

# 1 The National Cancer Plan

## Summary and Recommendations

The present Cancer Plan is based on the work undertaken by an epidemiological subgroup, which was commissioned to update the existing statistical data on cancer. This task included comparing the Danish statistical data with that of other countries, and ensuring that the comparison was as up to date as possible. For this comparison the Cancer Steering Group chose to focus on data from Sweden, Norway and Finland, as well as on lung cancer, breast cancer, colorectal cancer and testicular cancer. Comparative analyses have subsequently been carried out as to prevalence, survival and mortality rates. Moreover, it has been estimated to what extent the different treatment modalities (such as surgery, radiotherapy and chemotherapy) contribute, either separately or in combination, to curing various groups of cancer patients. Also, the potential of preventive activities and, for selected diseases, of screening as regards to prevalence and mortality have been assessed. The subgroup's entire report is included in the cancer plan as an appendix. (Preliminary Report 2)

One result of this mapping is that the number of cancer cases can be expected to increase in the coming years. This number can be estimated by making a projection based on the Danish Cancer Registry and population registers which partly takes into account the future changes in the population structure (more older people), and partly the prevalence of a number of cancers, which have been observed continuously over many years. All in all it is estimated that the number of newly diagnosed cancer cases will increase from approximately 27,200 patients annually at the turn of the millennium to almost 30,000 annually at about 2010, equivalent to an annual increase of approximately 1% annually. The number of patients suffering from or cured of cancer (in 1996 approximately 146,500 people) is expected to increase at least the same rate.

Moreover, the epidemiological data confirms that Denmark continues to have higher cancer mortality than Norway, Sweden and Finland. An analysis of the most recent data from the cancer registries of the countries in question thus shows that there was a lower survival rate for Danish patients as regards 4 common cancers (lung cancer, breast cancer, rectal cancer and cancer of the colon). The survival rate is approximately 10 % higher for Swedish than for Danish cancer patients, while the differences between Denmark, Norway and Finland generally are less significant. As for the fifth type of cancer included in this mapping – testicular cancer – there are no marked differences between the 4 countries in the survival rate. Generally, the survival rate has increased significantly during the recent years.

There is no one explanation for these differences, but it is a well-known fact that the intake of calories and the consumption of alcohol and tobacco are higher in Denmark than in our neighbouring countries. Especially, Danish women smoke more than their Scandinavian counterparts. Such general differences in lifestyle, smoking in particular, may explain why the prevalence of cancer is higher in

Denmark than in our neighbouring countries. This underlines the importance of prevention. The potential of preventive measures has been described in chapter V of the Cancer Plan.

Patients with certain cancers have a lower survival rate in Denmark compared to the neighbouring countries. The shorter life expectancy of a Dane with cancer is presumably caused by several factors. Perhaps Danish patients tend to consult a doctor at a comparatively late stage, perhaps the general practitioners in Denmark are slightly more reluctant to check their patients for cancer, e.g. because of their limited facilities for performing diagnostic examinations, as well as limited facilities for preliminary examinations in hospitals. A contributory factor in the poor results of treatment in Denmark could be slightly more reluctant/less radical treatment of patients – in particular in cases of recurrence. However it has to be emphasized that these hypotheses have not been proved in the previous work of the Cancer Steering Group. Such problems will be examined more closely, partly through an analysis of the need for scanner capacity in Denmark, Norway and Sweden, and partly through a transnational survey of the practice as regards referral in Denmark, Norway and Sweden. Part of the explanation may also be that - other things being equal - the average Danish cancer patient reduces the effect of the treatment through his or her lifestyle. In this connection smoking once again plays a significant part. These issues, among other things, are mentioned in chapter VI of the Cancer Plan, which deals with the efforts of the health service in general.

Certain types of cancer can be detected through screening. This issue has been touched upon both in chapter V of the Cancer Plan, which deals with prevention, and in chapter VI, which generally describes the work of the health service. Screening for cancer of the cervix has been implemented in Denmark, Norway, Sweden and Finland. Sweden and Finland have implemented nationwide systematic screening for breast cancer, while this is only carried out in 2 regions in Denmark, covering about 20% of the population. Norway occupies an intermediate position. Based partly on Danish research European medical circles have presented evidence and recommendations concerning the introduction of screening for intestinal cancer by the examination of stool samples.

In hospitals diagnostic work and treatment are of crucial importance. With a view to providing a more detailed description of the organisation of examination and treatment, Chapter VII contains a description of the present state of affairs as well as the problems and efforts concerning a number of relatively common cancers. The chapter draws on the contributions of several interdisciplinary medical working groups. The perspective includes the intended curative treatment efforts aimed at curing the patient, the effect of which can be estimated by the survival of the individual patient. But the perspective also includes preventive, rehabilitating and palliative efforts. On the basis of the previously mentioned descriptions of the state of affairs concerning the efforts in relation to the most frequently occurring cancer diseases, the Cancer Steering Group has not been able to point out systematic deficiencies in the efforts of the hospitals.

Chapters VIII and IX of the Cancer Plan examine the basis for more general recommendations concerning the planning of surgical treatment, radiotherapy and medical treatment of cancer. Generally speaking, surgical treatment is the primary form of treatment for most cancers. Thus, surgery still cures the most cancer patients. Yet, for many of the cancers it has been documented that radiotherapy and/or medical treatment has an effect on survival as a whole, and/or on symptom-

free survival. These treatments are either given separately or in combination with surgical treatment.

With regard to radiotherapy, the Danish effort has been less extensive than e.g. in Norway and Sweden. In the previously published Preliminary Report 1 the Cancer Steering Group has already recommended considerable expansion of the Danish radiotherapy capacity. Similarly, in the present report – in the section on medical treatment – there is documentation for recommendations for an expansion of the existing chemotherapy programme, so that it will be offered to a number of patient groups who, on the basis of our present knowledge, can be expected to benefit from this treatment.

Concerning surgical treatment of cancer it is not possible in the same way to describe how improved modes of treatment have led to a need for increased resources. This is due to the fact that these patients are to a large extent already being offered surgery. The development within surgical treatment which e.g. has led to more extensive and potentially better treatment of older and more fragile cancer patients can therefore not be demonstrated by financial estimates as with the modes of treatments mentioned above. In addition surgical treatment of the various cancers in Denmark is integrated in the functions of a surgical ward, and it is closely connected with the surgical treatment of other patient groups. This makes it difficult to estimate precisely the need for resources related to the surgical treatment of cancer patients.

But precisely because of the diverse character of the tasks in the field of surgery, local support and the allocation of resources are essential to ensure sufficient supplementary training, so that the surgical treatment of cancer is carried out at a high professional level. Moreover, it is important that resources are allocated locally to carry out quality improvement and quality control, e.g. by establishing clinical quality databases for the most frequently occurring cancers.

As a supplement to the account of treatment efforts, descriptions and recommendations in relation to palliative care and rehabilitation of cancer patients are given in chapters X and XI of the Cancer Plan. In the area of rehabilitation – living on after having undergone cancer treatment – several factors indicate that the Danish effort is less systematic than the Norwegian and Swedish efforts in particular. Whether rehabilitation has a measurable effect on the mortality rate is not yet known.

In chapter XII, the final chapter of the Cancer Plan, the financial consequences of some of the recommendations given are considered.

## The Cancer Steering Group's recommendations and suggestions for further work

On the basis of its review of the area, the Cancer Steering Group submitted the following recommendations. The recommended activities should be implemented over a number of years and be prioritised according to their effect and scope.

# 1. Prevention

In general the Cancer Steering Group supports the recommendations of the Danish government, as put forward in its health policy. In particular it has to be emphasised that smoking constitutes a major health risk. Smoking increases the incidence of a number of cancers. At the same time, smoking increases the risk of complications in relation to surgery, and it also lessens the effect of radiotherapy and chemotherapy.

It is estimated that more than a third of all smokers wish to give up smoking. There is evidence that efforts undertaken by health professionals (e.g. the general practitioners) cause people to stop smoking. It is recommended that the individual counties/HS (Copenhagen Hospital Corporation) plan and implement a 3-year intensive anti-smoking campaign. As part of the campaign, the general practitioners or other health professionals should ensure that smokers receive systematic guidance in giving up their habit. Also before a scheduled operation, all patients should be informed of the increased risks of smoking, and advised on how to stop smoking. If smoking can be reduced by 30%, the number of deaths from lung cancer will in the long term be reduced by almost 1000 deaths a year. In addition, there will be a reduction in morbidity and mortality, both for other cancers and other types of disease.

# 2. Training of health care personnel

For the most part, health professionals' knowledge of and attitude towards care and treatment of cancer patients stem from what they were taught in their student years. It is suggested that supplementary brush-up training is established in order to update the health care personnel's knowledge of cancer. The costs of this initiative will depend among other things on the extent of the supplementary training. For some health care workers a single day of training will be sufficient. For others a longer course will be needed. The majority of the brush-up courses can be taught locally. The Cancer Steering Group emphasises that the supplementary brush-up training should also be offered to general practitioners who are not in contact with cancer patients on a daily basis. For health care workers who are involved in the care and treatment of cancer patients on a daily basis, the brush-up training can perhaps best take place in those regions already offering health training.

The Cancer Steering Group will at a later stage issue more specific proposals for strengthening the knowledge of cancer and cancer treatment, both on the level of health care workers' basic training and on a tertiary educational level

# 3. Contact and referral

It is essential that patients, general practitioners, and other health care workers are alert to symptoms of cancer. In relation to the differences found between the Danish, Norwegian and Swedish cancer mortality rates it is essential to establish whether:

- Danish patients, when noticing symptoms of cancer, wait too long before consulting their general practitioner

- General practitioners in Denmark are too slow in referring patients with possible cancer
- The examination and referral of cancer patients are efficiently organized in the Danish hospitals.

The Cancer Steering Group has initiated an analysis of these factors, and the results of this analysis are due in mid-2000.

## 4. Organization of diagnostics and examination

The lower 5-year survival rate of cancer patients in Denmark compared to that of patients in Norway, Finland and particularly Sweden gives occasion for a critical assessment of the quality of diagnostics and treatment of cancer patients within the Danish health service. Therefore, it is recommended that local cancer groups be formed concerning the frequently occurring cancers. The groups should consist of radiologists, surgeons, pathologists, oncologists, care workers and other relevant health professionals. The groups should be set up regionally to facilitate the cooperation between the oncological centres and the primary counties. However, cancer groups may also be established at county level, if considered relevant.

The task of these groups is to identify work routines, working methods and other factors that may increase the quality of cancer treatment within a region or county. The individual region could e.g. compare itself with a similar region outside Denmark. Professional exchanges could be considered, so that the Danish cancer groups may build up an empirical basis through study trips and/or actual work in the foreign regions.

Each region should write a report on the exchange containing observations, considerations, conclusions and possible proposals for the reorganisation of cancer treatment. Copies of the reports should be sent to the Cancer Steering Group, who will incorporate these reports in its further work. The Cancer Steering Group suggests that resources be allocated for the work on quality improvement, so that this may be carried out without hampering the examination and treatment activities in the hospital departments involved.

## 5. Expansion of diagnostics and treatment capacity

As previously mentioned, more cancer cases are to be expected in the coming years. Quick diagnosis and fast treatment are significant to the treatment results. However, quick diagnosis and treatment cause a certain periodic over-capacity, e.g. because new cancer cases do not occur regularly through the year. Therefore, the diagnostic and treatment capacity must be expanded.

In the diagnostic field, we are in Denmark apparently lagging slightly behind our neighbouring countries in some parts of the technological area. Thus, colonoscopy, used for examining and diagnosing cases of suspected intestinal cancer, is standard procedure e.g. in Norway, while this method is applied quite irregularly in the

Danish counties. The Danish Centre for Evaluation and Health Technology Assessment is currently carrying out a health technology assessment of examination of patients showing symptoms of intestinal cancer.

Moreover, there is in Denmark presumably a lack of sufficient diagnostic imaging capacity. Consequently, the National Board of Health has taken steps to chart the need for and the possibilities of expanding the Danish CT and MR scanner capacity. The results are to be presented to the Cancer Steering Group at a meeting in the spring of 2000 with a view to getting supplementary professional recommendations in this field.

In most cases cancer surgery is a planned procedure. However, it must be ensured that the operations can be performed within acceptable maximum waiting times. Among other things efforts should be prioritized in relation to providing access to the necessary surgical facilities during daytime. Similarly, examination and treatment facilities such as endoscopic equipment should be expanded.

Providing radiotherapy for cancer patients is a regional task. The capacity for radiotherapy in the departments, which have already been set up, should be expanded. When the Preliminary Report 1 was published in June 1999, an estimate of the need for extra resources for the radiotherapy capacity was given. This expansion is already being undertaken in the counties/HS.

The radiotherapy capacity should be expanded by at least 65 % compared to 1998. As the radiotherapy departments in the centres are provided with equipment and trained staff, it should be considered whether establishing outreach clinics would be rational in the long term. If so, it should only be done in formalised collaboration with the regional hospital departments, in order to ensure that the quality of treatment as well as of clinical research in the outreach clinics is of the same standard as in the regional hospital departments.

Treatment of cancer patients with chemotherapy is undertaken in the oncological centre departments, and in the county departments for larger patient groups, who are included in established standard treatment programmes. In this respect there is also a need for an expansion of the capacity, taking into account new evidence of the effects of new chemotherapeutic regimens.

Moreover, it is recommended that each county carry out an analysis, which uncovers the basis for optimising the distribution of tasks and resources in the departments involved in diagnostics, examination, and primary treatment of cancer patients. This analysis can be based on the recommendations of the Cancer Plan regarding the individual cancers, and will be particularly important to the common cancers, which are treated in specialist units.

## 6. Concentration of surgical treatment expertise

For the majority of cancers, surgery is the most important treatment. Surgical treatment of cancer is based on teamwork, and setting up the necessary facilities in selected departments with a sufficient number of patients must be supported. Surgical treatment of cancer patients should be viewed as a specialist task, and

carried out by specialists with sufficient experience, routine, and interests. Further and supplementary training of surgeons for the treatment of cancer patients must have a higher priority, cf. the National Board of Health's report concerning surgical specialist training from 1994. Sufficient resources should be allocated for continuous supplementary training of the specialists involved.

Providing surgical treatment of patients with lung cancer is a regional task carried out in the country's thorax surgical units. Concerning the most common cancers, it is recommended that in each county surgical treatment of patients with breast and intestinal cancer be based in specialist units, and so that the size of the population serviced by these units is sufficient for sustaining the necessary expertise. It is recommended that surgical treatment of patients with cancer of the female genitals be concentrated according to similar principles. As for the surgical treatment of cancer diseases in general, we refer the reader to the National Board of Health's guidelines for the organization of speciality service and highly specialized regional functions in the hospital service.

## 7. Screening

Analogously with the findings in epidemiological surveys on cervical cancer, several surveys have shown that screening can reduce breast and intestinal cancer mortality. Therefore, the Cancer Plan supports the National Board of Health's recommendations for a gradual implementation of screening for breast cancer. Moreover, it is recommended that screening for intestinal cancer be implemented experimentally in e.g. 1 or 2 counties.

However, the Cancer Steering Group wishes to stress that there may be a number of drawbacks to screening. Among other things screening involves the risk that people are denounced ill, and in some cases even undergo treatment, without really being ill. At the same time, the Cancer Steering Group would draw attention to the fact that the wishes for screening may conflict with the wishes for an expansion of the capacity for diagnostics and the treatment of patients in the hospital service, as the same personnel and technological resources are involved. The costs of screening activities should always be weighed against the costs of an increased primary preventive effort for a given disease. In this connection the Cancer Steering Group has to emphasize that the documented effects of screening on mortality can only be achieved through an efficient and systematic calling in and examination programme. The participation rate must be high in order to achieve the desired effect.

## 8. Research and Development

The Cancer Steering Group holds that research on and development of the quality of cancer treatment should generally be supported through expansion (and the setting up) of clinical quality databases for the most common cancers. Thus, funds should be made available in order to support the ongoing setting up of clinical quality databases for lung and intestinal cancer. Moreover, the already established clinical quality databases for e.g. breast cancer, melanoma, cancer of the lymphatic system, cancer of the head and neck region and the gynaecological cancer diseases should be supported and developed.

In this connection it is important that the quality of the national Cancer Registry at the National Board of Health be maintained. The clinical quality databases do not replace the Cancer Registry at the National Board of Health. On the contrary, the clinical quality databases depend on the possibility of retrieving data from the Cancer Registry. It is advisable that data from the Cancer Registry is updated, so that the Danish data become just as up to date as that of the other Nordic countries.

It is recommended that clinical quality databases be set up and developed in close collaboration with the hospital owners and the professional staff, not least the research communities. Being responsible for a clinical quality database both involves taking care of the daily running and ensuring that meaningful reports are sent back to those departments which send in data within the arranged deadlines. At the same time, it is presumed that a professional council be set up in connection with the database. The professional council is to issue recommendations to all departments responsible for treatment. Departments reporting to the database must have free access to the data, so that research, perhaps in collaboration with the professional council, can be initiated.

Cancer related research on the health service, including health economic analyses and health technology assessments, should be strengthened in the coming years. The Danish Social Science Research Council and the National Board of Health (the Danish Centre for Evaluation and Health Technology Assessment) should be involved in the necessary initiatives.

Ongoing active clinical research environment, not least the highly specialized regional departments which provide the oncological treatment, is of great importance in order to ensure that the Danish treatment efforts continue to be of a high international standard. For many years this research has partly been supported by charitable organisations. But in view of the significance of this research in relation to patient treatment, an active research environment should be prioritised as part of the running of the highly specialized regional departments.

The Cancer Steering Group therefore calls for local as well as national collaboration with the Danish Medical Research Council, which attempts to chart the extent of and the need for medical scientific cancer research, with a view to estimating whether existing research resources are sufficient to ensure the best possible realisation of the activities suggested in the Cancer Plan. On the basis of this analysis it will be possible to make more specific proposals for strengthening the medical scientific cancer research in collaboration with the Danish Medical Science Research Council.

## 9. Rehabilitation

Rehabilitation after treatment may address the physical, psychological and social consequences of having suffered from cancer. In this connection important elements are: the need for retraining, dealing with psychological reactions, and perhaps getting help to return to the labour market. The goal is that the health service should support the restitution of the patients to the greatest possible extent, both during and in some measure after the treatment. This should be done in close cooperation with e.g. the social system. Rehabilitation should be regarded as an integral part of cancer treatment. All cancer patients should be ensured the necessary follow-up treatment so that the effects of the treatment are best relieved. The side effects of



cancer treatment may occur several years after the treatment has been completed. Therefore, it may be necessary to monitor certain cancer patients over a number of years.

Rehabilitation must be offered to all cancer patients and must be tailored to the individual patient's needs. It is recommended that counties systematically gather information about the experiences in this area and initiate an evaluation of the efforts. Moreover, central health authorities should initiate an examination of the area, gathering information about local experiences. This work should result in setting up professional guidelines for the rehabilitation of cancer patients, analogous with the guidelines issued on the palliative treatment in Denmark.

## 10. Palliation

Palliative treatment is relevant to the large group of cancer patients who are declared non-remediable, either at the time of diagnosis, during primary treatment or when experiencing a recurrence of their cancer disease. Surgery, medical treatment of cancer and radiotherapy can have a considerable palliative effect. Palliative care involves relieving symptoms (among other things pain management), prevention of symptoms (e.g. in the form of palliative surgical procedures) and a holistic psychosocial nursing approach. The goals must be defined in relation to the individual patient and should involve prolonged survival and/or an improved quality of life.

More resources should be allocated for the palliative treatment and care of cancer patients, which is frequently undertaken in the unit of primary treatment (surgery), in cooperation with other units and the primary sector. It is recommended that the counties and the municipalities evaluate the current efforts, with reference to the National Board of Health's report from 1996: *The Care of the Seriously Ill and Dying – on Hospice Programmes and Other Initiatives in Relation to the Palliative Efforts*. Moreover, it is recommended that the professional communities and educational institutions take an active part in implementing the *Professional Guidelines on the Palliative Efforts – Care of the Seriously Ill and Dying*, which the National Board of Health issued in 1999.

Finally, it must be noted that the relatively limited knowledge of the reasons for the higher cancer mortality rate in Denmark entails that the precise effect of the suggested measures is not known. The recommendations of the Cancer Steering Group should contribute to an improvement of cancer treatment in Denmark, but we cannot be certain that the implementation of the recommendations will reduce for example the mortality rate to the level seen in Norway and Sweden.