

# ANNUAL REPORT

# 2017

Health and Social Services Ombudsmen



## Preface

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This has been a busy year for the Health and Social Services Ombudsmen. We have seen a steady rise in cases in recent years, and this continued in 2017, when we had 15,200 enquiries. It is however important to point out that the Ombudsmen's annual report is not a report on the state of the health and social services. Most patients have a good experience and have no need to contact the Ombudsmen. Our experience is most important for identifying weaknesses are areas with potential for improvement. We shall be known and accessible all over the country. We shall help to increase quality and patient safety in the health services and work in an unbureaucratic and effective manner.

There is a risk in all patient groups that failure and unfairness may not be discovered or rectified. Those who are most vulnerable when failure occurs are often those who are most alone, those without a network or support around them. As they say, "you need to be healthy to be ill." When you are weakened by illness it can be difficult to find out about patient rights and insist they these are fulfilled. Families are a great resource in the health services, but we also encounter tired and dispirited family members during our working day. Over 4,000 of those who contacted us in 2017 were relatives of adult patients and users. About 800 were the relatives of children.

The Ombudsmen focus especially on helping those who need it most. We meet patients and users in all age groups and in all types of health and care services. It makes an impression when a single father of a small child has had his relief support removed for no good reason. It makes an impression when an elderly woman is terrified of what will happen to her if the health service employees should find out that she has contacted the health ombudsmen. There is a risk that those who are not familiar with the ever more complex rules do not receive the services that they need. Knowledge of the rules and competence in patient rights among health staff is also varied and often not good enough. This annual report will therefore focus particularly on showing how important it is for patients, users and service providers to increase their knowledge of patient rights. It is also important that the general public is aware of the Health and Social Services Ombudsmen service, so that they can make use of our expertise. We can be the support player that is needed.

Lisa Refsnes

Head of the Health and Social Services Ombudsmen's working committee and Ombudsman in the county of Sogn og Fjordane

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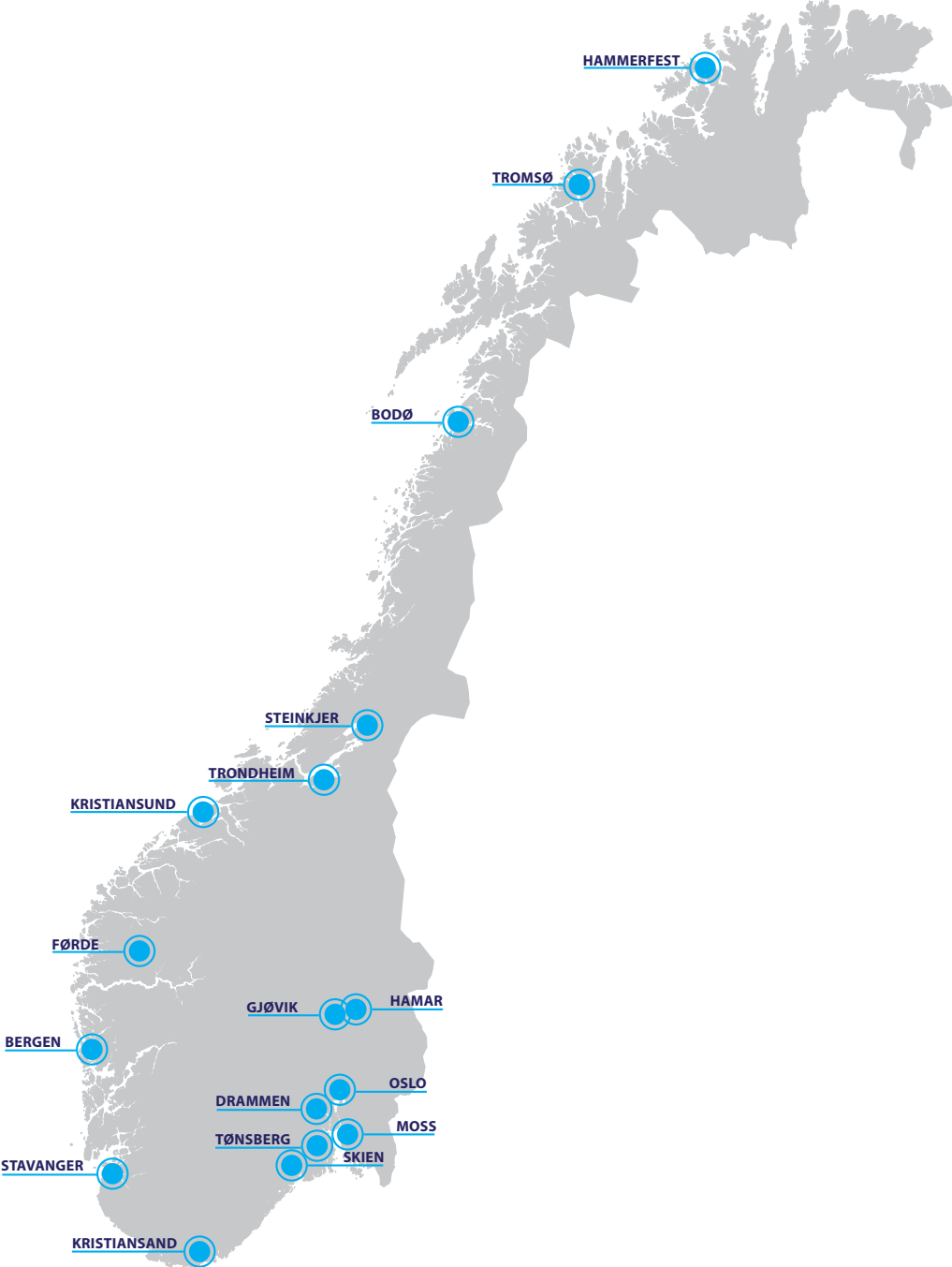
## The Ombudsmen recommend

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- All local authorities should offer preventive home visits to those aged over 80 who do not already receive health and care services.
- Employees in the health and care services should be given a competence lift in patient and user rights.
- Patients should be offered copies of referrals, discharge notes and test results.
- Measures should be taken to improve competence in the use of interpreters, so that the health service's responsibility for arranging interpreters if needed can be complied with.
- Young people aged between 16 and 18 should not have to pay when visiting a doctor.
- It should be natural for every stay in hospital to conclude with a briefing interview.

# Introduction to the Ombudsmen's activities

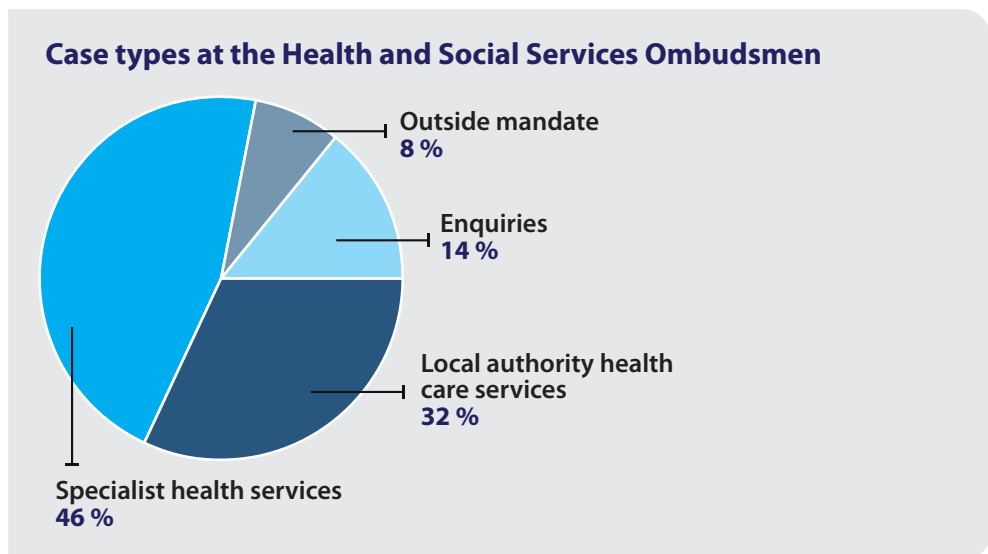
We are all over the country:



Section 8-1 of the Act on Patient and User Rights states that the Ombudsman's work is twofold. The Ombudsman shall:

- work on individual cases
- contribute to quality improvements in the health and care services

Around 15,200 people contacted the Health and Social Services Ombudsmen in 2017, and this concerned a total of 18,100 different issues associated with the health and care services. This is an increase in cases compared with the previous year. An individual often has several issues he or she requires advice, assistance, information or guidance about. Issues fall into the following categories



Questions in this diagram are enquiries that are not linked to a concrete place of care. For example, a general question on what rules apply for being able to read patients' medical records. Cases in the categories specialist health service and municipal health and care services are cases where the patient or user is not satisfied with how things were handled at a particular place of care. For example, a patient has not been allowed to read his or her general practitioner's records.

## Individual cases

Ombudsmen are important recipients and communicators of patient and user experiences. The Ombudsmen's work is characterised by close and direct contact with patients, users, relatives and service locations.

Anyone can refer themselves to the Ombudsman. Those who contact the Ombudsman are patients, users, relatives or staff in the health and care services. It is possible to make contact anonymously, and the service is free. Ombudsmen shall be an accessible low-threshold service for anyone who has questions, feedback or complaints in connection with the health and care services.

Ombudsmen attach importance to face-to-face meetings. The assistance is often based on listening, asking questions, providing information about options, helping to structure thoughts and ideas and offering advice.

If there are grounds for escalating a case, this will take place in cooperation with the patient. One or more of the following options will often be available:

- raise the case directly with the service location, provide feedback or ask for a dialogue meeting
- submit a complaint to the county governor
- seek compensation from the Norwegian System of Patient Injury Compensation

Some people wish to contact the service location and describe their experiences, submit a complaint or provide feedback. In a number of cases the Ombudsmen assist in establishing contact with service providers, and the Ombudsmen can also participate in meetings. The objective is to provide the patient or user with an opportunity to communicate their experience, be given a chance to ask questions, perhaps receive an apology, feel they have been understood and that their trust has been reinstated. The role of the Ombudsmen will then be to pave the way for a positive dialogue.

Such meetings can be of great significance to patients, users and relatives and can provide both parties with greater understanding and learning. A successful meeting can also result in cases ending up on the "right track", avoiding the need for the case to be escalated to other arenas, but to rather be resolved through the meeting. In order to achieve such solutions, it is crucial that the Ombudsmen have the mobility to meet people where they live and where services are provided. With an increased transfer of services from the specialist

health service to local governments, this becomes even more important. Present-day resources set restrictions in the scope of this work.

## **The work to achieve quality improvements across the services**

The Ombudsmen are in daily contact with staff at service locations in order to resolve cases. The patient and user experiences that these cases represent provide a good basis for offering input to service locations on how the services can be improved. We provide vital feedback within the relevant service areas and are used as consultants with an “outside” view.

The Ombudsmen attend the respective health authority’s user council and Patient Safety and Quality Committee. The Ombudsmen meet local council officials and politicians. The Ombudsmen conduct annual meetings with the health authorities, county medical officers, the Norwegian Board of Health Supervision, the Norwegian System of Compensation to Patients and other authorities that contribute to useful and important knowledge exchange.

Members of parliament also receive information about the Ombudsmen’s experiences through Ombudsman participation in parliamentary consultations and direct contact with the various counties’ MPs. The experiences of the Health and Social Services Ombudsmen are used in the annual Report to Parliament on quality and patient safety in the health and care services. The Health and Social Services Ombudsmen also contribute with consultation submissions within our field of activity.

## **External information about rights and the Ombudsman scheme**

The Ombudsmen work actively to enhance knowledge about patient and user rights and the Ombudsman scheme. We hold lectures for user organisations, staff at hospitals and in local government services, students, pupils, immigrants attending introductory courses, municipal councils, senior citizens’ associations, political and administrative committees. In external activities we gain much knowledge on how the services are perceived. The Ombudsmen are also used as lecturers at national and regional courses and conferences.

During Arendal Week, the Ombudsmen organised a breakfast meeting on the subject “Patient rights: do they give equal rights to everyone?” We also had stands and participated at a number of other events.



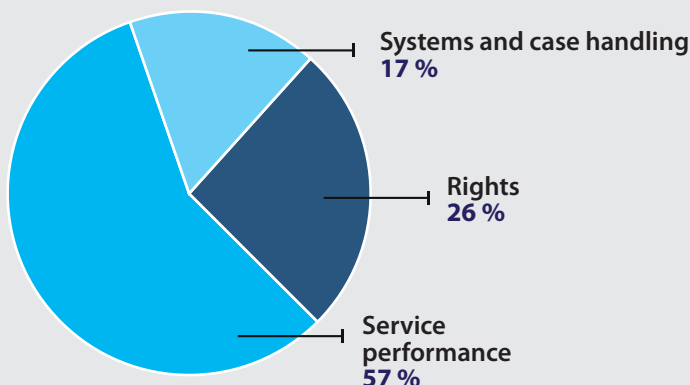
## Reasons why the Ombudsmen were contacted about a service location in 2017

Over half of the enquiries in connection with a service location were about dissatisfaction with the actual performance of the service. Patients or users found that the services were not satisfactory or caring, or questions were asked about whether the services were in line with good practice. For example, in this category there are cases about incorrect treatment, injuries caused, lack of referral, language problems or insufficiently caring help.

26 per cent of the enquiries were connected with rights. Usually, this was a suspicion that patient and user rights had been breached. For example, in this category there are rejections of requests for services, deadlines not kept, access to medical records or that the right of patients and carers to participate and receive information is not upheld.

We identified 17 per cent of the enquiries as a failure in systems that have been created to safeguard patient safety and the flow of patient treatment. These queries were about the organisation and routines of service locations. For example, lack of accessibility, interaction between agencies, case processing time or other muddle and time wasting in case handling.

### What patients and users are dissatisfied about in their encounters with the health and care services



## **Information**

In very many cases, and in all three categories, the Ombudsmen found elements of insufficient or poor information. Proper and appropriate communication between health personnel and those who receive services, including their relatives, is crucial to patient safety.

## About complaining, knowledge and competence

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Both users and patients have the common goal of good health and care services. Feedback from users is essential in this kind of focus on quality. From this point of view, speaking out about failure or unfairness is part of our collective responsibility to each other. Even so, many people are afraid to speak out. Many are afraid of reprisals or of being marked out as “difficult”. However our impression is that the services accept negative feedback better than the users might fear. The Ombudsmen seldom receive enquiries from patients or users who feel they have received a poorer service or have been received impolitely because they have complained. This way of reacting to a complaint would obviously be untenable.

Thus it is not the conduct of service providers involved in a complaint that concerns the Ombudsmen, but rather the case processing itself. Here we often see a lack of knowledge. Both staff and managers have too little competence in rules and rights. Health bureaucracy is used as a term of abuse. The consequence is that important legal guarantees of rights are misunderstood or swept aside as purposeless pen pushers’ law. Changes are made without clarifying the case or seeking the user’s views. Decisions are taken without endorsement or grounds. No information is given about the right to complain. Not enough is known about the content of the statutory patient rights. We see examples where other patients’ situations are used as grounds for rejecting services. “We only have one bag of money. If you get more home nursing it will be at the expense of all the others who need home nursing.” It is of little help to decide on new patient rights if the services have no knowledge of the rights or how to handle them.

The Ombudsmen repeat what has been said in earlier annual reports: employees in the health and care services need a competence lift in patient and user rights. In this annual report therefore, we will focus especially on pointing out lack of understanding of the rules, poor case processing and what consequences this has for patients and users. We will use experience of cases received in 2017 by ombudsmen all over the country to illustrate the situation and the need to increase competence.

The user had a permanent support contact. She was contacted by the local authority with the information that the scope of the service would be reduced. The message was given verbally, without warning and no reason was given. The user had no opportunity to safeguard her interests through the rights of participation or complaint. The Ombudsman took the case up with the local authority assignment office and ensured that a written decision with grounds was presented. Based on the information in the complaint, the assignment office saw the need to review the user's total situation, which is in line with what the user wished. The Ombudsman has taken up the obligation to give prior warning and ensure participation with the office in a separate dialogue meeting.

# Selected topics

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Below we have selected a number of topics that we believe should be singled out for attention.



# The Regular General Practitioner Scheme must be modernised

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The Health and Social Services Ombudsmen have sought an evaluation of the GP scheme for a number of years. Not because it is bad, but because changes in the tasks are a challenge. The Ombudsmen therefore consider that the Storting's decision to evaluate the GP scheme in autumn 2017 was both correct and necessary.

More and more tasks are being imposed on GPs as a result of political decisions and movement of task responsibilities, such as follow up and control after treatment in the specialist health services.

Other changes mean that GPs must spend more time on follow up of individual patients. The Coordination Reform has meant that people who are far more ill than previously are being discharged from hospital to the local authorities. The political objective that as many people as possible shall live in their own homes has increased the need for follow up by the GP, partly because they wish to have patients who do not come to the surgery but who need home visits.

The GP's participation is sought in municipal cooperation. This must be reinforced, so as to give a more uniform and holistic health care to patients with complex needs.

To an ever greater extent, patients are dependent on information about their rights, about quality indicators and about the right to decide the place of treatment for themselves, so as to be able to properly manoeuvre in the Patients' Health Service. We believe the GP scheme must safeguard this to a greater extent than today, but that this does not necessarily need to be done by the GP in person. This should be included in the primary health team pilots. Increasing rights, obligations and user participation will also take more time.

The general practitioner is the hub of the Norwegian health service and could also be thought of as a kind of door opener or gate guard. Most Norwegians have a regular GP. Considering the total number of consultations that occur between GPs and patients every single day, the number of dissatisfied people who contact the Health and Social Services Ombudsmen is very small. In recent years there have been around 2,000 a year. Although the figures themselves tell us little, we find that both GPs and most people will recognise the stories.

Many of the enquiries are about lack of accessibility. It can be difficult to get through on the telephone and few people know that 80% of all calls should normally be answered within two minutes. It can also be difficult to get an appointment within the desired time. This happens in cases when appointment is needed the same day, but also when an appointment is desired “within a reasonable time”. We see examples of regular GPs who find it necessary to remind people on their website that it takes 2 - 3 weeks to get an appointment with them and health secretaries who say that the usual rule is that getting an appointment within five days is “impossible”.

Local authorities should be in dialogue with GPs about their accessibility. Are the waiting times due to lists that are too long or poor organisation? At present it seems as if the General Practitioner Regulations - the Storting’s expectations for the Regular General Practitioner Scheme - have a life of their own and lack of compliance has no consequences whatsoever.

Knowledge about patient rights among health personnel is a prerequisite for patients being able to receive their rights. In some cases, we can see that it does not work like this. It should be self-evident that the patient receives a copy of his or her medical records on request:

A man contacted the Health and Social Services Ombudsmen because the doctor’s surgery would not give him a copy of his summary care record. He had asked both verbally and in writing. The reply he received from the secretary at the surgery was that she did not have time to copy the record and give it to him. The ombudsman wrote to the surgery on the man’s behalf. The man then received a copy of his record immediately.

The same applies to the right to a second opinion:

The patient contacted the regular GP to request a second opinion from another GP. The patient was told at the surgery that no such scheme existed. The ombudsman took the case up with the surgery, which has now changed its practice in line with legislation.

Another problem arose in connection with entering information into the medical records:

The patient contacted her GP and asked to have a note put on her summary care record that she was allergic to penicillin. The GP replied that she could not do this. The ombudsman contacted the surgery to find out whether it had started to use the summary care record. After internal discussion at the surgery, the ombudsman was informed that the summary care record was now in use and the patient had the information included at the next consultation.

In many cases it is the GP who knows the patient's health best, apart from the patient him or herself. It appears to be natural that the GP should assist by reviewing or correcting the summary care record if the patient so requests.

Some GP's surgeries do not have universal design so that patients with mobility difficulties can get into the building. Others have premises that were not designed with protection of privacy in mind:

The patient found visiting the GP's surgery very uncomfortable. There were no screens between the health secretary/switchboard and the waiting area. All information that was exchanged with the staff at the counter was overheard by those waiting for a consultation. Several patients had taken this up with the doctors at the surgery, without finding any agreement that this was unacceptable. The ombudsman wrote to the surgery and informed them of the obligation to prevent outsiders gaining access to confidential information. The surgery then immediately contacted the owner of the building and an enclosure was built in front of the counter so that patient information could be exchanged without other patients hearing.

If local authorities enter into agreements with regular GPs who do not have the necessary facilities, the local authority must follow up to ensure that this is rectified.

When we meet GPs in the municipalities, we find that they are seeking closer follow up from the local authorities. The ombudsmen are also seeking greater



commitment and follow up from the local authorities. Routines for follow up of quality in day-to-day operation and for following up complaints and feedback from supervisory authorities must be established.

Patients are seeking responses with all test results and not what happens today: “you’ll get an answer if something is wrong”. A number of serious complaints actually refer to poor follow up of test results:

A patient visited the hospital for an examination after the GP had found abnormal blood results. The discharge notes from the hospital to the GP stated that the patient must have regular follow up with further blood tests. The patient was not informed of this and the GP did not follow up. After several months, the patient contacted the doctor’s surgery with increasing symptoms. New blood tests were taken, which showed major abnormalities. The GP did not refer the patient, but set up a further check-up several weeks later. After this the patient had an acute admission to hospital, where it was found that he had cancer. The patient’s wife contacted the ombudsman to complain about a lack of information and follow up. The ombudsman found that the patient had not received proper treatment and the case was referred to the county governor.

### *Copies of all test results should be offered to patients.*

Local authorities must have a clearer focus on agreements that are entered into and following up on these, there must be active prevention of situations with a relay of substitute and temporary doctors and there must be assurance that the GP speaks Norwegian well enough to give the proper medical care.

With an increasingly multicultural population, there is an increasing need for cultural understanding and the use of interpreters:

A patient contacted the ombudsman and explained that she found it difficult to convey her needs to her GP, so that she had little benefit from her appointments. The patient had asked for an interpreter during consultations with the doctor, but this did not happen. When approached by the ombudsman, the doctor replied as follows: “I see no reason to get an interpreter in, since this would provide no additional information - for me.”

The ombudsman contacted the local authority's chief medical officer, who ensured that the doctor about whom the complaint had been made was made to understand a GP's obligations in this respect, and an interpreter was organised.

Using an interpreter is an obligation in cases where this is necessary in order for the patient to understand the information that is given. Cultural understanding applies to both understanding illnesses and informing of symptoms, but also understanding of our health service. This means that the consultation takes longer. *The health service's obligation and responsibility for ordering an interpreter when needed must be complied with.*

Referrals to specialist health services must give sufficient information, so as to give the recipient the opportunity of quickly clarifying the patient's need for specialist health services. Poor referrals were recently discussed in the Office of the Auditor General's Document 3:4 (2017-2018): "The Office of the Auditor General's investigation of the work of the authorities in ensuring good referral practice from regular GPs to the specialist health services":

*"General practitioners and hospital doctors do not collaborate well enough over referrals, which often lack essential information. The investigation shows that in many cases general practitioners and hospital doctors have a different understanding of what essential information in a referral means. Half the hospital doctors in the selection regularly find that the referral does not properly clarify why the patient needs specialist treatment and 9 out of 10 hospitals find that the quality of referrals varies greatly."*

The Ombudsmen believe that one of several measures to improve this situation would be to *give patients a copy of the referral.* This would make it easier to clarify any misunderstandings and could ensure better quality.

GPs who have or receive information that people on their lists have a need for medical care, but do not seek help themselves, shall offer consultation or a home visit. According to the General Practitioner Regulations, this only applies in cases where the patient has a known disorder and based on a medical assessment has an obvious need for treatment or follow up. What about the situation where a neighbour or similar voices concern about a person who does not have a known disorder. Who has responsibility then? Who is responsible?

In last year's annual report, the Health and Social Services Ombudsmen called for a change in the own-contribution rules for young people aged between 16 and 18, so as to ensure that the legal status in health issues actually places the age of majority at 16. We repeat this. *Young people aged between 16 and 18 should not have to pay when visiting a doctor.*

## “Away is good - but home is best”

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It is an express political aim that people shall live in their own homes, including those with a great and complex need for services. The Ombudsmen encounter patients and users with varying problems and experiences in relation to the quality of services given in the home. Below we wish to draw attention to a lack of individual adaptation of services, safeguarding the interests of families and the situation for the elderly.

### **Yes, this is about life**

In October 2017, the Norwegian Board of Health Supervision published the report “This is about life”, which was about inspection of local authority health and care services for people with developmental disabilities. The report revealed extensive and sometimes serious failures. In many places the services were inadequate and not adapted to the individual. The report pointed out a lack of user participation and information. The Ombudsmen share the Norwegian Board of Health Supervision’s findings in this.

In such cases it is almost always the families that contact the ombudsman. Families report non-existent or non-functioning coordinators, the lack of plans for measures, the frequent use of temporary or non-professionally trained personnel and little information or participation. In many cases the services take the form of collective service for a whole user group with no opportunity for individual adaptation. In such cases, the Ombudsmen are happy to meet with users/families together with service managers so as to ensure better information, coordination and individually adapted services.

We encounter users and families who have had to fight to ensure day-to-day things that most of us take for granted:

One local authority had an offer of joint activities for users in a residential community. One of the users did not wish to participate in such joint activities, but enjoyed going for a walk to the local pub for a glass of wine now and again. But this was not done because of the service’s lack of capacity. The ombudsman met with the family and the service to ensure that individual assistance with leisure activities was organised.

## Respite

Hospital stays are becoming shorter, patients are discharged to go home more quickly. The input of families is often vital to this social development. Measures to provide respite are offered to persons and families with a particularly heavy burden of care. Measures to provide respite shall prevent excessive load and give carers essential free time and holidays and the opportunity to take part in normal social activities. It is important that relatives' need for respite is met, including from a preventive perspective. The input of relatives is a great resource.

Few complain about decisions on respite measures, but the ones who do often win through. Figures from the Norwegian Board of Health Supervision's annual reports for the years 2014, 2015 and 2016 show that almost half of all cases where families complained to the county governors about respite provision were fully or partially upheld. Over the three-year period the county governors handled an average of 207 complaints about respite provision per year. It is a matter for concern that in almost half the complaints the decisions of the local authorities have been found wanting. The Ombudsmen have also found a lack of knowledge and understanding of the rules in this area among local authorities. In 2017, the Ombudsmen received 128 enquiries about the provision of respite care. In these, questions about rights represented a significantly greater proportion than among cases in general. 65% of the enquiries about respite referred to questions of rights, usually about these rights not being met.

**En aleneforsørger for et lite barn opplevde plutselig at kommunen reduserte, A sole carer of a small child suddenly found that the local authority reduced, moved and changed a respite measure that had been working well. The child needed safe, stable surroundings and the great changes could have had negative consequences for the child's development. The mother was only advised verbally and had no opportunity to express an opinion about the changes in advance. The local authority gave no reason why the arrangement was being changed other than that they believed that the new arrangement was reasonable. The ombudsman assisted the mother when meeting the local authority. The local authority stood its ground, but admitted that a written decision on the change and reduction must be issued. The ombudsman assisted by complaining about the decision. The local authority executive then contacted the ombudsman maintaining that**

there was no right of complaint with such decisions. The local authority later maintained that it had received a verbal go-ahead from the county governor before making the change. It was found that the case officer at the county governor's office could not recall this description of events. The case was finally decided when the county governor cancelled the local authority's decision as invalid and determined that the original respite arrangement should apply. The little family had by that time been without a respite arrangement for several months while awaiting the outcome of the case.

This case revealed a lack of knowledge of absolutely basic legal rules among the local authority's executive and key persons. The question is, how many others have received the same response from this local authority that they have no right to complain.

In many cases we see that the local authority cannot distinguish between the relatives' need for respite and the patient or user's need for care. Decisions are taken where respite is linked to the patient or user instead of the carers. Some relatives perceive it as an imposition when a patient or user is sent a decision when it is the relative's need for respite that is being discussed. There are also examples where the need for respite is assessed exclusively on the patient's level of disability, without reviewing the extent of care given by the person who is seeking respite. Many people seek better continuity and routines for giving respite, so that leisure time can be planned. A number of cases refer to cancellation of respite due to illness among employees and a lack of planning of staffing levels.

The parents had been granted regular respite for their mentally handicapped child. The family had a heavy burden of care for the child, in addition to care responsibility for other small children. The respite was vital if the family as a whole was to function. Several times during the year, the local authority advised that respite would have to be cancelled because of illness or holiday leave among their staff. The family twice had to cancelled planned foreign holidays because the local authority cancelled the respite. The ombudsman attended meetings between the local authority and the parents and proposed a contingency plan for illness or holiday leave among the staff.

## Care for our elderly - secure for life?

The local authorities are responsible for providing services of good quality and caring assistance to the individual. Much of this works well and we know that there is increasing work on quality improvements and a greater focus on patient safety in the local authorities. But we also hear about services in the home that do not come at the agreed time, visits that are too short, frequently changing helpers, a lack of expertise, a lack of clinical registration and errors in medication. Such experiences create insecurity and anxiety among both users and relatives. Media coverage tends to be about unfortunate events. This challenges the confidence in the system that we all depend on having.

Services are given to the individual depending on individual need. A nursing home place is only for those who cannot be given satisfactory health care and assistance in the home. As a general rule, the question of a nursing home place only arises if the individual needs such comprehensive assistance. The ombudsmen have found that practise varies when it comes to offering or granting a place in a nursing home. One local authority for example may offer a nursing home place because the person concerned needs more than three home visits per day, while other local authorities are willing to go much further with home visits because they find this to be more appropriate than offering a place in a nursing home. Local variations and geography seem to play a role here.

With regard to services for the elderly, it is often a relative who contacts the Ombudsmen. We hear about patients who are discharged from hospital and sent straight home, even though hospital staff have clearly expressed a need for a convalescence place. Relatives ask themselves why the local authority does not follow the professional advice of the hospital doctor as to what the patient needs after discharge. Many relatives cannot understand why what is being offered by the local authority is less than what the hospital doctor thinks is correct for the patient, based on professional assessment. The system is that the hospital has no authority to instruct a local authority on what a patient should be offered. However the hospital's assessment creates clear expectations on the part of the patient, and many have difficulty in understanding why there is no obligation on the local authority.

Relatives also tell of convalescence stays that have been granted, but where what is offered during convalescence seems to be very sparing. Many seek to have more activity and describe a convalescent stay as "storage". There is often a conspicuous need for clarification of expectations.

The Ombudsmen are contacted by despairing relatives who cannot get nursing home places for those close to them. In many municipalities, nursing home places are still a scarce commodity. We hear about varying quality from both those in nursing homes and their relatives, and there can be variations from one ward to another. There may be a lack of medical supervision or insufficient help with basic needs such as eating and using the toilet. Important measures such as individual adaptation of services and convalescence fail to occur. We hear about injuries from falls, bedsores, undiscovered fractures and incorrect medication, as well as cases of malnutrition and dehydration. Deficiencies in the quality and expertise in the health care that is given lead to unnecessary hospital admissions and re-admissions, as well as causing stress and insecurity to patients. This concerns the Ombudsmen.

We hear stories of elderly people who are in and out of hospital: swing door patients. Are they discharged from hospital too soon? Do local authorities have good enough services for them?

We also hear stories of frail elderly people who are moved many times during the course of their illness: from home, via GP's surgery, to hospital or A&E and home again. New places, new beds - and moved around in their frail condition. Many people react to the number of movements.

Sometimes it can be difficult to understand the difference in care between place in a nursing home and staffed sheltered housing. What services the elderly should apply for presupposes knowledge of the different services and what is considered best for the individual. The nursing home and sheltered housing are covered by different legislation. Residents of sheltered housing pay rent for the accommodation and must apply for health care services. If medical help is needed it is the regular GP who is to be used. Patients in nursing homes pay for their accommodation. What is paid depends on whether it is a short-term or long-term stay. For nursing home patients, it is the nursing home doctor who is responsible for medical supervision and follow up. Nursing home patients are also entitled to other health services depending on need. This is to be handled by the nursing home and does not depend on the patient specifically applying for these services - as patients in sheltered housing must. These differences are not always clearly shown and can be difficult to understand. Sometimes the two can even be located in the same place and the description of what is offered can cause confusion.



The local authorities consistently provide many services to the elderly. An increasing number offer preventive home visits. The ombudsmen are in agreement that this is a key instrument in the local authorities' preventive work. Discussions during such visits can provide information about opportunities, create security, offer prevention and ensure that rights are safeguarded. *The Ombudsmen believe that preventive home visits should be offered to those aged over 80 who do not already receive health and care services.*

To summarise, the Ombudsmen emphasise the importance of creating services of good quality that create the necessary security and confidence among the elderly and their families.

# Those who are dependent on drugs or alcohol must be secured a better sequence of treatment

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Those who are dependent on drugs or alcohol often need different forms of help at different times. This depends on such measures being coordinated. Interruptions to the sequence of treatment can be vulnerable times of transition, causing many to fall back to the beginning. Such situations may for example arise from the time the patient requests treatment until detoxification begins or in the period from the end of detoxification until treatment begins. Other transitions are a delay after the end of treatment until accommodation is in place, or until school, work or other activities are in place. This must be planned, and work on it should preferably start before treatment begins. The more active use of individual plans could help to improve the sequence of treatment. The Health and Social Services Ombudsmen find that many who are dependent on drugs or alcohol still do not have an individual plan.

Once a patient has an individual plan care must be taken to ensure that the plan is not presented as a goal in itself, but as a necessary tool for coordinating different measures and tasks, something that has also been pointed out by RIO, an NGO that represents the interests of substance abusers.

During the course of 2018, packaged sequences are being introduced for interdisciplinary specialist treatment. The effects should be carefully monitored and evaluated on an ongoing basis. The packaged sequences shall be based on national and international professional guidelines for investigation and treatment, wherever these exist. The aim is to constantly improve the treatment offered and reduce undesirable variations, so that everyone receives treatment that is as good and effective as possible. They shall not reduce individual adaptation. There are few ready answers to what treatment actually obtains the desired result, which poses a greater problem for standardised sequences than in many other areas.

As well as seamless sequences, there is a need for more participation in the choice of medication and various conditions relating to collection arrangements and the use of urine samples. We continue to receive complaints from patients who have medication assisted rehabilitation and who tell us about a lack of user participation in the choice of medications. They tell us that their experiences are

not listened to and that the national guidelines are followed too slavishly, especially in choosing substitution medication. It must be a prerequisite in this part of the health service too that patients have an individual assessment of their condition.

A patient was discharged from an institution for detoxification and examination because he took drugs after gaining access to a medicine cupboard. He immediately appealed and gave a written request to have this reversed. This was rejected and the decision was upheld. The patient was then told that he could appeal this to the county governor himself. He then contacted the ombudsman, who had the story confirmed when contacting the institution. On behalf of the patient, the ombudsman sent a complaint to the county governor, as well as a request to assess the institution's routines for processing cases and appeals. The county governor concluded that the discharge meant that the patient's right to essential medical care had not been fulfilled. The county governor also pointed out that the institution had defective procedures for processing complaints and asked the health authority to change its procedures in relation to the relevant legislation.

Patients and the ombudsmen are seeking better grounded decisions that enable a better understanding of the decisions and if appropriate give a better basis for an appeal.

## Prioritising children and young people - less talk and more action

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There is an ever greater focus on prevention, not least in respect of children and young people. This is positive. The Health and Social Services Ombudsmen still find however that health services for children and young people do not sufficiently meet real needs.

The municipality shall offer health promotion and preventive services, including health services in schools and health centres.

One condition for reaching not only parents but also children and young people is that they are familiar with the services and that they perceive these as being easily accessible. At present there are great differences in children and young people's access to health centres and school health services, cf. Report IS-2543 Review of FTEs in the health centres and school health services.

A mother of twins aged almost 3 years contacted the Health and Social Services Ombudsmen and explained that they had not been called in for a 2-year check-up. She had contacted the health centre several times and was told that there was no doctor available and the 2-year check-up was therefore on hold. Health centres in other parts of the municipality were able to accommodate 2-year-olds. After the ombudsman made contact, the twins had a check-up the following month. The district medical officer explained that the waiting list for 2-year check-ups was due to problems in recruiting a new doctor, but that an extra doctor had now been appointed and resources were increased for a time so that they could get up to date with the 2-year-olds.

The Directorate of Health wishes to have a guideline staffing standard for public health nurses in health centres and school health services, but does not wish this to be legally binding, which is explained in the report: Investigation of binding staffing standards in health centres and school health services. A corresponding standard was sought in 2010, without achieving the desired effect. It is uncertain whether earmarked funding or other solutions are the answer.

There is also concern about what is offered to children and young people with mental disorders. Parents, young people and employees of the services are seeking an increase in capacity at out-patient clinics and in-patient wards, as well as greater collaboration between local authorities and specialist health services, so as to make better use of each other's expertise and resources.

A young girl with a serious eating disorder found that she was being sent from pillar to post around the health service. According to those providing treatment in the child and adolescent psychiatric unit, she should have been offered in-patient treatment, but this was not available due to lack of capacity. The parents were advised that discrepancies over lack of capacity were reported on a number of occasions, without the situation changing. The parents received no information about opportunities for complaint. Only when they approached the Health and Social Services Ombudsmen were the parents informed of their right to complain and they received assistance with this. The case is now being processed by the supervisory authority.

As elsewhere in the health service, there is a need for better knowledge and observance of patient and user rights among managers and staff. More people should SPEAK OUT when the help that is offered does not correspond to the need. We find that employees of the health service do not do enough to inform patients and relatives about how they can complain.

## **Young people's councils in hospitals**

Article 12 of the Convention on the Rights of the Child says that young people have a right to express their opinion and be heard.

In the National Health and Hospitals Plan for the period 2016-2019, the government asked that, as part of the work of creating the patients' health service, young people's councils should be established in all health authorities. The young people's council at Akershus University Hospital has been praised from many quarters, including the Ombudsman for Children, for its important input as a driving force to accomplish this. Not all health authorities have yet succeeded in establishing such a council. They are missing out on a great deal of knowledge of how services for children and young people in hospitals can be im-

proved. This applies for example in the transition from young patient to adult patient, as well as in being a child or young person who is a member of the patient's family.

Through enquiries to the Ombudsmen and from contact with young people's councils at hospitals, we have been made aware that the transition from children's ward to adult ward can cause patients some real problems. Interaction can be tested during the transition, which affects patients. They experience lack of information and poor flow in the sequence of treatment and explain that this causes insecurity.

The assignment documents to the regional health authorities for 2018 made clear that they must now ensure that the health authorities have good routines for the transition from child- to adult-oriented health services. The routines shall be based on the best available knowledge. According to the documents, the routines shall cover the internal transfer within the hospital and also that between hospital and primary health service. It is the Health and Social Services Ombudsmen's assumption that the young people's councils should become a vital partner in this important work and that hospitals that do not have such councils should establish them.

## Patients' progress – Challenges

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Patients wish to have safe, predictable courses of treatment of good quality. The treatment sequence normally starts with contact with the regular GP, followed by possible referral to a specialist health service or in acute cases hospital admission. Many people tell of meeting skilled and committed health professionals, but many also experience a sequence of events that cannot be described as seamless.

We know that there is continuous work on improvements in both quality and efficiency. Even so, the Ombudsmen would like to highlight a few points that challenge a good sequence of treatment for patients, such as:

- Poor referrals and varying assessments of them
- Lack of internal referral in the examination phase, so that the patient may have to go back to the GP for a new referral
- No planning of the next treatment measure, such as a concrete operation date or the next check-up
- Lack of cooperation, both internally and between places of treatment
- Lack of information to the patient and relatives, both during the course of treatment and at discharge
- Lack of interaction between service levels, especially at discharge
- Early discharge and the risk of re-admission: the swing door problem
- Systems/ICT solutions that do not support the tasks and different systems that do not talk to each other

### Free choice of treatment

When patients need medical care in the specialist health services, patients normally have a right to freely choose where a referral is to be sent for assessment and which place of treatment is to be used. This is essentially good. However the experience of the Ombudsmen indicate extremely varying knowledge of this right, among both patients and health personnel. We also note a varying

willingness to inform about other places of treatment when capacity is limited and the patient might be better served by being transferred to another place of treatment. If the services themselves do not inform patients about and assist with their right of free choice of treatment, this right will only benefit those who know about it and have the resources to use it. Does this correspond to the objective stated in the Act on Patient and User Rights that the population shall have equal access to good quality services?

The patient had been assessed and examined at the local hospital with an unclarified condition relating to skin changes. The patient wished further treatment to occur at another hospital in the same health region and asked to be referred there. The patient received a rejection at first from that hospital, for the reason that they must prioritise patients who lived within the boundaries of the health authority. The patient appealed against this rejection and the case went to the county governor. The county governor concluded in this case that the hospital had the wrong interpretation of how the right to free choice of treatment should be practised. After the review by the county governor, the hospital took the matter up with all its units that receive referrals and advised that common guidelines had been prepared in this area.

We have also found that the area of application of free choice of treatment is not well enough known and that the way it is practised in the services differs. The issues that arise in practising this right can be seen both before the start of medical aid and during the course of the treatment. During the acute phase, there is no free choice of treatment.

Some patients or relatives wish to change hospital during the course of treatment for practical reasons. This may also be due to lack of confidence after an unfortunate experience or incidents at the hospital to which they have been admitted. The Ombudsmen have found that in some cases hospitals refuse this because they believe that this right only applies before hospital admission and not after examination or treatment have begun. In one case the hospital recognised that the patient had such a right but still refused to transfer the patient. The Omdurman assisted the patient by sending a complaint to the county governor.



The system is organised so that people can themselves choose the place of treatment by using the website Helsenorge.no or by telephoning 800 HELSE (800 43 573). The Ombudsmen are aware that very many of these enquiries are referred to patient advisers in the health regions who have specialist expertise in the service for selection of place of treatment. The Ombudsmen have found that patients receive very good guidance from these patient advisers. The people they talk to are experienced nurses with very up to date knowledge.

## **During the course of events**

The Ombudsmen receive enquiries that show that patients' expectations for the sequence of treatment are not met and that patients' rights are not complied with.

In last year's annual report, the Ombudsmen expressed concern that the focus on not missing deadlines affects the quality of the overall sequence of treatment. The Ombudsmen still have this concern. It might appear that the governing documents, with rules about the financial consequences that might result if deadlines are missed, are more important to follow than the patient's right to a proper sequence of treatment.

The Ombudsmen have found that health authorities focus on not missing deadlines, so as to avoid financial consequences, with a lesser focus on helping patients to consider using another place of treatment with a shorter waiting time. New places of treatment are mainly presented to patients as an option if the hospital can see that it does not have the capacity to give the treatment within the deadline, with a risk of financial consequences.

A woman was referred to the hospital. During out-patient examination she was told that an operation was needed to remove two cysts. When the woman had heard nothing further about 2 months after the consultation, she made contact to enquire about the date of the operation. The hospital advised that they "could not find her" listed for an operation. However a pre-operative consultation was set up for her a few days later. During the consultation, she asked about the date of the planned operation. The hospital could not give an exact date but advised that she would receive a notification in the post. She received no such notification and telephoned again about two months later to find out about the operation date. She was

told that she was set up to have the operation soon. A couple of days later she received a different message, that the operation would have to be further postponed. The woman then contacted the ombudsman, who wrote to the hospital. The hospital was informed that the patient had reacted to the lack of treatment/follow up and the lack of information. The hospital was also informed that the woman had lost confidence in the hospital because of the poor handling of her case and that she was considering exercising her right to choose treatment at another hospital. Shortly afterwards the woman was contacted by the hospital with the offer of an operation a couple of days later. The operation was successful and the cysts proved to be benign. The hospital advised that its assessment had been that there was a low risk of the cysts being malignant, which was why she had not been prioritised earlier. This information had not been communicated to the woman. She had experienced several months of groundless fear of a malignant illness, as well as being involved with a hospital where she had to follow up herself in order to have the planned operation performed.

## Contact doctor

Patients in the specialist health services wish to have a permanent doctor whom they can relate to. There have been various attempts to resolve this in the past. With effect from September 2016, patients with a serious illness, injury or disorder that requires treatment or follow up by the specialist health services over a certain period of time have the right to have a contact doctor appointed. This is a right that the patients in question shall be informed about and the specialist health services have an obligation to advise who the contact doctor is. However the Ombudsmen have found that this patient right is not being satisfactorily followed up. At some hospitals it appears that this arrangement only acts as a right on paper.

Based on this experience, the Ombudsmen emphasise the importance of establishing arrangements that work in practice.

The examples below come from the whole country:

A patient was followed up for incurable cancer. The patient told of many episodes that gave an impression of muddle, disorganised systems and generally very poor information. The patient had been in contact with the hospital to try to arrange for a contact doctor. The hospital responded that this was something the ward was unable to do. The ombudsman sent a complaint to the hospital. The patient was given a contact doctor, but informed the ombudsman that the arrangement was not working. The ombudsman approached the hospital to find out why the contact doctor arrangement was not in place.

The ombudsman was informed that some doctors object to taking on this type of function because they are not aware of the content of the contact doctor scheme.

A woman contacted the ombudsman about her mother, who was under palliative treatment at a hospital. The patient found she had a different doctor for each consultation, with poor communication and cooperation between departments. The doctor on duty could not answer questions. Nobody could tell her who the contact doctor was. The ombudsman and daughter had a meeting with the hospital. The dialogue meeting was good and beneficial for both parties. The daughter received proper feedback. The senior doctor on the case expressed understanding for much of what had been discussed.

Even though routines have been established for contact doctors, it can be seen that the employees are not always aware of them:

Relatives contacted the ombudsmen because they found that there were many doctors involved in examining and treating the patient. The doctors said different things, gave different answers to the relatives' questions and left an impression of disagreeing with each other and not cooperating. The relatives became uneasy, lost confidence and were tired of communication that was both tiring and irritating. The ombudsman informed about the right to a contact doctor and asked the relatives to request this. When the

relatives contacted the hospital about this it was found that the doctors did not know about the scheme. Even so, it was their opinion that the contact doctor on their ward should be “whichever was on duty at any given time”. The ombudsman took up the case in meetings with the health authority’s user committee, the health authority management, clinical managers and departmental managers. It emerged that routines had been established for the contact doctor scheme but that neither the patient right nor the routines were sufficiently well known among the health personnel.

The contact doctor scheme is important for children and young people who must combine treatment, family life and school as well as possible over an extended period. This is not always facilitated, as this case shows:

A young patient was involved in a lengthy sequence of examination and hospital treatment because of a chronic disorder. The examinations took time and seemed to be badly planned. Among other things, an essential referral to more specialist services remained unprocessed for an unreasonable length of time. At times, communication between the hospital and parents, school and GP was not good. The consequence of this was uncertainty about medication and poor progress in establishing schooling for the child. There was one doctor who had primary responsibility for the examinations and to whom the parents had related. This person was only available every five weeks, which was a problem because of the need for information and the work of establishing a holistic and adapted programme for the child. The ombudsman took this up with the hospital, which acknowledged the actual nature of the case and ensured that the patient was given a contact doctor who was more accessible.

Patients are entitled to information and participation and they expect coordinated services. The ombudsmen find that at present the contact doctor scheme does not appear to work as intended. The aim of the contact doctor scheme is that follow up of each individual patient shall be better, more secure and more effective. Much work remains before this is in place.

## Back home with knowledge in the luggage?

Treatment at Norwegian hospitals is given as either planned services or immediate help. The planned activities represent the majority, about 80%. The average stay in Norwegian hospitals is becoming ever shorter and in 2016 it was 4.2 days (cf. 7.5 days in 1989). Patients now have short hospital stays and their perception is that health personnel are very busy.

Over the years patients have been given the right to information and to access their own records. Some take their discharge notes home with them. Even so, we find that both local authorities and patients seek information about the treatment received, what they should do after discharge and what needs to be followed up. Lack of information is a recurring theme in most cases handled by the ombudsmen.

A woman had an operation on a broken hip. After discharge from hospital, she was perplexed about what she could do and should not do, so soon after the operation. She seemed to remember that some information had been given by a doctor while she was still affected by the anaesthetic, but she could not remember the conversation. Neither had she received any written information. The health personnel had not ensured that the information had been received and understood by the patient. Neither was there any record of the information having been given.

The Ombudsmen have emphasised the importance of a discussion at the time of discharge. In our experience this does not occur nearly often enough. This makes patients and their families uncertain and it has unfortunate consequences.

A patient had undergone extensive and complicated treatment in the special health service. After discharge from hospital, the patient was left with a number of unanswered questions about the treatment and prognosis that made her uncertain. She therefore made contact with the relevant department at the hospital for information. The hospital department said that they did not have the capacity to respond. The patient was told that she must ask her GP to refer her to the department again if they were to set aside time to give relevant information about the treatment. The ombuds-

man advised the patient about the right to receive information and the right to essential information about her state of health and the content of treatment. The patient contacted the department again and informed them of this and received the information she needed.

The PasOpp surveys in which patients in somatic wards answer a number of questions indicate that the hospitals receive their lowest score for information given on discharge. The results of these annual surveys show little improvement on this point. "Safe discharge" is one of the measures in the national patient safety programme. *The Ombudsmen expect such briefing interviews on discharge to become a natural conclusion to every stay in hospital.*



