

Procedure for registering exceptional case histories

1) The medical practitioner, the patient or the relative contacts NAFKAM in writing concerning “best case” and “worst case” histories: We need the following information:

- Full name and date of birth
- Diagnoses and year of diagnoses
- CAM and conventional medicine treatment schedule
- The effect and side effects of the treatment
- Self-evaluation of what has had the most impact on the course of the disease
- The patient’s consent if the medical practitioner or family contacts NAFKAM

2) All communication with NAFKAM is strictly confidential. Selected medical histories will be closely examined. We will contact the patient or the relatives to get permission to collect additional information.

3) The medical practitioner or the patient will collect additional data and send it to NAFKAM. The documentation will include:

- The patient’s medical history
- All treatment given to the patient within the public health services and from CAM practitioner
- Results of pathology reports and medical imaging etc. (X-rays, CT, MRI, ultrasound)

4) NAFKAM will assess the need for additional pathology samples and necessary image material for a second opinion by a pathologist and radiologist who are affiliated with the project.

5) A selection of the medical histories will routinely be evaluated by independent research panel consisting of CAM- and conventional medicine experts.



Contact Information

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Tell us about
exceptional case histories

What is an exceptional case history?

A clinical course of serious disease that is very different from what was expected based upon medical examinations: The clinical course of the disease could either be exceptionally good, and presented as a “best case”, or it could be exceptionally unfortunate, and presented as a “worst case”.

A “best case” could be full- or long-term recovery of cancer or other serious disease with a poor prognosis after treatment with complementary and alternative medicine (CAM).

A “worst case” could be when the use of CAM gives serious side effects or contributes to delayed conventional medical treatment, with serious consequences for the course of the disease.

Why collect exceptional case histories?

Is it possible that factors relating to the patient, the treatment or the medical practitioner can explain why some courses of disease seem to take an exceptionally good or an exceptionally unfortunate turn? We will explore these possible explanations by collecting information from several sources, and by doing in-depth interviews with patients and medical practitioners. The information will be examined and evaluated by an independent panel of scientists. Our goal is to:

- Seek out therapies to be the focus for further research
- Help patients to choose treatment based on correct information

Who do we wish to get in contact with?

- Patients who have an exceptional case history
- The relatives of patients who have an exceptional case history
- CAM practitioners who have witnessed exceptional case histories in their practices
- Conventional medical doctors or others within the established health-care system who have met patients with exceptional case histories

What diseases are of interest?

- Cancer
- Disabling diseases such as asthma, arthritis, multiple sclerosis
- Other serious diseases

Are you a CAM practitioner?

Please contact us about exceptional case histories, both “best cases” and “worst cases”. NAFKAM will evaluate the case histories with the help of independent CAM- and conventional medicine experts. The aim is to shape future research projects.

Who is evaluating the case histories?

The case histories will be evaluated by a panel consisting of researchers from NAFKAM, CAM experts and conventional medicine experts. The panel is bound to professional secrecy and will not report any possible violation of the law.

Ethics

- All contact with NAFKAM is confidential.
- All personal information will be kept secure.
- The research panel will also evaluate material that does not identify individuals.
- The project is approved by the Norwegian Data Inspectorate and recommended by the Regional Committee for Medical Research Ethics, Northern Norway.

Feedback

Individuals will get access to the research panel’s evaluation of their case history upon request.

Will NAFKAM provide information?

NAFKAM will provide an annual report that will be available to the public on our web-page. The annual report can also be ordered from NAFKAM.

“It is important for patients, relatives and health authorities to have a body that takes care of the knowledge on case histories that do not develop “by the book”. Exceptional case histories are taken seriously, and the gathered knowledge can make a basis for hypotheses on disease progression and treatment options that can be explored.”

Significance

- Similarities between “best cases” can provide the foundation for new research projects
- Misunderstandings or misdiagnosis in possible “best cases” can be clarified and thus prevent treatment based on incorrect information
- “Worst cases” can help reveal treatment modalities
- NAFKAM can not estimate the occurrence of exceptional disease progression (incidence)

Who are we?

The National Research Center on Complementary and Alternative Medicine’s (NAFKAM) job is aimed to coordinate and implement research on complementary and alternative medicine (CAM) in Norway.

NAFKAM is established on the initiative of The Norwegian Research Council. One of our research projects is to collect “best cases” and “worst cases” following CAM treatment. The project is supported by the Norwegian Cancer Society.