and interested management are important factors for good ethics-based work. In today's hospital system, it is unrealistic to believe that ethics work will be prioritized if management does not give clear signals that they see this work as so important that its members must be able to dedicate time to it.

Each committee should have its own budget which can cover but is not limited to: increasing the competence of members, seminars and teaching for hospital employees, the ability to compensate the chair and/or secretary for their time when possible. An alternative to compensation is dedicated time. However, dedicated time is impractical if it goes above and beyond the normal working hours of the chair or secretary. This can make it difficult to complete the committee's administrative work and to recruit busy and engaged hospital employees to the most time-consuming positions. Therefore, some sort of compensation or relief from their ordinary tasks is necessary. If the chair is not compensated, it is especially important that he/she has assistance from the secretary, for example by giving the secretary more time or compensation, or having a secretary with a relevant professional background (health, ethics or law).

Experience suggests that the chair and secretary combined should have dedicated time that is equivalent to a 20-60% position. It is the management's responsibility to see that the committee functions as it should, as well as making it a committed and integrated part of the health trust's quality assurance work.

Ensuring that the committee is known and used properly is another important part of the foundational work, and can be done in cooperation with the person responsible for information and education within the trust. This is a continuous exercise for both the CEC and the hospital trust management.

1.3 Raising the profile of the committee amongst clinicians, management, and patients

To ensure that the committee is known within the hospital, information about the committee and the committee's work can be published in the internal newspaper, on the hospital website, and presented at staff meetings and relevant seminars such as those concerning quality assurance work. Other examples include: informing new employees about the CEC in introductory training, in management forums, in brochures, through CECs arranging seminars, or by working on ethical guidelines.

Brochures that are given to patients, and information on hospital websites, are important ways for patients and their relatives to hear about CEC.

Information about the committee should include information about composition, mandate, and how the committee works, such as procedures and methods. Experience has shown that it is important that people know how the committee works if they are going to bring in a case for discussion, or participate in a discussion at a CEC meeting. It is important that they know what to expect. For example, there seems to be an ingrained notion that the CEC is a sort of judging panel defining right and wrong. This raises the threshold for contacting the committee. In information to employees it must be made clear that the committee provides decision-making support in ethical questions, and that the committee may not be able to, nor want to, draw conclusions about decisions. It is our experience that this information must be repeated frequently, even if the committee has been functioning for many years.

1.4 Appointing members to the committee and composition of the committee

It is most commonly the organization's management who appoints the new members, after input from CEC or other relevant parties. The committee reports directly to the CEO. This means, for example, that the annual report and meeting minutes should be sent to management (but not detailed minutes, and identifiable patient information must be eliminated).

Some important criteria for the selection of new members from the hospital trust are:

- Good professional skills and knowledge
- Good clinical ethical judgment and interest in value questions
- The possibility to often allow CEC-work priority over other tasks
- Personal aptitude, the ability to work in a group

It is very important to ensure continuity in the committee because it takes time to build competency and good group processes. It is our experience that it is useful to replace some of the members from time to time. One reason is that in this way, ethics competence and knowledge of committee work is dispersed around the hospital. Another reason is that it helps increase diversity when many parts of a large hospital are involved in ethics work. It is important that those who take on the responsibility of being a committee member commit to being present for meetings. CEC members who do not come to meetings, or in other ways do not function within the group, should be replaced before their term is up. Newly appointed members should be informed by management of how to prioritize CEC-work in relation to their other work.

Committee size varies from 7 to 12 members. For the sake of group relations and meeting efficiency, the committee should not be too big. To ensure representativeness, it should not be too small, either. One of the most important aspects of the committee is that it be cross-disciplinary and representative of the clinical staff. At least two doctors and two nurses from different wards should be members. The same goal should be set for other health personnel such as nurse aids, social workers, physiotherapists, psychologists and clergy. Clergy often do not belong on any specific ward. This gives them a type of independence. Hospital clergy have ethics competence and can contribute with valuable input to the committee's work. As important as the committee members' professional backgrounds, is their interest in CEC-work and personal attributes. Committee members should, for example, be able to work well in teams, compromise, and have the ability to listen to and tolerate uncertainty and disagreement. It is also important to remember that the CEC must be religiously neutral. CEC-members only represent themselves, not their employer, profession or ward. The members' contributions to CEC must not be re-examined by their superiors.

It is important for the work of a CEC to avoid letting one person's or a specific ward's interests, values, or point of view dominate. CEC members should have the ability to form a representative way of thinking where the interests of all involved parties are taken into account. Due to the fact that case discussions can be contentious and involve opposing interests, it is advantageous if some of the committee members are trained in conflict resolution. Conflict and disagreement are often central elements of especially challenging ethical dilemmas.

The development of internal norms, cultures or loyalty groups which make it difficult to evaluate a case in an impartial way is a danger. Many committees have found it helpful to have lay representatives. To contribute an external point of view to internal cases it is beneficial for the committee to have at least two members who are not employed by the hospital. These could be representatives from primary health services, ethicists, lay men, lawyers, or patient representatives.

Committee Secretary

The secretarial role in a committee is important for maintaining contact between the committee and the hospital's health personnel, for calling meetings, writing minutes, archiving, practical help tied to planning and organizing seminars or case discussions, writing the annual report, updating the website, etc. A good secretary is "the glue" of the group, and can help relieve the chair of some duties. A 20-30% position for committee secretaries is the most common in Norway, but it is also possible to have a larger percentage if, for example, the committee is very active, or the chair has less time to devote to committee work. Some committees have a person with a background in ethics, law, and/or health as their secretary. This can increase the quality of the written documentation and the quality of case preparation.

Committee Chair

The chair of a CEC has a very important role in committee work. Based on the 1998 evaluation, one recommendation was that the chair be an experienced and well-respected clinician. One reason for this was to signalize that physicians are central to ethics work, and to avoid that ethics work is perceived as detached from medical decision-making. Yet, the most important quality for a CEC-chair to have is interest and

enthusiasm about the work, along with leadership skills. In some countries, the chair is required to get a masters-level education in ethics. This can contribute to better quality, but more important is the combined knowledge and competence of the committee, especially when most activities, such as case discussions, are done in the group as a whole. Openness and the acceptance of different opinions, the ability to create a safe environment, as well as structured and systematic work, are important leadership qualities. A good chair utilizes the diversity of the committee and strives to get the best out of each individual member. Few ethical questions have simple answers and, therefore, it is important to leave room for doubt and critical comments. A chair should also be aware of and master the balance between independence in committee work and a good relationship with the hospital management. The committee chair must be loyal to the committee's work and goals. This means, for example, that the hospital's interests in a given case cannot overshadow the interests of other parties, such as patients or staff.

Committee member with legal knowledge

Health care is increasingly governed by laws and regulations. Research on CEC work suggests that CECs should seriously consider strengthening their legal competence.³ A CEC member with legal knowledge can clarify the boundaries that the law sets. It is, however, important that discussions about implications of health legislation do not dominate the discussion so that more nuanced ethical discussions are lost. If there are no committee members with legal knowledge, it is very important that the committee brings in someone with legal knowledge when a case requires it. This applies to both specific cases, and to discussions of principles. The County Governor (as representative for the Norwegian Board of Health Supervision) has legal health care knowledge and can be contacted if the hospital does not have this sort of competence available.

Committee member with ethics knowledge

Ethics knowledge can contribute to a committee's analytical capabilities and help to clarify explicit and implicit values in the decision making. Clinical judgement is, as a rule, always value-laden to a large or small extent. Ethicists are specially trained to highlight relevant values and norms. A CEC member with such competence can be useful in

³ Pedersen R, Førde R. Fuzzy law encountering life, death, and morality: a report on nine clinical ethics committees' legal considerations. *Ethics, law and society* 2009;4.

structuring discussions, for conceptual clarifications, and to describe the principle elements of a case. In the same way as members with legal knowledge, members with ethics knowledge can be too dominant in a committee. No one, not even an ethicist, has all the right answers to complicated questions. It is the broad and open discussions that first and foremost give CEC-work its strength. So far, experience in Norway shows that ethics competence strengthens committee work, gives the work legitimacy among health care workers, and can contribute to ethics education for the other CEC members. The same can be said of legal competence in CECs.

A layperson / Patient representative

Such a member can be an important member of a CEC because they represent “all of us,” society, or patients. A patient representative should not represent only specific patient groups or other special interests, but can contribute to voicing and specifying all patients’ perspectives through a representative form of thinking. Some committees have been successful in having a politically active person as their lay member. One benefit to having an external member who represents patients and/or society, is that he/she can help prevent difficult discussions from being colored by the hospital’s internal culture or close ties to those involved on the inside. External members have a critical and independent viewpoint and can more easily see prejudice among individual members in the discussion of patient cases. Furthermore, external participants can contribute to bringing knowledge about ethical dilemmas in health care to the world outside the hospital.

Member from the hospital management

Having a member from the hospital management in CEC can be a challenge both for management and for the committee. The advantage of involving hospital management is that it can make it easier to integrate the CEC into the hospital trust. A management representative can see to it that problems uncovered on an individual level have practical consequences, for instance by improving routines in all parts of the hospital. Having a management representative can also contribute to larger, ethically challenging administrative issues being brought to the committee. In this way, topics such as efficiency or priorities can be highlighted from many angles. However, the committee should be conscious of being used as an alibi in difficult decisions. Because many

clinicians have a misconception that CECs function as a control body, where right and wrong are determined, and bringing cases to the committee can feel like “tattling,” having a management representative in the group can intensify these misconceptions. Management from different administrative levels as CEC-members can thereby raise the threshold for employees wanting to approach the CEC. This can be especially true in cases where middle management is involved, or employees fear sanctions from management. Another problem is that CECs role as “ethical watchdog” can be questioned if legitimate critique of the organization and leadership is muted as a result of management CEC-members. In some countries, management members are not allowed. However, there are many cases which cannot be properly handled without involving some level of management. Our recommendation is to evaluate and explore thoroughly when deciding whether or not to have representatives from management as members of CEC.

Representative from primary healthcare

Primary health care workers often see hospitals from the outside and can therefore give useful input. They represent an important element of health care, and may bring alternative viewpoints that can highlight new perspectives of the patients’ and relatives’ situation. Family practitioners may, for example, have had a more continuous, committed, close, and perhaps a more equal relationship to many patients and patient groups than hospital doctors have had. Representatives from the primary health services can also bring challenges from primary health care in for discussion, clinical ethics challenges that the administration should deal with, for example cooperation with nursing homes and home-care services. Experience suggests that external representatives from primary health care are valuable members of CECs.

How to build competence

Knowledge and competence relevant to CEC-work can be gained in many ways. Working in the committee builds competence, but it is important that members also attend ethics seminars and courses and read relevant literature. Both material specifically related to clinical-ethical dilemmas relevant for the committee, and more general ethics theory can be informative. The same is true of meeting minutes written by other committees.

CME holds an annual seminar for all committee members where both theoretical and practical questions are discussed, and where committees can share their own experiences. CME also holds an introductory course for new members (1-2 days), in-depth seminars, and seminars on specific topics. Starting in 2016, CME will hold 3 annual courses: medical and health ethics, clinical ethics, and facilitating clinical-ethical reflections. Especially the last two courses will be relevant for CEC-members. The Norwegian Medical Association has a free internet-based course in clinical ethics showing films based on concrete patient cases. The CME website gives an overview of seminars and courses. Here CEC-members can find contact information, information about other relevant websites, and references to literature.

In the start-up phase many committees have learned a lot from discussing their own ethical dilemmas. Such exercises will of course be different from real case discussions, since only committee members are present. Yet, these discussions can give the committees confidence in using necessary tools - such as systematic case discussion - as well as thinking through how a real discussion would proceed - who should be present, and practice in using ethics theory in case discussions. Many new committees have benefited - both academically and socially - from holding internal seminars (preferably away from the workplace). Here, more in-depth study of specific topics, and exercises in case discussions have been central. CME or other teaching institutions have often contributed to the committees' internal competence-building. Our experience is that the establishment phase of a new committee lasts 6-12 months, and it is important that new members are given appropriate courses and training.

1.5 Meeting frequency

The meeting frequency for Norwegian committees varies, but on average they meet once a month. Many committees have found it beneficial to have a regular meeting time each month. This could be, for example, the first Wednesday of every month for the last 2-3 hours of the day. This sort of predictability makes it easier to accommodate busy clinicians. It is also recommended to set aside a few hours each month (i.e. two hours between regular meeting times) to discuss urgent cases.

1.6 One or more committees in each hospital trust

In 2000, Parliament decided that there should be a CEC in every hospital. This was later amended to a CEC in each hospital trust. Most hospital trusts consist of more than one hospital. Management in many of the hospital trusts want CEC-structure to mirror the organizational structure of the trust. In this way, the trust management has one committee to go to for input on principle questions. However, there are problematic sides to only having one committee shared by several hospitals. Time is scarce in health care services today, and hours of traveling can easily become a hurdle for busy clinicians. Another problem with having one CEC serve multiple hospitals is the distance from clinical realities.

Large geographic distances between facilities within a hospital trust can be a reason to have more than one committee, perhaps with fewer members in each committee, and some common functions (for example seminars and guidelines work). Some hospital trusts have created local committees for the individual hospitals and a central committee that is made up of members from the local committees. The local committees discuss problems that are relevant to their hospitals, while the central committee coordinates and discusses cases which have more principle and overarching issues.

Some CECs have found video conferencing to be a satisfactory way to solve distance problems. In this way everyone can participate in the meeting without having to travel the long distances. However, when video conferencing is used, many of the more subtle aspects of communication are either lost or more difficult to perceive. It is, therefore, important that the committee also meets physically every once in a while. Another way to solve the distance problem is to have fewer but longer meetings.

When psychiatric and somatic hospitals share a committee some may feel like somatic questions dominate the discussions. This means the committees must pay special attention to ensure that the committee work feels relevant for all parties, including those working in psychiatry. Another field that probably should be given more attention in CEC work is treatment of drug dependency.

2.0 Tasks and work organization

The committees have traditionally had four main tasks: Discussion of cases related to individual patients, discussion of cases which are not related to individual patients (for example a group of patients), courses and seminars for employees, and work with guidelines. In this manual we have chosen to devote most of the space and attention to case discussion related to individual patients. This does not mean that the other tasks are less important, but that the discussion of individual patient cases is perhaps the most challenging task a CEC has. This is because these cases are often very different with complex variations and can be conflict ridden. They can also quickly have consequences for patient treatment. Moreover, these cases can contribute to breaches of confidentiality if the CEC does not have good routines in place.

When we highlight the importance of procedures and methods for working with complicated cases, we should also emphasize that there has to be room for local adaptations in these individual cases. In Norway, CECs are not regulated or authorized by special legislation, but existing health legislation does guide CEC-work.

2.1 Discussing cases related to individual patients

A systematic discussion of ethical dilemmas linked to an individual patient can have many aims:

- Advancing good practice
- Time and space for systematic, thorough and multidisciplinary ethics discussions
- To secure that all voices, especially that of the patient, are heard
- To raise ethical consciousness, ethical competence, and to share experiences within the hospital
- To ensure that relevant judicial constraints are clarified
- To contribute to conflict resolution and to highlight respect for different viewpoints
- Decision-making support for the treating clinician
- Ensuring the quality of difficult moral decisions
- To advance responsibility and documentation in ethically difficult choices
- To give advice if the involved parties ask for it

The goal will vary from case to case. Feedback from clinicians who have brought cases for discussion to a CEC shows that most of them found it to be beneficial.⁴ Getting a systematic examination of an ethically difficult decision is just as often the purpose for contacting the CEC, as is getting concrete advice on the right course of action. Another reason stated by the clinicians was that the case discussions highlighted patient- and next of kin perspectives properly. Critical feedback from referring clinicians: lack of systematic discussion, not enough attention paid to medical realities of the case, concerned parties were not present, or not properly included in the planning phase of the case discussion. The latter led to discussions lacking ethically relevant information, such as a patient's level of functioning, a patient's preferences, or the perspectives of relatives.

2.1.1 Who can bring cases to CEC

Everyone, in theory, should be able to bring a case to a CEC. However, a CEC should always make sure that the cases are relevant to the committee's mandate. At the present time, CECs have primarily functioned as a forum where hospital employees, including management, can discuss difficult clinical ethical questions. The National Mandate allows for inclusion of patients and relatives, though CEC should make sure not to assume the role of Patient Ombudsman, Chief County Medical Officer, Care commissions, or user organizations. Pure complaints should be referred elsewhere. When complaint cases raise important ethical questions, CEC should not get involved in the aspects of the case that are the responsibility of others, but extract the principle ethical elements.

2.1.2 Written or oral referrals

A brief written description of the problem can be useful for CEC chairs to have in order to prepare the case discussion properly. Some clinicians may find that taking time to write down a description is an obstacle that hinders referral to CEC. Therefore, oral referrals should be allowed too. It may be a good idea to create a form or checklist for referrals. A short written orientation of the case, written by either the CEC chair or secretary, distributed to the CEC-members before the meeting, allows them to prepare

⁴ Kalager et al: Is the discussion of patient cases in clinical ethics-committees useful? http://tidsskriftet.no/article/45788/en_GB; Forde R, Pedersen R, Akre V. Clinicians' evaluation of clinical ethics consultations in Norway: a qualitative study. *Med Health Care Philos* 2008 Mar;11(1):17-25.

properly. This may be especially valuable to members with legal- or ethics competence, since they then can prepare relevant literature, and thereby contribute to the most comprehensive discussion possible. For the other members, a written orientation of what is to come can be helpful because it may allow them to reflect on similar previous cases.

2.1.3 Is this problem for us?

This is an important question! There is always the danger that too many things are labelled “ethics,” thereby allowing everything difficult and unwanted to be sent to CEC. If this happens, a problem can be rendered harmless, be delayed, or not be solved where it originated – on the ward or in management. For this reason it is important that every referral is considered in this light. Is it a question of medical science, to be solved by medical professionals? Is it a question belonging in management, or a case for Patient Ombudsman, Chief County Medical Officer, Care commissions, or Research Ethics Committees? Maybe the case should be handled in conjunction with one of these parties? In the course of a CEC-discussion you may find that some elements of the case should be handled by someone else. An example of a case which had judicial, professional and ethical components follows: A patient ombudsman came to CEC because he believed a malpractice case had important ethical implications. The case discussion revealed that, among other things, the hospital lacked satisfactory routines for safeguarding and continued follow-up of patients, relatives, and involved clinicians in the event of serious incidents.

Typical themes or areas that the majority of committee discussions are about: withdrawal of life-prolonging treatment, patient autonomy and informed consent, use of coercion, clinical communication, confidentiality, and assisted reproduction. Situations that commonly create ethical challenges are characterized by involved parties being unsure of - or in disagreement about - what is the right course of action, with an outcome of great consequence for those involved.

2.1.4 Preparing a case

An important question both for the planning of and discussion of a case is why the case is being brought to the CEC. What do the clinicians wish to achieve by discussing the case? Is it to resolve an internal conflict, or to get advice, or to get support that a decision

that has already been made took all values into consideration? This needs to be clarified before the meeting.

An important prerequisite for good ethics discussions of individual cases, is to be as factually accurate as possible. In addition to specialized nursing- and medical issues, it is important that all involved parties are heard. When several people are discussing a case and many questions arise, supplementary information is often needed. When some of the involved parties are missing from the discussion, and are not represented properly by someone else, this information may be hard to get. Therefore, an important question to ask before the discussion is: who can illuminate the case from a medical perspective, a psychosocial perspective, and an ethical perspective? When dealing with complicated medical questions we might need an internist, surgeon, anaesthesiologist, neurologist, physical therapist, social worker, family doctor or psychologist to be present in the discussion. A central question is then, who knows the patient and next of kin (from home) and can represent them if they themselves do not wish to, or cannot, participate?

Discussing cases related to single patients in a CEC can mean that people that are not involved in the treatment are given identifiable patient information. This is a breach of confidentiality unless the patient has been asked and has consented to the discussion and/or disclosure of patient information. Therefore, the patient or next of kin should always be told that there is a need for the case to be taken to CEC, and should be asked whether or not it is ok to disclose patient information that is relevant to the case. When a good case discussion is possible without revealing identifying patient information, the discussion can take place anonymously without consent of the patient or next of kin. However, informing the patient or next of kin of the case discussion will make it easier to involve them before, during or after the discussion, which may be necessary, directly or indirectly.

All cases that are brought forward to be discussed should be anonymized as much as possible. Even when the patient/next of kin have given their consent to such a discussion and participate in the discussion, disclosure of private, confidential patient information should be done with care.

2.1.5 Where should the case be discussed?

Case discussions can take place in the committees' regular meeting place, on the ward, or in other meeting rooms in the hospital. Discussing the case on the ward that "owns" the problem can help those involved feel less vulnerable and estranged than if it were discussed in the committee's home court. In cases where several wards are involved, and especially where there is conflict, CECs meeting room may feel more neutral.

2.1.6 Who should participate in a case discussion?

This is a principle question, and different Norwegian committees answer it in different ways. There is no *one* recipe for success. Different set-ups have different strengths and weaknesses. On the one end you have committees discussing the ethical questions behind closed doors, based on information gathered by CEC-members ahead of the meeting through conversations with involved parties, or through information that was sent in. This information can then be summarized in written notes that form the basis of the discussion. The advantage of this method is that information can be sorted and systematized beforehand, which will most likely lead to a more structured discussion. Another advantage may be that tensions and conflicts are reduced, for instance regarding professional disagreements, since the different parties are not present together, which again leads to an "easier" meeting. Discussions that take place internally in the committee may also demand less resources since the involved clinicians are not spending time in the committee meeting.

One of the drawbacks of only participating in the preparation of a case is the danger of relevant questions not being asked or answered. In evaluation studies, some clinicians pointed out that it was problematic to not be present in discussions of their case, and that a discussion behind closed doors can make the committee's work seem excluding or esoteric. Another drawback is that a dialogue between involved parties is not possible, thus limiting the chance of creating understanding of the others' perspective. Underlying many ethical dilemmas is uncertainty or disagreement of the facts, which again will remain unresolved until the case is discussed with all involved parties, with relevant expertise, and with help of the committee's multidisciplinary knowledge. In the course of a discussion, it may become obvious that information needed to illuminate the case's many sides is missing, which in turn shows why it is problematic that the person who

could supply this information is not present. This can make it impossible to complete the discussion, and a new meeting must be called. In this way, the case demands more resources, and is less efficient.

A “closed” committee case discussion can make involved parties feel excluded, and it may feel unnatural for those who “own” the problem not to participate in its discussion. Participation in the discussion can be an arena for learning for the involved parties, as well as leading to a better understanding of the different perspectives of the case.

If the discussion is to take place with all of the involved parties present, or through proxy representation, it is important that the discussion is planned carefully. This type of meeting demands more of the chair and/or moderator. Clearly, this type of meeting takes time to plan, finding time for all the different people to meet. The advantage is that in such a forum new questions might be asked, approaches might change with the disclosure of new information, everyone can participate, and everyone hears everything. When information is gathered by only one or two people it will always be colored by them.

A disadvantage to a more inclusive discussion is that it can be hard on participants, precisely because of the size of the group. Ethical dilemmas are often emotionally demanding for those involved, there is often underlying conflict, disagreement, insecurity, and vulnerability. An important goal for the committee will then be to make the discussion feel safe, to create a secure and comfortable atmosphere. The committee should have at least one member with competence in conflict resolution, and in some cases it would be advantageous to let that member lead the discussion. In cases riddled with conflict, one option is to have a two-part meeting. First, addressing all questions, and then allowing the CEC to discuss the case alone and in that way reach a conclusion.

An in-between solution is to have the case discussed by two or more of the committee members along with the involved parties, or with the involved parties separately. This type of discussion is likely to feel less threatening and formal since the clinicians and patient/next of kin don't need to meet many strangers all at once. The weakness is, again, that the thoroughness and openness of the discussion is reduced by having fewer

perspectives brought in. Multidisciplinarity and interaction between group members are important aspects of ethical deliberations. Some Norwegian committees have found it helpful to have at least the 3-4 members with the most relevant background present, if the committee doesn't meet as a whole. Experiences from other countries show that in "clear" and less complex ethical dilemmas such a model may be the right choice. In some cases, just sending an "ethics expert" as a participant in a discussion between involved parties is enough. On the other hand, in cases where tensions are high or there is great complexity, discussion in the full committee (or at least with a majority) is recommended. In cases with a high level of conflict and mistrust, an approach with as much openness as possible is especially important, in order to maintain as much trust among the parties as possible. With fewer participants comes a higher risk of an uneven discussion. For better or for worse, everyone brings in their own professional and personal standpoints and perspectives. Therefore, if parts of the committee have participated in a discussion, it is important to review it with the whole committee present afterwards (remembering to inform the involved parties). This gives the remaining committee members the opportunity to add supplementary comments and questions. This kind of follow-up discussion will ensure that the committee gets information, a learning opportunity, and that the involved members get appropriate feedback. It is important that it is not always the same committee members that are chosen to participate each time, as this could lead to a form of "A" and "B" membership.

2.1.7 Should the patient or next of kin be present in the case discussion?

This is a very important question without a "right" answer. As many cases deal with very sick patients, it is often the next of kin or someone else who knows the patient well who participates. Those committees who have included relatives in meetings have had a positive experience. Many case discussions address very difficult questions, so openness and a sense of security while thinking out loud about these difficult questions is essential.⁵ Clinicians and committee members often wish to protect patient and relatives from information which can create unnecessary anxiety for people in such a vulnerable situation. Generally, such concerns have been exaggerated; however, the presence of patients and/or relatives can contribute to an atmosphere where difficult ethical and medical discussions are curbed, which in turn will affect the quality of the discussion

⁵ Førde R, Hansen TWR. Involving patients and relatives in a Norwegian clinical ethics committee: what have we learned? *Clinical Ethics* 2009;4(3):125-30.

and, in the end, the patient's treatment. Therefore, when deciding whether or not to bring in the patient or next of kin, different factors have to be considered: patient participation, the most reliable information about the patient's preferences and values, openness of clinicians, opportunity to bring up disturbing information and questions. In retrospective cases (after a decision has been made), where the learning aspect for the employees is more central, there may be other and more weighty reasons for patients not to be represented (See Section 2.1.10). If it is possible for the case to be discussed anonymously, the committee does not necessarily need to involve the patient, or use patient-identifying material, but this can mean that the case is not elaborated on in enough detail. This is something to keep in mind.

Even though it can be difficult, we believe that CECs should strive to give patients the option to participate directly or indirectly (via a representative), especially in prospective cases.⁶ An interview study conducted with parents who had participated in CEC-discussions regarding life-prolonging treatment for seriously ill children showed that these parents found participation to be important and meaningful.⁷ Patients' interests and values are best communicated directly, and allowing their presence can signal respect and a wish for openness. Because communication and conflict often play a central role when clinicians experience a situation as an ethical challenge, it is not desirable for one party to represent the view of another. Difficult ethical questions demand good communication. We recommend as much openness as possible in the discussions. Sometimes good communication can help ethical problems solve themselves. In some cases, it will be impossible to bring together all of the people involved in a case. Patients' and next of kin's points of view can also be represented by health personnel who know the patient well and have their trust, if patients or next of kin approve. It is preferable that this is a person who is not responsible for treatment on the ward. This could be, for example, a social worker, family doctor or other professional.

⁶ Prospective cases are cases where a decision has not yet been reached. This is the opposite of a retrospective case which are discussed after a decision has been made.

⁷ Førde R, Linja T. "It scares me to know that we might not have been there!": a qualitative study into the experiences of parents of seriously ill children participating in ethical case discussions. [BMC Med Ethics](#). 2015 Jun 6;16:40. doi: 10.1186/s12910-015-0028-6.

In some cases, there is a need to discuss a case which, for various reasons, is impossible or problematic to invite patient or relatives into. Examples include cases where there is great conflict, cases where patients are marked by strong emotions, or cases where involving relatives likely will worsen the patient's relationship to them. Another example could be cases where there is disagreement about what kind of information to give the patient (where the patient's presence will lead to him/her getting information someone - for instance relatives - thinks they should be spared). Such cases must still be possible to discuss if clinicians feel that this will increase the quality of their decision-making. Here, the case must be discussed anonymously, discussing either more principle elements of the case, or more overarching questions. The committee must keep in mind that essential information may be missing. Committees are increasingly being contacted, often by management, to discuss difficult principle questions, for instance matters of prioritization. In these discussions, it is not natural to involve patients or next of kin.⁸

Another example of case discussions lacking the patient voice is when CEC is contacted by the person responsible for treatment for a more informal discussion of the case. In such discussions patient-identifying information can be avoided, and sometimes only a few members are present. This kind of CEC-work is more informal. Again, we want to underline that the committee's advice in this type of discussion, based on limited knowledge of involved parties, should point out that some elements of the case may not have been highlighted, making the conclusion less dependable. Such cases should nevertheless be documented and archived (the question, background, purpose, and conclusions). This is important because in the aftermath there may be differing views on CEC's contribution to the case. For instance, clinicians may believe that because CEC did not clearly disapprove of a proposed solution, that solution was "approved" by CEC.

When patient or next of kin participate in case discussions a more comprehensive understanding of the problem is possible, and it gives them certainty that their voice is taken seriously. Yet, certain criteria must be met. The first is that committee members and participating clinicians who are presenting information are aware of, and comfortable with, the presence of patient/next of kin. The second is that patient/next of

⁸ Førde R, Hansen TWR. Do organization and clinical ethics in a hospital setting need different venues? HEC Forum 2014 Jun;26(2):147-58. doi: 10.1007/s10730-014-9237-5.

kin are properly informed about CEC's mandate, that the committee will contribute to illuminating difficult questions, not be a jury or decision-maker. If patient and/or next of kin are to participate in a committee discussion it is important to be aware that it may be a tough experience for them in their vulnerable state, to meet a large group of treatment and hospital staff who represent authority, safety, power, and use special jargon. Not everyone in this situation will be able to assert their best interests. The third criterion to consider is therefore whether or not patient/next of kin are in a place where they can participate in, and make use of, such a discussion. The fourth criterion is to make sure there is a plan for follow-up of patient/next of kin after the discussion. You never know how information and thoughts that emerge in such a discussion affect people in vulnerable or chaotic situations.⁹ The committee and the involved clinicians should collaborate on this.

A compromise, in order to safeguard the many considerations in difficult cases, could be that patient/next of kin attend part of the meeting in order to present their case and maybe divulge some facts, but that they are not present for the discussion itself. In this scenario, it is important that patient/next of kin receive sufficient information about what happened at the meeting, either by a trusted clinician summarizing it, or by a member of CEC getting in contact to discuss what happened. Discretion must be used.

2.1.8 Questions of impartiality

This is a question that can appear paradoxical as it is the ideal for committee members to think representatively and not represent certain interests. The demand of impartiality can also seem strange because it is very clearly formulated that the committee is not a decision-making entity. (It is the treating clinician who has the final responsibility when a difficult ethical decision needs to be made.) The discussion of important value questions in a CEC are a way to ensure the quality of difficult decisions. Confidence in the decision depends on a judgement-free discussion, and therefore questions of impartiality must be taken seriously. This may be hard to achieve in small work environments.

⁹ Førde R, Linja T. "It scares me to know that we might not have been there!": a qualitative study into the experiences of parents of seriously ill children participating in ethical case discussions. [BMC Med Ethics](#). 2015 Jun 6;16:40. doi: 10.1186/s12910-015-0028-6.

It is, of course, impossible to prevent personal experiences, feelings, and personal ties from coloring an ethical evaluation. We are all partial, and sometimes this partiality, for example as engagement or being especially knowledgeable about/having insight into a problem, can be a strength. An example of this could be that the hospital chaplain, who often is a committee member, has previous knowledge of the patient and his/her values. This chaplain can then contribute in a positive way to the discussion, as long as patient/next of kin allows it, and confidentiality is respected.

Having distance from a situation can sometimes make it easier to sort, analyze, and illuminate differing arguments and interests. Especially in conflict-ridden cases, and in particular in cases where decisions have dramatic consequences, the committee's impartiality and ability to see all sides of a complicated case is important.

A CEC is not an administrative body (and neither is the health trust), but administrative laws including the impartiality rules apply to the trust's activities. In practice, however, these rules are rarely binding for CEC's discussions since CECs do not make legally binding decisions or act as an authority. A committee discussion should, nevertheless, make sure that problems are discussed impartially and thoroughly. This is especially important for patient/next of kin. If there are close alliances between committee members and involved parties in conflict-ridden cases, these members should withdraw from the discussion. External members have a special responsibility to ensure impartiality, but every single member should in all cases evaluate whether they have ties or relationships that can weaken confidence in the committee's work. In some cases it may be best to hand over the case discussion to a CEC at another hospital. This would apply if many of the committee members have a conflict of interest, or if the concerned parties do not have the necessary confidence in their own CEC. This has been done on several occasions with good results.

2.1.9 Prospective cases

These are cases where the ethical problems tied to the treatment of a patient are discussed before the case is settled. A reason for such questions being brought to the committee could be that a clinician or patient/next of kin wants a systematic and thorough examination of the ethical problems before a decision is made. Here, it is not a

problem if the committee does not reach a unanimous decision. Sometimes clinicians may want the committee to give them concrete advice about which solution to choose. In these cases it can be problematic if the committee cannot come to a common conclusion. Many cases are so complex, with many competing considerations. There may not be *one* correct solution. Here, the conclusion will have to be that several courses of action are ethically acceptable. Since the committees are supposed to be multidisciplinary, regarding professional, ethical, and personal points of view, there will often be a multitude of differing opinions, or nuances. This strengthens the quality of an ethical discussion, differing it from more uniformity, or false consensus. The main purpose of a discussion is to discuss the ethical problems in a thorough, systematic, and open way. If the involved parties wish to get specific advice, this should be clarified early on. The committee can then consider whether they feel the need to discuss the case on their own after the involved parties have illuminated the case sufficiently.

Regarding participation and information to patient/next of kin, the rule of thumb should be that when clinicians bring prospective cases, the clinicians themselves should ask for permission to convey patient-identifying information that is necessary to complete the discussion. The patient and/or next of kin should be told by the clinician or the committee itself what a CEC-discussion is, and mention the possible need for information from all involved parties, either through participation or through representation.

2.1.10 Retrospective cases

These are cases that are brought to the committee after a decision has been made or a case is closed. The reason to discuss retrospective cases can be to look systematically at a solution that was chosen, at the process of decision-making, or at events occurring after a decision was made. An example of the latter is when a case has been exposed in the media. Did we handle it appropriately, why did it become so conflict ridden and controversial? Were we able to see the ethical problems we were faced with clearly? Could something have been handled differently? How do we prevent this from happening again? Behind the last question lies the ideal that experiences from relevant ethical dilemmas should be shared with others. By going through a case we can uncover a need for increased awareness about certain questions. Does the hospital need to

change its routines, or arrange a seminar for the staff? This kind of discussion may uncover lacking routines for follow-up of health personnel in the aftermath of serious incidents; lacking routines for when and how to contact child protective services; or routines for handling Jehovah's Witnesses who refuse life-saving blood transfusions, to name some examples.

Retrospective case discussions are very meaningful, both because they can have positive consequences in practical matters, but also because they allow for processing ethically complicated – and sometimes emotionally difficult – situations. In complicated medical questions with many involved parties – who in turn may have differing viewpoints, interests, competence, and responsibilities – and in suboptimal conditions, it may be impossible to see the best solution. Yet, there is still a need for dialogue afterwards to deal with doubt, uncertainty, or moral agony. Such cases can be emotional burdens for all involved. Some of these cases are exposed in the media, CECs sometimes discuss these.

Experience with retrospective discussions shows that they are a great arena for learning. Because there are often strong emotions involved, they are demanding in both the planning stage, and in the actual discussion. In these cases, as well, it is important to carefully consider who should be present in order to illuminate the case most thoroughly. If the conflict level has been high it may be impossible to gather all the involved parties at the same meeting. It is especially important to clarify that CEC-discussions are not carried out to judge what was done, but instead are a way to openly and non-judgementally discuss in order to see why things turned out the way they did, to illuminate the different parties' perspectives, and to see what lessons can be learned for future similar events. In some retrospective cases it is not possible or desirable to bring patient or next of kin into the discussion. This could be because it may be too much for them to handle, or if the patient is dead and next of kin are grieving, or if it is unethical to reopen the matter. If consent is not gained from the patient, patient-identifying information must be anonymized.

2.1.11 Central points of the ethical discussion (The Six-Step Model)

The main goal of a case discussion is that all sides are thoroughly illuminated. Good and systematic routines enhance the quality of the work. CECs have increasingly relied on a specific procedure for case discussions. There are many procedures that can be used in ethical discussions but in this manual we will present the model we are most familiar with, and that we find works well. An alternative method is *Casuistry* that focuses on earlier examples and experiences as normative guidelines for what to do or not do in the present. In practice, such elements should be part of every case discussion, and therefore we have included it as an element of the model we present here.

The procedure can be written on a board at the beginning of a discussion, and elements can be written in as they are brought up (preferably not by the person leading the meeting). In this way, it is easier to both follow and later summarize the meeting, both orally and in the written meeting minutes. This can also be written directly into a word-document if you have access to a computer and a projector. Even if it may feel natural to start with point 1 and 2, ending at 6, a discussion will usually proceed by shifting between all of the points during a discussion. The most important point of the list is to ensure that all these sides of an ethically problematic situation are covered.

1. What is the ethical problem /are the ethical problems in this case?

This question is a useful starting point because it forces the committee to address whether this is a case best handled by an ethics committee, or if it is a question for medical professionals, or a complaint. Sometimes it is obvious what the ethical dilemma is, but more often it is difficult to define the ethical dilemma. As the case becomes more illuminated and complexity increases, new ethical dilemmas may emerge. This is in itself part of the goal of a discussion; it is often the hidden (and governing) values or conflicts that are important to reveal and discuss. An example of this: There is disagreement about whether or not to treat a critically ill patient. The treating physician might say treatment is pointless and therefore unethical. The discussion can uncover that the doctor sees life with a serious disability as worse than death. Differing perceptions of the term useless or meaningless treatment, or quality of life, will therefore become central in such a discussion.

2. What are the facts of the case?

This point can never be taken lightly. It involves ensuring that all involved parties, everyone able to shed light on the case, either are present, or have in other ways informed the discussion. What are the medical facts, results of treatment, short and long term prognoses, risks of the treatment, suffering involved in the treatment, and not least – how certain are we of these facts? Quite often, a problem in medical-ethical dilemmas is that there is not satisfactory knowledge, yet a decision needs to be made. It is important for the uncertainties to be identified. In some cases, when the consequences are especially dire, it can be important to point out the uncertainty of medical facts, and maybe bring up the possibility of a second opinion. Part of talking about the facts is also to look at the patient's situation, for instance quality of life, capacity to consent, relevant wishes and values. Are the patient's values and preferences known, who can convey that information, and how certain and relevant is this knowledge? Has the patient conveyed clear and unambiguous statements? Does the patient have a living will, and is it relevant to the matter at hand? Could the patient have changed his/her mind?

3. Who are the involved parties and what are their viewpoints and interests?

That the patient is an involved party is a given, but next of kin, including parents, siblings, and children, can be important involved parties as well. Involved parties are also health personnel and others inside and outside the hospital who have been central in the course of the patient's treatment. If the treatment is especially resource-draining, other patients and society as a whole can be considered an involved party.

4. Relevant values, principles and virtues, experience from similar situations and judicial constraints?

This point is closely tied to the question of the ethical dilemma. What a relevant value, principle, or virtue is will be inspired by different ethics approaches, such as utilitarianism, deontology, principlism, ethics of proximity, virtue ethics, and discourse ethics. In addition, norms of professional ethics will give insight. All committee members should know about such ethics approaches and norms. How was a similar case solved before? Are there relevant experiences or guidelines locally at the hospital, at other hospitals or nationally? Health legislation does not usually give an answer to what is good practice, yet the legal framework of the case at hand needs to be clear. If the case

has complicated legal ramifications, it may be useful to invite a lawyer into the discussion.

5. Possible courses of action

This is the point action-oriented clinicians feel most comfortable filling in. It is important not to narrow the ethical discussion of possible actions to only include treatment alternatives. Remember to include things like care, palliative care, communication, quality assurance, and if necessary – whistle-blowing. When many people meet, it is possible to find new alternative actions, while others can be discarded as a result of well-founded objections. Sometimes it is a good idea to start with this point.

6. Discuss the above and attempt to formulate one or more acceptable actions and a conclusion / summary

Who and what weighs the heaviest of the ethical considerations? Should, for example, the duty to uphold life come before the duty to prevent suffering? Should the interests of the next of kin be prioritized at the cost of other interests? How should this be justified, and which values and considerations are then left behind? The goal is to reach a consensus of what to do. When this is not possible, you should, through the discussion, clarify who is responsible for the final decision, and give all parties information concerning complaint options.

If the participants reach a consensus, the process to follow can be discussed under this point. Who should be brought in, how will a treatment plan be carried out? Another important point is how conclusions should be carried out. If patient and next of kin have not been present it may be beneficial for one of the committee members to meet with them to present main points of the discussion, perhaps along with one or two members of the treatment team.

After the discussion

A good rule of thumb is to review and evaluate the case discussion at the next committee meeting. Was it a good discussion, was it balanced, what could be improved regarding how the meeting was led, planned etc.? Were all relevant factors brought forward? What

happened after the discussion? Were there consequences, why not? All cases are different and a review of this kind allows for the opportunity to learn and improve.

2.1.12 Meeting minutes from the case discussion

The committee must record meeting minutes from their discussions. The minutes are a documentation of the discussion that can be read by all involved parties, even those who weren't present. All treatment of patients requires documentation, and ethical discussions are not an exception. Clinicians who have used CEC for a case, see the minutes as a sign of professionalism.

Meeting minutes can also be used as a tool for learning and quality assurance in the organization. The minutes may be brought out at a later time if there is a need for a closer look at the case, or the assessments made afterwards, or if a similar case shows up later. Thorough documentation can also be valuable material when studying how CECs work, can be the basis of improvements, and can contribute to developing the field of clinical ethics. Minutes from case discussions are also documentation of what is happening in and with health services. Which ethical dilemmas arise when patients and next of kin become more involved, and what are the most important reasons for disagreement concerning treatment at the end of life? Case discussions from different parts of the country, or from a given period of time, can be analyzed and can give us valuable information. This is illustrated by a review of cases discussed in the CEC at the Norwegian national hospital over a six-year period. The review revealed that the most common cases involved ethical dilemmas concerning treatment limitation and treatment of children. The review also found that problems with information and communication were an important reason why the ethical dilemmas arose in the first place, and became hard to solve on the ward.¹⁰

Another important reason for keeping good meeting minutes is that these can provide valuable teaching material if the CEC (or others) want to teach clinical ethics. Using the minutes in this way, or in quality assurance, or research, of course requires that the

¹⁰ Førde and Vandvik, 2005; Førde and Ruud Hansen, 2009.

affected parties have adequate protection of privacy. One should take extra care to ensure that they are anonymized sufficiently, removing all person-identifying information, even if that means removing or changing facts. If adequate anonymization is not possible, consent must be sought from the people involved. If the minutes reveal information about health care personnel, and it is likely that they may find this difficult, consent must be given by them as well.

2.1.13 How should the minutes be written?

It is a good idea to have more than just the secretary be responsible for writing the minutes. This will help ensure that relevant information is not left out. A rule of thumb can be that once a draft is written, it is sent to all those who were present in the discussion for feedback. This can contribute to all important information being included. Meeting minutes should describe the discussion, if possible following the six-step model. In addition, the following should be included: Who contacted the CEC and why? (For instance uncertainty or conflict in a case, if one's back is up against the wall, concrete advice was wanted, etc). When and where did the discussion take place? Who was present/not present for the discussion? What, if anything, will CEC be doing as a result of the discussion?

Because the meeting minutes may be read by people who are not well acquainted with the nature of a CEC, some CECs have chosen to start all minutes with a standardized text describing what CEC is and what they do. In this way they hope to prevent misunderstandings. The CEC of Health Bergen uses the following text:

The Clinical Ethics Committee's mandate is to offer an impartial discussion of cases that are ethically challenging in the treatment of patients. We can advise in specific if asked, but our advice is not legally binding. It is the treating physician who has the final decision-making authority.

CEC at Oslo University Hospital uses the following introduction to their minutes:

The Clinical Ethics Committee is a forum used for a broad discussion of difficult clinical-ethical questions. CEC can give advice, but has no decision-making authority. This lies with the treating physician.

The minutes should be written using accessible language, without unnecessary use of (unexplained) medical terminology. This is especially important if the minutes are to be

read by patient and/or next of kin. Terminology or wording that could be interpreted in a negative way should be avoided.

The meeting minutes should be written and archived in anonymous form in CEC's archives, after those who were present have accepted the document. If it is not possible to anonymize sufficiently, or there are other relevant reasons for not anonymizing, the hospital should apply for permission from the appropriate legal authorities to archive the minutes in CEC's archives. A central question then becomes: what is sufficient when it comes to anonymizing?

In prospective cases it is recommended that the minutes also are added to the patient's chart, unless there are good reasons not to. Archiving all or parts of the minutes in the patient's chart is necessary if the discussion is "relevant" or had an impact on the health intervention, for example by having direct consequences to the intervention that is chosen. It is the treating clinician, not the committee, who is responsible for this evaluation and documentation. If the case is discussed in anonymized form, without involvement of patient or next of kin, the minutes are usually only given to those involved in the discussion. Here, again, it might be prudent to add all or parts of the minutes to the patient's chart. If this is done, the patient has the right to access it. This could be another reason to involve patient or next of kin right from the beginning. In retrospective cases that first and foremost have learning potential, the health intervention has already taken place, and usually there is no reason to put the minutes in the patient's chart. If the discussion discloses significant harm done to the patient in treatment, the patient should be informed of this. However, this is the responsibility of the hospital and treating clinician, not the ethics committee.

If there has been a disagreement, or criticism of health care staff in a case, one objection to putting the minutes in the patient's chart – or even to writing minutes – could be the fear that it could be used in a malpractice case, if troublesome conditions were uncovered. Yet, control commissions and courts must do an independent evaluation of the information in CEC's meeting minutes. In addition, CEC's own evaluation of the case has no bearing on possible sanctions applied to staff members or the hospital as a whole. It is important to remember that deviation from expected behavior or good practice

doesn't necessarily equate to breaking the rules and the use of sanctions. For instance, if CEC discusses a case retrospectively, the health care staff is not necessarily to blame, morally or legally, even if they acted against what we see as ideal when looking back at the event. If the discussion uncovers circumstances that can endanger life or health, or circumstances that have or could have led to serious injury, the committees should encourage the treating clinician (or management) to uphold their legal obligation to report such circumstances.

There is an ongoing discussion about whether CEC-work is best described as patient treatment or as procedure and accordingly how it should be regulated legally. In patient treatment (which is not what CEC does) health care laws and confidentiality are central. In procedural work or practice of authority (not CEC's place either), the Freedom of Information Act and the Public Administration Act are central. Either way, minutes or other case material from CECs that contain confidential information (such as patient-identifying details) should not be made public. If the committee is uncertain whether people can be identified, the case should not be made public. Health care workers' rights to confidentiality are not as strongly monitored as those of the patients, but as a CEC we should avoid spreading identifying information about staff members. Internal and/or preparatory memos can also be kept away from the public. Specific inquiries for access – for instance by journalists - need to be evaluated on an individual basis. If access is given, you must ensure adequate anonymity. This means going through the minutes again, making necessary amendments etc. before handing it over. CEC is a new entity in health care, and has been developed following the main principles of the laws. This means that the laws are not necessarily fit to apply to CEC's work. Health care staff often have limited experience with laws. They can, however, consult the hospital administration or similar entities. CEC should always make it clear to those who appoint the members (often hospital management) where and how CEC plans to archive its documents, both electronically and manually.

2.1.14 Referring to cases in CEC's annual report

CEC's annual report will usually give an overview of cases CEC handled, and this is often widely distributed, for instance on the intranet. Here, the case information needs to be shortened and thoroughly anonymized, unless there are extenuating circumstances, and consent has been given. The clinical-ethical dilemma, and the most important

professional, ethical, and legal points are possible to describe, even when specifics about the patient and their circumstances are left to a minimum. The case overviews in CEC's annual report can be informative both for clinicians and for management. CME reads these reports thoroughly because it gives ideas for topics of future courses, and an overview of the committees' activities and challenges. This is important information when clinical ethics work is to be presented to political health authorities.

2.1.15 How to get cases

Most of the CECs both in Norway and abroad wish they had more cases to discuss. There are several reasons why CECs do not get enough cases. First of all, most dilemmas are solved properly on the ward. CEC is a new entity, many people are unaware of its existence. Working to make CEC known is an ongoing process. But another reason is that there is a high threshold in the medical community for discussing problems with outsiders. There is reason to believe that ideas about how no one other than those with medical competence in a specific case can have well-founded arguments and solutions, are alive and well. A third reason can be that people feel that it is a sign of defeat to ask for help. Or perhaps it feels like whistle-blowing to contact the committee, especially if the case is conflict-ridden.

The most important condition for being used, is that clinicians and management find it useful and meaningful to discuss their case in CEC. It is also necessary to try to fight against the impression some have of CEC as morally superior, holier-than-thou, or a place of judgement. It can be useful, on a regular basis, to send one or two committee members around on the wards to present their work, and ask about areas that create ethical challenges. Going to the wards for an informal discussion of cases they are struggling with, can be a way to supplement the more formal case discussions, and helps to tie ethics work to practice. Some hospitals have established reflection groups or other ethics arenas on the wards. Here the staff meets on a regular basis to discuss ethical dilemmas in practice. Such forums heighten value consciousness, and that in itself can lead to more cases being brought to CEC. CEC-members can be useful initiators and facilitators in these kinds of reflection groups. However, very complex cases, or conflict-ridden cases may be better handled by CEC who have a wider range of competence, and members with more distance to the case. Hospital management also has a responsibility

to bring ethics questions to CEC, especially cases of a more principle or overarching character.

2.2 Discussing cases that are not related to individual patients.

A large proportion of cases the committees have been involved in are clinical-ethical dilemmas that are not related to one single patient, but to a group of patients. The form and content of these discussions can still follow the recommendations in chapter 2.1, for instance using the six-step model. However, there is one important difference: in these cases it usually is not necessary to include patient-identifying information. Involving patient and/or next of kin is usually also less likely, though, as a rule, you should always ensure that the user perspective is highlighted. One way to do this is to invite patient/user organizations. There is not a big difference between these more general discussions and smaller thematic/case-based seminars. Examples of topics for such discussions: procedures for late-term abortions, resource allocation issues artificial insemination for couples where one has a serious illness and short life-expectancy, whether to have exceptions to allowing organ transplant to patients who do not change their lifestyle according to the requirements, or if electroshock therapy can be justified for a seriously depressed patient lacking capacity.

2.3 Seminars

All Norwegian committees have arranged seminars. Their annual reports show the variety of topics presented. This is an important part of clinical ethics work, because the seminars gather a wide variety of people, and thereby contribute to heightening awareness of value questions in practice. There are many ways to organize seminars, everything from big seminars that are open to all employees, to internal mini-seminars on a ward that often touch on principle matters concerning single cases.

The larger seminars often highlight general ethical questions such as treatment limitation or ethical problems related to patient information. Most CECs in Norway have held seminars about the *National guidelines concerning limitation of life-prolonging*

*treatment for seriously ill and dying patients.*¹¹ By doing this, CEC has put this topic on the agenda, and spread knowledge of the document itself. Topics with a more narrow scope can be brought up in smaller forums, inviting those with special interest in the topic. It increases the learning potential if the seminars use specific clinical cases/problems as the starting point, followed by more principle and general questions raised by the concrete case. The more involvement by the audience, the more useful the seminar will be.

Using anonymous or constructed cases, and dialogue (or team work) increases activity and thereby the seminar's usefulness. An example of a mini-seminar could be how a seriously ill patient from the third world is met if he/she by Norwegian standards is in need of extensive and expensive treatment, but is not covered by Norwegian public health care, nor can pay for it him/herself. Perhaps there were strong and differing viewpoints within a treatment team on whether or not to treat such patients. Which dilemmas do such patients bring to the treating clinician? What are the viewpoints of hospital management, patient organizations, and authorities regarding this? What should the treating physician do? Seminars where different involved parties discuss the same questions from their point of view are often very fruitful. It can be a good idea to spread information about significant contributions, and maybe conclusions, from a seminar of this sort to all members of the organization, as well as writing about it in the committee's annual report.

2.4 Working on guidelines

Norwegian committees have, either due to their own initiative or because they were asked by management, been asked to help formulate guidelines for ethically complicated areas, or have been asked for input on guidelines created by other entities. For example, guidelines for use of social media ("should patients and staff be Facebook friends?"), DNR-orders, routines for autopsy, organ donation, or handling mistakes.

One survey found that there was very limited knowledge of ethical guidelines in Norwegian hospitals. If this is the case, guidelines have limited value. Therefore, the way

¹¹ <http://www.med.uio.no/helsam/tjenester/kunnskap/etikk-helsetjenesten/manualer/norge/>

that guidelines are created and made known is essential to increasing the value of doing this kind of work. Guidelines and the main conclusions can be published in appropriate journals or in news media.

Developing guidelines is time-consuming work that requires a significant contribution from both dedicated clinicians and a suitable working group. In addition, the implementation process, and later the evaluation of the guidelines, is important and work-intensive. It should always be clarified early on who will be responsible for this, since it will often require more resources than CEC has to give. Therefore, some CECs have chosen not to use their resources on guideline work.

If the committee is going to contribute to development of guidelines, it should be done systematically in order to have an effect.

1. Before starting, management and the relevant clinical environments need to agree that these guidelines are important. A good start is to hold an open seminar where the topic is highlighted from several sides. One example of this was developing guidelines for treatment limitation of seriously ill patients. In this case, the initiative came from different professional groups and from the government. The work started with a seminar where all significant parties were invited, and important problem areas were identified. What is recommended, or regular, clinical practice in this area? What is the status of relevant research? In addition, the influence and implications of ethical and legal sides of the matter, patient- and next of kin- perspectives, as well as religious and cultural factors must be illuminated in the guidelines.
2. What guidelines for this field exist already, nationally and internationally? What is the experience with these?
3. When a draft has been written, it should be passed around in relevant professional groups or on the wards, hoping for comments and ideas from those who will be using the finished guidelines. By doing this you are also creating a sense of ownership among the professionals by allowing them to contribute, and increasing interest in and recognition of the finished product. It is often a good idea to invite patient/user organizations to contribute to this process too, either

by being part of the committee/working group, or by reading through and commenting on the product.

4. By using input from the above groups, the final draft can be presented in a new seminar, through teaching on relevant wards, on the intranet, in procedural handbooks, on CMEs website, or by inviting new employees to a seminar.

Whether or not to present all or parts of the guidelines to patients/next of kin should be considered. In this way, we contribute to a common understanding of difficult challenges.

5. The guidelines should be evaluated after some time. Do the clinicians use them, or do they remain unknown? Do they need some adjustments? Are they meaningful to clinical work, or have they just created new problems?

3.0 Clinical ethics committees and problematic practice

As mentioned earlier, the medical community is sensitive to criticism from both the inside and outside. Uncertainty and criticism is hidden, and the critics themselves start to look suspicious. Because of this, we lose the chance for quality enhancement. In addition to having an authoritative medical community who mutes criticism, many people say that the new organization of health trusts requires stronger loyalty, especially regarding measures that are in place to save money. The law governing health care workers requires them to inform the regulating authorities if they witness circumstances that can be a danger to patient safety. Sometimes, a staff member may still be alarmed by routines at the hospital, or decisions that are not serious enough to contact the authorities over, yet they are still seen as a danger to patient welfare, or to the staff's ability to do their work in the best possible way. An example could be spending cuts that are seen as endangering patient welfare.

Discussing it in CEC could be an alternative in cases that are hard to bring up on the ward or with management. CEC can evaluate whether it is wise to “de-personify” the problem and discuss it more as a general or principle question. This can be done in the form of a seminar in order to contribute to dialogue and critical reflection about treatment of certain patient groups (examples include Jehovah’s witnesses, dying patients who need palliative sedation, or patients who require treatment that borders

on illegality.) Such a discussion can be a way to see whether this primarily is an ethical problem, and to find out where and how to address the problem so it can have a constructive solution. CEC can thereby contribute to focusing on problematic practice, and to changing it. CEC can also, more generally, contribute to discussions of how informing about problematic practice should take place, and how these practices should be handled. This is especially true in cases that have more ethical than legal dilemmas. CEC should not contact the control commissions in circumstances where health care workers are required to report such circumstances. In circumstances where laws have been broken, or serious malpractice has taken place, CEC should encourage the clinician him/herself to contact the involved parties – including management – and inform them of their individual requirement to inform the appropriate authorities.

One question that needs to be asked is whether management always needs to be informed that a question regarding their ward/hospital is going to be discussed by CEC. As a rule of thumb, management should be informed if a question regarding their area of responsibility is to be discussed in a forum outside the ward. In important and difficult cases it may be hard to follow up the suggestions/conclusions from the discussion, without involving management. On the other hand, an absolute requirement to inform management could lead to certain questions that really should be discussed, not being discussed. In our opinion, CEC needs to be allowed to function as an entity where these types of difficult questions can be brought in. These kinds of discussions can be important for both staff and patients/next of kin. A rigorous rule of always informing management of CEC-involvement, is likely to lead to the end of conversations about controversial value questions.

It is important that CEC is willing to bring up the controversial questions where existing attitudes and practice are questionable. Yet, it is important to find a balance between having the courage to talk about controversial cases and participate in critical questions, and being seen as a sort of “value police” or as a threat to clinicians or management. CEC should be a forum for ethical discussion, not a jury, and not a whistle-blower. Ethics work can still be used to identify practices that need to be changed, both on the level of the ward, and on management level. One example is legally dubious practice, or when finances are put before medical quality. By inviting CEC into regular managerial

meetings, or by giving CEC a role in the hospital's quality assurance work, the insight that comes with ethics work can be fully utilized.

4.0 Possible collaborators

In the beginning of this document we mentioned that it is important for CEC-work that we clarify whether the problem at hand is primarily an ethical problem, or if it is a problem better handled by others because it regards malpractice, a purely medical question, or a managerial issue. Some entities work in similar/bordering fields, and can be useful collaborators for CEC. Examples include ethics advisories in professional unions, patient organizations, chaplains, abortion advisory boards, or control commissions. Patient ombudsmen may uncover questions or cases that have important ethical implications that CEC should be involved in. Patient ombudsmen should be invited to seminars, both as participants and as lecturers. In the same way, members of ethics advisory boards in the unions may have experiences that are useful in these settings, or they can be encouraged to take a case, or to comment on the more principle matters of a case CEC has already discussed. This can be a fruitful way to elevate relevant questions out of the hospital setting.

Many municipalities have put significant efforts into ethics work in health care, and some have created ethics advisory boards or committees. These committees are natural collaborators. Some health trusts have, like many municipalities, started up reflection groups that discuss ethical dilemmas on the ward. These are usually led by an ethics advisor or facilitator, and some have had success using CEC-members as facilitators. Lately, many health trusts have hired lawyers to work with health law, and many committees have members with legal knowledge, or call upon one when needed. Several universities and colleges have employee researchers with ethics competence on the level of Master's degree or Phd, with a special interest in clinical ethics. Some health trusts in Norway have employed such a professional ethicist to contribute to CEC-work, and our impression is that this has been an important contribution to ethics work in the trust.