Cancer and living conditions

Summary of findings from a study among people with cancer in Norway

This report is an English translation of a summary of the findings from a study of living conditions among people with cancer (Fafo-report 2009:06). There have been four main research questions:

1. How does having cancer affect the employment and job situation?
2. How is their financial situation affected?
3. What sort of support and follow-up do people with cancer get from their private network and from the treatment and support system?
4. How is a child’s financial and material situation affected in the event that a parent gets cancer?

The analyses are based on qualitative interviews, a questionnaire designed specifically for cancer survivors and register data. The study was conducted by three Norwegian research institutions: Vestfold University College, Telemarksforskning and Fafo Institute for Labour and Social Research, and was commissioned by The Norwegian Cancer Society.
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Preface

This report is an English translation of a summary report that presents the main findings of a study of the living conditions of people affected by cancer. The summary report is based on three individual reports. The project has been concerned with four main questions: How does having cancer affect the employment and job situation of the people concerned? How is their financial situation affected? What sort of support and follow-up do people with cancer get from their private network and from the treatment and support system? How is the children's financial and material situation if mother or father gets cancer?

The analyses are based on qualitative interviews, a specially designed questionnaire for cancer survivors and register data from the historical event database FD-Trygd (Forløpsdatabasen Trygd). In order to be able to carry out a project based on such composite data sources, we have been dependent on assistance from many people. Bente Kringlebotn and other members of the Norwegian Cancer Society’s staff helped to recruit informants for the interviews. The management and staff of the Cancer Registry of Norway, the Cancer Centre at Ullevål University Hospital, Vestfold Hospital – Tønsberg, the Department of Oncology and Medical Physics at Haukeland University Hospital, and the Cancer Department at St Olav’s Hospital, Trondheim, contributed to the work involved in the questionnaire survey. Martin Veel Svendsen at Medical Services Clinic, Section for Occupational Medicine at Telemark Central Hospital was responsible for much of the practical work involved in the questionnaire survey.

The project had a reference group consisting of Ole Alexander Opdalshei, Bente Kringlebotn, Bente Øverli, Paal Bendixen and Grethe Werrin at the Norwegian Cancer Society, and Alv. A. Dahl and Sophie Fosså at Rikshospitalet University Hospital. Thank you all for your valuable contributions.

Many thanks to Agneta Kolstad and Bente Bakken of Fafo’s Information Office for work on the layout and preparation of the reports for publication.

Above all, a very big thank you to all those who have completed the questionnaire or agreed to be interviewed for the project. Your participation has enabled us to gain some insight into the situation of people with cancer that cannot be obtained by reading public registers.

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1 The expression ‘people with cancer’ is in this report used for the Norwegian word ‘kreftrammet’ and covers both people with cancer and people who have survived cancer.
1 Background

“It was a bit strange for me to have to have help. I’m highly educated, articulate and familiar with administration. But I just got tired and overwhelmed. Felt that they weren’t on my side. I didn’t understand it. There was such a fuss. I found that case officers differed enormously. There are an awful lot of applications to NAV, and they each had to have specific medical certificates! And you have to pay some of the costs in order to be reimbursed. Some things are handled differently. [. . . ] There’s such a lot to find out!”

(Female informant)

Are the financial and social consequences of long-term illness under-estimated? This was the fundamental question at the start of the project on cancer and living conditions. The project has looked at the situation of children and young people in families affected by cancer, financial support schemes, the working life situation and the consequences the disease has had for the individual’s income and the family’s financial situation.

Three reports have been published from the project. The first dealt with people with cancer’s experience of support from the public sector, his or her local community and the workplace. The second report looked at the situation of children in a family affected by cancer. The third report presented analyses of questionnaires and register data associated with the topics of work, financial situation, rehabilitation and social support. The results of all the three sub-reports are summarised in the present report.

We have used four types of data in the project. A thorough description of methods and underlying data has been provided in the three reports from the project, but the underlying data is briefly as follows:

- 18 adult cancer patients were interviewed about their experience with the support system, working life and daily living conditions before, during and after being ill with cancer.

- Interviews were conducted with ten children and young people aged 10-20 years who live with a parent with cancer, to find out how children experience the family’s material and financial situation after their mother or father has been affected by cancer.

- A questionnaire survey was conducted among persons aged 25-60 who had been diagnosed as having one of the ten most common types of cancer in men or women in the course of 2005 or 2006.

- Register data from Statistics Norway has been used. The data come from the historical event database FD-Trygd.

It is important to be aware that the selection in the questionnaire survey is not representative of all persons affected by cancer. Only the ten largest diagnosis groups for men and women, respectively, were included in the selection for the survey, and patients from four hospitals were selected as survey participants. Those most seriously affected by cancer, in the sense that they have passed away during the survey period or been too ill to be included in the survey, are not covered by the survey.
In 1997 there were slightly over 21,000 cases of cancer in Norway. The number of cancer cases is increasing steadily, partly because people live longer and diagnosis is better. In 2006 almost 25,000 persons were diagnosed as having cancer in Norway.

The four most common types of cancer are prostate, breast, colon and lung cancer. In 2006, these four types accounted for approximately half of all new cases of cancer. If we look at all types of cancer together, the 5-year relative survival rate for those diagnosed as having cancer in the period 1997-2001 was just over 55 per cent for men and just over 60 per cent for women.

The number of cancer cases is rising, while at the same time the proportion of those who survive cancer beyond a certain period has increased markedly. This is partly due to improvements in treatments and diagnosis. As a result, the number of cancer survivors is increasing. At the end of 1996, there were just over 115,000 persons alive in Norway with a cancer diagnosis. Ten years later this number had risen to almost 175,000.

Cancer appears to strike randomly, and there is little indication that particular groups are especially susceptible. The causes of cancer are uncertain, but factors that are known to increase risk have been identified. The best known is smoking of tobacco. An unhealthy diet and obesity are also regarded as risk factors for several types of cancer, as are radiation and a number of chemicals.

The great majority of persons who get cancer are up in years. Of those diagnosed as having cancer in 2002-2006, 85 per cent of the men and 75 per cent of the women were over 55, and well over a third of both male and female cancer patients were over 75. Thus cancer among children and young people is not very common.

Consequences and life prospects are very different for the different cancer diagnoses. The fact that more people get cancer and more survive creates a need for more knowledge about the living conditions generally of people with cancer, and about their financial and employment situation in particular.

The information on this page comes from the Cancer Society’s website www.kreftforeningen.no and Cancer in Norway 2006 (Norwegian Registry of Cancer 2007).
3 Changes in employment

“I got into rehabilitation quite quickly. I had neither the desire nor the health to go back to my old job. I received a lot of help from the social worker at the Radium Hospital, with whom I discussed the matter before I contacted the Public Employment Service (Aetat). [. . . ] I contacted occupational training myself, and asked if I could sit in on sessions. I went to an interview, and was offered a 50 per cent position, which brought me back into work again. At first I had a subsidised salary, because Aetat paid half my salary. After a while I got a permanent position there.” (Female informant)

People with cancer generally have the same employment situation as others before they develop cancer.

In a five-year perspective, employment among cancer survivors is reduced somewhat more than in the general population. The difference is small for men, all the same, but somewhat larger for women.

The questionnaire revealed that far more people have changed their main occupation because of cancer than have dropped out of working life.

Physically heavy work appears to be an important factor leading to a change in main occupation for cancer patients. The psychosocial working environment also has an effect on whether people change their main occupation; those under heavy work pressure and with a low degree of self-determination have made changes more often than others.

Among the various diagnoses, lung cancer survivors come out worst with respect to employment, while survivors of skin cancer come out well.

Qualitative data show that the way back to working life is complicated, and some critical views were expressed about lack of follow-up and flexibility, on the part of both The Norwegian Labour and Welfare Administration (NAV) and employers.
4 Changes in working hours

“What we used to spend 30 minutes on before, we spend hours doing now.”
(Female informant)

A fifth of the participants in the questionnaire survey had reduced working hours because of cancer. We do not know whether this is a permanent change or a more short-term adjustment.

Heavy physical work and heavy work pressure are the working environment factors that had a particular effect on whether people changed their working hours.

Confirmation of metastatic cancer, chemotherapy, having been through several types of treatment, and having many other health problems in addition to cancer are illness-related factors that have a particularly strong influence on whether people changed their working hours.

The percentage of self-employed who have reduced their working hours is larger than the other employed groups.
5 Work capacity and absence

“[. . .] this past year my energy level has increased substantially. And it’s taken two years. My last chemotherapy course, a year and a half ago in November 2005, knocked me out so much [. . .], at any rate, you feel that you are completely burned out. I was actually supposed to have nine courses in succession, but I couldn’t take the ninth one because I was so knocked out that they wouldn’t give it to me. And I was in terrible shape right up to the spring, then suddenly [. . .]” (Male informant)

Many people with cancer report that they feel completely exhausted. This may be due to aspects of the disease, the treatment, and/or there may be a mental reaction to the overall strain of having cancer.

About 60 per cent of those in work believe that their work capacity has been reduced because of their cancer. Nevertheless, as many as 90 per cent respond that they cope relatively well with their work. Those who have dropped out of work have a lower work capacity than those who remain in work.

Older people report a lower work capacity than younger ones, and those with less education a lower capacity than those with higher education. There is a connection between physically demanding work, heavy work pressure, low self-determination and little social support at work and a low work capacity. High work pressure was the most important factor.

People with metastatic cancer and those who had undergone chemotherapy report higher sickness absence and a lower work capacity than others with cancer.

Register data shows that approximately four fifths of the cancer patients were on sick leave during the first year after their diagnosis. After five years, absence due to illness among people affected by cancer was substantially reduced, and approximately the same as for the general population.
6 Follow-up at the workplace

“We have a business developer who helps us in the company, and he happens to have an ex-wife who happens to be an oncology nurse, and he has been in companies before where people have had cancer, so he is concerned [. . .] that I don’t start anything I am not ready for; after all my health has to last me for many years, we’ll see…”

(Male informant)

People with cancer found that employers and colleagues showed sympathy and understanding immediately after the cancer was diagnosed, and maintained contact during the period when the employee was on sickness leave. About two-thirds of the people affected by cancer found that their employer took this into account when planning work tasks.

The majority experienced good follow-up, but ten per cent report that their manager did not show compassion or understanding. The most common adjustment is to reduce working hours. A number have also been given other or fewer tasks in order to reduce the strain on them.

A third felt that they needed adjustments that were not made.
7 Developments in employment income


- At the outset, cancer patients have the same salary level as comparable persons without cancer (i.e. persons of the same age and level of education)

- Cancer patients have poorer wage development than others. Five years after the time of diagnosis, men with cancer had on average seven per cent lower wages than men without cancer (for the same age and education), while women had a ten per cent lower salary than women without cancer.

- Metastatic cancer has a negative effect on the salary level of both men and women. For people with cancer, as for the population generally, salary increases with age and level of education.

Source: Register data
A number of factors have to be taken into account in order to understand how cancer affects the income of people with cancer. In order to investigate the degree to which public transfers compensate for the fall in salary that many of them experience, we have looked at developments in total income, i.e. the sum of occupational income, capital income and transfers, less tax.

A comparison of developments in median income for persons diagnosed with cancer in 1999 and a matched control group shows that there is no difference between those with cancer and the control group. This indicates that, all in all, public transfers compensate for the loss of income due to reduced paid work.

Nor, when developments for men and women are studied separately, are there signs that the median income of people with cancer develops differently from the median income of the control group. Similar comparisons have been made for different age groups, different educational groups and persons in and outside working life, and they all show the same tendency.
9 From sickness benefit to rehabilitation benefit

“I was very worried about money when the benefits were reduced to 66 per cent.”
(Female informant)

Source: Register data

Median income among persons diagnosed with cancer in 1999. Comparison of men and women who changed from sickness benefit to rehabilitation benefit during the first year after their initial diagnosis, and other cancer patients during the period 1998-2004. Total income (wages, capital income, benefits) after taxes. 2004-kroner

- Persons who are on sickness leave for more than 52 weeks are transferred from sickness benefit to rehabilitation benefit. Basically, this means that they go from a scheme with full salary compensation to a scheme with 66 per cent compensation. Eight per cent of men and ten per cent of women who were on sick leave for the first year following their cancer diagnosis transferred from sickness benefit to rehabilitation benefit in the course of 30 days after completing their period with sickness benefit.

- The qualitative study reveals that the transition between sickness benefit and rehabilitation benefit is a critical situation for those who experience it.

- The register-based analyses also show that the transition from sickness benefit to rehabilitation benefit means a fall in overall income. The reduction in income remains evident several years after rehabilitation benefit is granted.

- Five years after the cancer diagnosis has been made, the difference in median income between men with cancer who have received rehabilitation benefit and other people with cancer remains substantial, i.e. over NOK 40 000.

- The pattern of income development among women is somewhat different. This is because only those who have previously been employed receive rehabilitation benefit. In the women’s comparison group, we find women both in and outside the labour market, and this group thus has a much lower median income at the outset. During the period studied, however, the comparison group closed the income gap, and after five years had a median income approximately NOK 10 000 higher than those who received rehabilitation benefit.
10 Experience of own financial situation

“I can’t say we were badly off financially; that would be an insult to those who really have financial problems. But things were tight for a while, and we considered moving.”
(Female informant)

<table>
<thead>
<tr>
<th>All</th>
<th>Of those who have experienced a change</th>
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<tbody>
<tr>
<td>Have not experienced change in financial situation</td>
<td>63 %</td>
</tr>
<tr>
<td>Financial situation has improved</td>
<td>7 %</td>
</tr>
<tr>
<td>Financial situation has deteriorated</td>
<td>30 %</td>
</tr>
<tr>
<td>N</td>
<td>1296</td>
</tr>
</tbody>
</table>

Source: Survey data

How cancer patients have experienced their financial situation since their diagnosis.

- Almost two of three report that they have not experienced changes in their financial situation since being diagnosed with cancer.

- Almost one of three have found that they have a poorer financial situation following their cancer diagnosis, while the financial situation of seven per cent has improved. When persons with cancer find that their financial situation has changed, the changes have largely been for the worse:

- The experience of having a poorer financial situation was distributed in much the same way within the different demographic groups. The groups that stand out because a particularly large proportion of their members suffered a deteriorated financial situation are those with metastatic cancer or recurrence of the disease, those who have two or more illnesses in addition to cancer, those who have undergone more than two types of treatment, and those who were undergoing treatment at the time of the survey.

- Most of those who report a poorer financial situation associate the deterioration with their cancer.
11 Financial problems

“Before I fell ill, my husband used to work extra when we needed something extra. He had a much higher income than I did, because I only had a 50 per cent position when I fell ill. When I became ill, he wasn’t able to work any extra. So it was chaos immediately [. . .]. We struggled with a backlash for a year and a half afterwards.”
(Female informant)

Most cancer patients are satisfied with their financial situation. 60 per cent say that their financial situation is satisfactory, while only eight per cent feel that it is very poor or quite poor.

Among those who were interviewed in depth, concern over their financial situation was quite common. The more difficult the initial financial situation of the person with cancer, the sooner and more urgent the financial worries. A number of informants report increased expense in connection with their cancer.

One of four cancer patients reports that they had problems in managing day-to-day expenses and/or that they could not manage an unforeseen expense of NOK 5000. This is high, compared with figures for the population generally.

It is particularly those with little education, single persons and single providers, those who are not in working life and those who have changed their civil status following the cancer diagnosis who report financial problems. We also see that those with more than one illness in addition to cancer and those who have undergone several types of treatment struggle financially.

Source: Survey data

Percentage of cancer patients who state that they often or occasionally have problems in managing running expenses and/or that they cannot manage an unforeseen expense of NOK 5000.
12 Financial support in connection with illness

“I have said a lot that is positive, haven’t I? But if I have to say what I miss, it is actually financial help here and there, so that I don’t have to [. . .] change too much in my life, now that everything has changed so much.” (Female informant)

Source: Survey data

Percentages of people with cancer who are fully/partially in agreement with the statements in the figure.

- Two of ten people with cancer feel that the health service has a poor overview of relevant financial support schemes for people with cancer. An equal number believe that the health service has a good overview of this area.

- Three of ten have found that they did not have a good overview of relevant financial support schemes. Women and persons with a high education feel to a larger extent than men and persons with less education that they needed more information.

- One of four persons with cancer feel that public benefit schemes do not meet the financial needs arising from their cancer. In particular, patients with a poor financial situation, with spreading and with more than one illness in addition to cancer feel that the public schemes are not adequate.

- Almost seven of ten persons with cancer have been in contact with Norwegian Labour and Welfare Insurance (NAV Trygd). Half of them have been satisfied with the help they have received, as opposed to 70 per cent of NAV’s users overall.

- Raising a loan or borrowing money from family or friends appears to be a marginal phenomenon among those affected by cancer. People with metastatic cancer or recurrence have nevertheless raised loans somewhat more often than people with cancer on average.

- The family’s financial contributions are found to be more important than financial contributions from the public sector by the majority of those affected by cancer who have taken part in the survey. This tendency is even more pronounced in persons whose illness took a serious course.
13 Rehabilitation and other public sector support

Percentage of those who have considered that they need various rehabilitation options, by whether the person concerned has received this option, and whether the option has been used. (The number of respondents who have expressed a need for the various services is given as N on the left-hand axis in the figure.

“I was offered [contact with the hospital social worker], but I said no thanks. The offer came at a very bad time. [...] Because it comes when you’re in the middle of chaos. I said that you actually shouldn’t be asked about it, they should just come. You say no thanks because you can’t face talking to people, but I should have talked to them, because they remind you that you can contact your insurance company, you can get a reduced insurance premium, or reduce payments you are making, study loans etc. This is the sort of thing you find out or think of when you get your head a bit more above water. So actually you shouldn’t be asked, they should just come. And say, get in touch with me later, you can reach me on this number.” (One of the informants’ description of contact with the hospital social worker).

- The qualitative data indicate very limited use of local government services. This is confirmed by the questionnaire survey. Only one of ten state that they have had assistance from the local authorities in connection with their cancer.
- Many people with cancer have needed one or more types of rehabilitation and have been offered it. However, some have needed rehabilitation but not been offered it. Overall, only about half of the respondents were satisfied with the rehabilitation option.
14 Support from family and friends

“I must say I am devoutly thankful that I am married and have a wife and house.”  
(Male informant)

“I’ve said to my close friends that you can forget the people you’ve shared a laugh with, but never those you’ve shared tears with.”  (Female informant)

- Most people with cancer have needed and received one or more types of emotional or practical help and assistance from family and friends.
- The amount of help is greatest in the youngest age group, and women have received more help than men.
- Although the majority are satisfied with the help they have received, a small minority – 14 per cent – say they would have liked more help. The unmet need for help is greater among women than among men, and greater among single persons than married persons or cohabitants.
15 Being the spouse of a person with cancer

“I wanted him to take sick leave, but he wouldn’t, and I think that was a good thing. He had to get out of the house, that was a normalising factor [. . .]. He made many choices; he refrained from travelling and chose a less steep career ladder. But those choices were necessary; he had to look after the children.” (Female informant)

About a thousand of the respondents had a spouse, cohabitant or partner. Eleven per cent responded that their spouse’s work situation had changed as a result of their cancer.

Only five spouses or cohabitants stopped working in connection with the illness, while three began. Thirty-four spouses worked less, while nineteen worked more. The most common adjustment to the illness by spouses, cohabitants or partners was to take sick leave for more than a month, work less or take extra holiday or unpaid leave.

It can be concluded that it is relatively rare for spouses of persons with cancer to change their employment situation. When it happens, it is most frequently in connection with metastatic cancer or recurrence.
16 Being a child in a family affected by cancer

“I was so afraid, and I didn’t dare to ask.” (Child informant)

“I get so angry when I think about it – what it was like at the hospital.”
(Child informant)

“At the hospital there was a nice lady who said she could answer all the questions I had about cancer and that sort of thing. That was very kind.” (Child informant)

“Be with friends a lot! Do what you usually do! Do something that’s fun!”
(Advice from a child informant to others in the same situation)

- Children and young people who experience a mother or father with cancer are in a vulnerable situation. This is particularly evident when mother or father is in hospital for assessment or treatment. If children or young people in a situation like this find that they are overlooked and not taken into account as close family, both their vulnerability and the strain on them increase.

- There is a connection between openness about the illness and the ability to adjust to everyday life at school. Spending time with friends had been very important to them and helped them to maintain an ordinary everyday life.

- Positive experiences of hospitals were of three types: a positive impression of those who worked at the hospital, good conditions for patients, and being met with openness and taken seriously by the personnel.

- Negative experiences of hospitals were of four types: a bad impression of those who worked at the hospital, poor material conditions for patients, poor arrangements for close family, and that children felt overlooked and treated as though they did not exist.

- Young informants found it important to maintain as normal a life as possible outside the home. Doing so gave them a break from fear, anxiety and worry.
"The thing is, my mother isn’t getting what she used to get. But I haven’t noticed so much that we’ve been short of money or had more money; but I think that we might have had less if we hadn’t got that inheritance, that has kept things quite stable. But I’ve paid for most things myself for the past few years.” (Child informant)

Children’s stories from the qualitative interviews reflect the fact that the financial situation is not the children’s greatest concern if one of their parents becomes ill.

Some of the children have taken on a greater responsibility for their own financial situation than they would otherwise have done. They were afraid to burden their parents with financial matters at a time when more important matters were at the centre of the family’s everyday life.

In interviews, children of cancer patients gave examples of how they experienced the family as not being well off, and they connect this with the worsened financial situation after one of their parents developed cancer.

Several of the children expressed anxiety concerning their future financial situation.

Approximately 30 per cent of the questionnaire respondents had children under the age of 18 living at home. The majority of them state that their cancer has not caused financial problems to the extent that it has affected the children’s consumption or activities. Sixteen per cent reply that their cancer has affected the children. They also indicate in other ways that they are stretched financially.

Some groups are more vulnerable than others to financial difficulties as a result of the cancer. This pattern is repeated when it comes to financial constraints on the children’s activities. Single parents are more vulnerable than couples. Cancer patients who describe their own health as poor, or neither good nor bad, are more susceptible than others to financial problems that may affect the children. Persons who were in work at the time of the interview have experienced to a lesser extent than others that their financial situation became so strained that they felt it affected the children.
18 Contact with the Cancer Society

“The best help I have had was from the regional Cancer Society and the social workers there.” (Female informant)

- More than a quarter of the cancer patients in the survey have been in contact with the Cancer Society.
- Most of those who have been in contact have attended courses or meetings; a fair number have also had individual conversations with a social worker or nurse.
- The great majority have a favourable view of the help they have received from the Association.
- Less than five per cent of those with cancer have applied for financial assistance from the Cancer Society, and the majority of these applicants are not in work.

Percentage who have been in contact with the Norwegian Cancer Association (N = 1343) and percentage of those who have been in contact and who have received help/support of various kinds.
Food for thought

We opened this summary report with a quotation to the effect that there is such a lot to find out. In the project on cancer and living conditions we looked at the situation with regard to work, the financial situation and the encounter with the support system. We also investigated the family’s situation with respect to both how family members are affected and how the local community functions as a support system.

The general impression obtained from the project is that many of those with cancer get through the illness without any living condition problems worth mentioning apart, of course, from health problems. Many remain in or return to work. If we look at people with cancer generally, their income remains at the same level as that of a comparable group in the general population. Most are satisfied with the follow-up and support they get from family, friends, public authorities and the Cancer Society.

Despite this positive general impression, the project also shows that a large number of people with cancer experience problems relating to working life and their financial situation in connection with the disease, and that there is potential for improvement in the public support system. This challenges the welfare state and the civil population on the issue of whether there are other ways of working or other types of measures needed to make the overwhelming situation in which many find themselves when they contract cancer simpler to relate to.

Should something be done with the sickness benefit scheme?

Analyses of the income development of people with cancer indicate that public transfers curb losses due to reduced income for paid work. If we look at overall income, people with cancer as a group therefore have roughly the same income development as the rest of the population. However, those who go from sickness benefit to rehabilitation benefit experience a loss of income and poorer income development than others. This raises the question of whether the sickness benefit scheme functions well enough for those who are ill in the long term.

People with cancer often go through a very long treatment programme. The question is then whether the possibility of an extended sickness benefit arrangement could reduce finance-related stress, and thereby also contribute to getting more cancer patients back in work. Some people are on partial sick leave during treatment. Might it be possible to establish some kind of time account scheme for those who are not on full sick leave?

Can more people get back into work?

Very many people with cancer are in work when they fall ill, and many come back to work at the end of their illness. The percentage of employment among cancer survivors is almost as high as in the population generally. Nevertheless, we see that a relatively large number have to, or choose to make changes in their main occupation, and one of five change their working hours. This is probably because many find their work capacity is reduced.
The great majority of the participants in the study experienced good follow-up from their workplace in connection with their illness, and adjustments were made to their work situation. Nevertheless, approximately a third report that they need workplace adjustments that have not been made.

Very few have been in contact with NAV Labour or the occupational health service. How can the occupational health service, the employer, NAV, other public services, unions and interest organisations work together, so that the measures needed are implemented as early as possible?

**Are the psychosocial support schemes good enough?**

The private support people with cancer receive appears to function well. The great majority receive practical or psychosocial support from family or friends, and the great majority are satisfied with the support they get.

Professional help is in shorter supply. Few have received assistance from the municipal authorities, and few have had an individual plan drawn up for them. Many need physiotherapy and physical rehabilitation. A number state that they are not offered various types of rehabilitation that they need, and only about half are satisfied with the overall rehabilitation options they have been offered. Moreover, many people who need psychosocial follow-up do not appear to be getting it.

Do we need a new discussion on what the support system should provide in terms of psychosocial follow-up? What can and should be done to enable the support system to pick up the problems of those who do not have networks that function well enough? And how can we ensure that the rehabilitation needs of all patients are met?

**Does the health service have adequate knowledge of the various ways in which cancer affects the living situation?**

The qualitative interviews revealed that many people felt that the health professions possess too little knowledge of the financial support schemes that people with cancer can draw on. Two of ten people in the survey confirmed this impression. Although register data shows that the majority who are affected by cancer experience little or no effect on their income, the in-depth interviews show how the financial situation can be a major source of concern when the disease strikes. The questionnaire survey showed that almost one in three found that they were worse off financially after being diagnosed as having cancer, and that eight of ten associated this with their illness. One of four people with cancer reported that they had problems in dealing with running expenses and/or in dealing with unforeseen expenses.

These problems arise despite the fact that the income of the majority is not substantially worsened, compared with others. This suggests that other factors play a part, such as increased expenses or general problems in dealing with financial issues when the disease strikes. The findings point
to a need for better information and professional help and counselling on how to deal with the family’s financial and social situation. The unnecessary additional burden of finding one’s way in the insurance and rehabilitation jungle must be avoided.

◆ Is enough attention paid to the children’s situation?

The children in families where mother or father contracted cancer assumed a lot of responsibility. They were concerned with maintaining as normal a life as possible. Adjustment to everyday life, including school, appears to be an underestimated challenge.

Children and young people are concerned with being seen and taken seriously as close family, not least when one of their parents is in hospital. They want to be informed, and the information must be adapted to the age of the child.

There is a need for greater attention to be paid to the local community, friends, family and children – both as a resource for the patients and as a challenge for the support system.

◆ Is there a need for more help from the municipal support system?

A number have an unmet need for rehabilitation and psychosocial support from the municipal welfare services, and there are also a number who want more practical help from the local authorities. Many of the informants in the qualitative survey mentioned the need for home help, for example. Only one of ten in the survey stated that they had received assistance or practical support from the municipality in which they lived. This may perhaps be interpreted as indicating that there is little need for support, but it is equally probable that the low figure indicates that there is not necessarily any help available. The finances of many municipalities are tight, and the needs of different groups have to be weighed up against one another. Nor is it certain that those with cancer are aware of their rights with respect to the municipality. Improvements in municipal follow-up of those affected by cancer will very probably help to ease the situation of many people with cancer and their families. At the same time, we must bear in mind that family and friends will probably feel a strong need to assist the person with cancer while they are sick, and the question of where the limits of public responsibility should be arises again. Can we expect there to be public assistance in all difficult situations, or will this lead to a welfare state that is larger (and more expensive) than anyone wants?

◆ Which groups is it most important to focus attention on?

If we consider the public sector and voluntary options for cancer patients together, it is clear that there is a broad range of options available. But is today’s overall care for cancer patients – the health service, social welfare services, working life and voluntary organisations – sufficiently focused on the particularly vulnerable groups? The analyses in the project have shown that some groups have more problems than others, and that the dividing lines go through both socio-economic and
illness variables. Examples of groups who have a difficult time in several areas are those who have lost their partner after they fell ill, single parents, persons with little education, those with heavy physical work, persons with more than one illness in addition to their cancer, and persons with taxing treatment. It is important to be aware that people with cancer are not a uniform group, in terms of either illness and health or social position. Some groups will therefore have special financial, psychosocial and practical needs.

◆ What support is needed from the Cancer Society and patient organisations?

The help and support that people with cancer get from the Cancer Society and patient organisations is regarded as positive. The living condition study does not deal with the activities of the Cancer Society, but several of the results of the study stress areas on which it is important that the Cancer Society, as one of the cancer care agents, should focus attention. One such area is assuring the income of people with cancer and the question of how public schemes can meet the needs of those with long-term illness to the greatest extent possible. Another area is the need for rehabilitation and making accommodations. Responsibility for these has been placed with the public sector, but the Cancer Society can play an important part in this work, for example by helping to provide NAV Labour and individual companies with information about the situation of people with cancer.
This report is an English translation of a summary of the findings from a study of living conditions among people with cancer (Fafo-report 2009:06). There have been four main research questions:

- How does having cancer affect the employment and job situation?
- How is their financial situation affected?
- What sort of support and follow-up do people with cancer get from their private network and from the treatment and support system?
- How is a child's financial and material situation affected in the event that a parent gets cancer?

The analyses are based on qualitative interviews, a questionnaire designed specifically for cancer survivors and register data. The study was conducted by three Norwegian research institutions; Vestfold University College, Telemarksforskning and Fafo Institute for Labour and Social Research, and was commissioned by The Norwegian Cancer Society.